Supporting Families of Children with Serious Emotional or Behavioral Disorders in a 24/7 World

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Workshop #29

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April Burris
Christine Shea

Training Institutes 2004
National Technical Assistance Center
for Children’s Mental Health

Georgetown University for Child & Human Development
San Francisco, CA
June 26, 2004
Panel Members

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Coordinator, Fu Yau Project, RAMS Inc, San Francisco, CA
Workshop Objectives

Raise work-life issues with parents, service providers, and community-based resources.
Identify the key elements that support families with children who have serious emotional or behavioral disorders in the child care environment.
Describe how parents and workplace supervisors can join to create family-friendly/workplace-sensitive partnerships.
Parents' Need for Family Support

A focus group study of employed parents caring for children with mental health needs identified six areas of difficulty for their families:

- Parent employment
- Child care
- Schools
- Transportation
- Financial resources
- Household tasks and management

(Brennan, Rosenzweig, Ogilvie, & Zimmerman, 1999)
Key Concepts

Family Support
Community Context
Work-Life Integration
Flexibility
Family Support

Simply defined: The provision of assistance and resources that families can use to meet their goals.

Family support is intended to help families maintain balanced lives for all members that are not overwhelmed by the needs or behaviors of the child or by the demands of the services designed to help.

(Rosenzweig, Friesen, & Brennan, 1999)
Community Context

Workplaces & families attempt to coordinate work and family opportunities within the context of the communities in which they are embedded.

The community context includes both resources and demands that assist or detract from the efforts of workplaces and families to support work-life integration.

(Voydanoff, 2002)
Work-life integration emphasizes a meaningful connection between the ways in which work and family are joined together.

Although individuals seek to find some comfortable level of integration their decisions are not based on individual choice but occur within the context of values and assumptions operating at a variety of system levels (Lewis, Rapoport, & Gambles, 2002).

The ways in which families integrate paid work with the rest of life are diverse.
All families seek greater integration of work and family life through flexibility in the work, family, or child care system (Emlen, 1997).

Work flexibility is the latitude to adapt the times or location of work to respond to family needs (Lewis, Kagan, & Heaton, 2000).

A lack of community supports, such as child care and education, force parents of children with emotional or behavioral disorders to accommodate their child’s needs through employment adjustments (Rosenzweig, Brennan, & Ogilvie, 2002).
APRIL’S STORY
April

April Burris, single mom
Kyle, 18; Cecilia, 15
Attended PCC, will attend PSU in the fall, seeking summer work
I want to share with parents that although there is not much support, it can be done!
I first noticed a change when Kyle was 2 and a half, but the behavioral pediatrician did not want to give a formal diagnosis....at 4 and a half he was diagnosed with ADHD through school. It was not until Kyle turned 11 that he was diagnosed with bipolar in day treatment. Before that time, there was confusion about what was going on and day treatment was kind of a warehouse. With the diagnosis, and medication, he was able to attend school and participate more fully in society.
April Reflections: Family Support

Employers

- Family support is lacking. There is willingness to reduce work hours, but not a lot of supports for the parent and the family.

Service-providers

- Support to me personally, but not much recognition that I was employed or that the care needs of my child interfered with my ability to work.
April’s Reflections: Child Care

That was really hard. The child care facilities do not have enough information about children who may have special mental health needs.
April’s Reflections: Family-Friendly Employment

I have experienced individuals who are family-friendly. Many of the daycares I worked for had mission statements that were family-friendly, but employees were not able to access the flexibility.

In my perspective, employers do not know how to be family-friendly. It seems there has not been enough research on it, so businesses do not have enough information about how to make flexibility work in their workplace.
April’s Reflections: Work-Life

Community Context
- There is a lack of information about how to access services in the community.

Work-Life Integration
- Parents make choices within the options they have, but the options available to them may not be workable for that person.

Flexibility
- In my experience, employers allowed me to leave, but I was not able to make up the time and could not afford to leave work because I did not have benefits due to working part-time hours.
April's Wish List

I would like to see families be taken seriously by service providers. To be taken seriously, there would be an attitude and behavioral shift on the part of the providers, and those who train service providers that parents know what is best for their child; it is the families live with the kids 24/7.

There are so many systems of care, but there needs to be more continuity of care. It would be helpful to have consistent providers over time.
CHILD CARE

Models of Inclusion in Child Care
Portland, OR

Fu Yau Project
San Francisco, CA
Child Care as Family Support

Child care as an unmet need for many families.

The Models of Inclusion Research Project.
Characteristics and practices of inclusive centers that support families.
Barriers to inclusion and strategies to overcome those barriers.
Child Care as a Crucial Unmet Need

Families of children with emotional or behavioral disorders have a very difficult time obtaining and maintaining child care (Rosenzweig, Brennan, & Ogilvie, 2002).

When they do make child care arrangements, parents having children with emotional or behavioral challenges have reported lower quality and less stability of care than other parents.

Children with behavior problems were 20 times more likely to be dismissed from care than other children. (Emlen, 1997)
Child Care as a Crucial Unmet Need

A stable, nurturing child care arrangement makes it more possible for family members to integrate their work and family responsibilities. Child care can also provide links to other important services for families affected by their children’s mental health needs.
Models of Inclusion in Child Care Project

Supported by:

National Institute on Disability and Rehabilitation Research (grant # H133B990025), United States Department of Education, and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.
Project Personnel

Eileen Brennan, Ph.D., Principal Investigator
Jennifer Bradley, Ph.D., Project Manager
Shane Ama, B.A., Research Assistant
María L. García Gettman, MSW, Ph.D. Student
Andrea Doerfler, MSW, Ph.D. Student
Peris Kibera, B. A., Graduate Student Intern

Project Advisory Board & Consultants

(For more about the study, see the monograph by Brennan, Bradley, Ama, & Cawood, 2003, Setting the pace, available at: www rtc pdx edu).
Aim of Models of Inclusion in Child Care Project

To investigate programs and strategies that result in improved access for families of children with emotional or behavioral disorders to child care that is:

* Inclusive,*
* Family-centered,*
* Culturally appropriate,* and
* High quality.*
Inclusion

The delivery of comprehensive services to children with emotional and behavioral challenges in settings that have children without these challenges, and the participation of all children in the same activities, with variations in the activities for those children whose needs dictate the adaptation. (See Kontos, Moore, & Georgetti, 1998).
Research Questions:

1. What are the characteristics and practices of child care programs nominated for their inclusiveness which are associated with quality care for children and youth having emotional or behavioral disorders?

2. What are the barriers to achievement of inclusive child care in these programs, and the strategies successfully used by providers and family members to overcome these barriers?
Family support organizations, state level child care administrators, and heads of child care resource and referral networks nominated 109 programs throughout the United States.

Nine programs were selected for intensive study by an advisory panel of family members, child care experts, researchers, and children’s mental health practitioners.
### The Nine Centers

<table>
<thead>
<tr>
<th>Broken Arrow Clubhouse, OK</th>
<th>Kinder Haus Center, WV</th>
</tr>
</thead>
<tbody>
<tr>
<td>St Benedicts Center, KS</td>
<td>McCambridge Center, MO</td>
</tr>
<tr>
<td>Fraser School, MN</td>
<td>River Valley Child Development Services, WV</td>
</tr>
<tr>
<td>Family Resource Center, NC</td>
<td>Wayzata Home Base, MN</td>
</tr>
<tr>
<td>Little Angels Center, OR</td>
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### Participants and Procedure

<table>
<thead>
<tr>
<th>Participants</th>
<th>Number</th>
<th>Data Collection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Directors</td>
<td>9</td>
<td>Interviews, Archival Data</td>
</tr>
<tr>
<td>Staff</td>
<td>40</td>
<td>Interviews</td>
</tr>
<tr>
<td>Family Members</td>
<td>40</td>
<td>Interviews</td>
</tr>
<tr>
<td>Children</td>
<td>25</td>
<td>Observations</td>
</tr>
</tbody>
</table>
## The Interview Sample

<table>
<thead>
<tr>
<th>Directors</th>
<th>Staff</th>
<th>Family Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managed centers with between 32 and 1300 children</td>
<td>87% European Am. 7.5% African American 1% Asian Am. 1% Native Am.</td>
<td>76% Europ. Am. 8% His./Latino 8% Mixed/Other 5% African Am. 3% Asian Am.</td>
</tr>
<tr>
<td>Managed between 5 and 80 staff</td>
<td>Job tenure: 6 months to 21 years</td>
<td>Employment: 58% Full-time 25% Part-time</td>
</tr>
<tr>
<td>7 female 2 male</td>
<td>95% female</td>
<td>59% (n=21) emot./ behav. disorders.</td>
</tr>
</tbody>
</table>
Characteristics and Practices of Inclusive Centers

Center staff adopted a philosophy of inclusion.
Families were being supported in the centers.
Families played a crucial role in the centers.
Attitudes toward inclusion were targets for change.
Child care practice was strategic.
Cultural competence was critical.
Center staff adopted a philosophy of inclusion.

Value and accept all children
Provide a natural environment for care.
Adapt the program to meet individual needs.
Deliver family-centered services
Promote a successful experience for children and families.
Families were being supported in the centers

Indicated high levels of satisfaction with child care services.
Reported feeling confident that their children would be retained in care despite their difficulties
Had close connections with the child care staff, who made themselves personally accessible.
Were linked other needed services in the community, and received a comprehensive type of family support.
Families played a crucial role in the centers

Directors and staff recognized that partnership with families was critical to their success in including children with challenges. Families and staff were able to develop trusting relationships in which information could be exchanged freely for the benefit of the child. Families often worked with mental health consultants who provided assistance with the child’s center and home behavior.
Attitudes toward inclusion were targets for change

Exposure to children with challenges being successfully cared for in inclusive child care centers:

- changed the attitudes of parents of typically-developing children, and
- recently-hired staff members, and
- provided children with positive early experiences of differences in others.

Stigma experienced by children and parents was reduced.
Child care practice was strategic

Child care workers developed promotion strategies, which were practices designed to promote social and emotional development in children. They also employed transformational strategies to convert negative emotions and difficult behavior to positive feelings and actions. Mental health consultants and parents were often involved in designing and carrying out these strategies.
Cultural competence was critical

Staff strove:
- to develop a greater awareness of the ways in which the cultural backgrounds of families affected their daily work, and
- to become more competent in respecting and dealing with children from different cultures.
“They provide more of a family setting to all the children, and it’s weird because even though you have children of different learning levels, different disabilities or some kids don’t have disabilities at all, but different races, they all treat them the same. And it helps my daughter a lot because she doesn’t notice a difference in people, and I love that because it’s very rare.”
Barriers to Inclusion and the Strategies Used to Overcome Barriers

Negative attitudes/persistent efforts to change views.
Service gaps/advocacy and partnership with parents.
Cultural misunderstandings/outreach.
Negative attitudes/ persistent efforts to change views

Administrators and staff held firm:
- to their strengths-based approach and their belief in inclusion and
- worked patiently to change negative attitudes and decrease the level of blame placed on parents for their children’s behavior.

Staff handled safety concerns through communication with families and their competency in handling potentially hazardous behavior.
Service gaps/advocacy and partnership with parents

Long waits for mental health assessment and treatment were common in communities surrounding some of the centers. Transitions between one service system and another were not always smooth. These gaps were addressed by child care providers and parents forming partnerships on behalf of individual children; with older children, personnel from the schools were also involved in these partnerships.
All three groups of participants discussed the challenge of working through language differences and cultural misunderstandings. These were offset by outreach to families by staff, and the use of skilled language and cultural interpreters.
A Mother Talks About Family Support in Child Care

“I remember feeling so lost in what was going to happen to my child, and who was out there that was going to be able to help me help him to grow up and be a nice decent individual. I think finding a program like this really helps relieve some of that stress. Because, no matter what, [my son is] always going to have those social barriers to overcome, and being in a program like this is just that much more support I get as a working mom.”
Implications of the Study

Inclusive care requires creative and innovative practice based on:

- knowledge of individual children and their families,
- consultation with mental health service providers, and
- collaboration between families and child care staff.
Implications of the Study

The adoption of a staff philosophy that embraces inclusion is critical for maintaining children with challenges in child care, and serving their families. Family support needs to be part of the services offered in inclusive centers (Friesen, 1996; Rosenzweig, Friesen, & Brennan, 1999).
Overview of Fu Yau Project

Population served.

Project staff - culture and language.

Services provided - prevention, early intervention, consultation, treatment.

“Clients” - centers administrators and staff, family childcare providers, parents, families, children.
### Fu Yau Project: San Francisco’s Demographics (Population 780,000)

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Census 2000 0-5 years old</th>
<th>Census 2000 All Ages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian</td>
<td>27.0%</td>
<td>30.8%</td>
</tr>
<tr>
<td>White</td>
<td>25%</td>
<td>35.0%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>20%</td>
<td>14.1%</td>
</tr>
<tr>
<td>Black/African</td>
<td>9.0%</td>
<td>7.8%</td>
</tr>
<tr>
<td>Multiracial</td>
<td>19.0%</td>
<td>10.8%</td>
</tr>
</tbody>
</table>
Fu Yau Project: Program Demographics

More than 1200 children

Covering working poor, TANF/CalWorks, new immigrant families

Clients of diverse ethnicity, multicultural

Single parent/disrupted families common

Covers 21 center based sites and 12 family child care providers
Fu Yau Project: Staffing

1 part-time child psychiatrist

10 mental health consultants
- Marriage family therapists, clinical social workers, clinical psychologists

Language/culture - Chinese, Spanish/Latin, African American

Administrative support
Prevention (Who Will Be Involved)

Parent involvement

Program consultation

Early referral and resources

Case example
Early Intervention
(Who Will Be Involved)

In natural setting

In collaboration with other staff

In collaboration with other community organization

Case example
Consultation – Case Specific (Who Will Be Involved)

- Working with the child
- Working with family members
- Working with childcare
- Working the community

Case example
Treatment (Who Will Be Involved)

Crisis intervention
Individual child
Parent – child
Group – children
Group – parent – child
Case examples
Summary

Importance of matching language and culture
Prevention and early intervention
Involving the system
Limitations
Where to Find Me

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Chinatown Child Development Center
415-867-4435
415-392-4453
Fuyau@ramsinc.org
THE FAMILY-FRIENDLY WORKPLACE
Common Ground? Families and Employers
Julie M. Rosenzweig, Principal Investigator
Kitty Huffstutter, Research Assistant

Supported by:
National Institute on Disability and
Rehabilitation Research (grant # H133B990025), United States
Department of Education, and the
Center for Mental Health Services, Substance Abuse and
Mental Health Services Administration.
Common Ground?
Project Goals

To understand and describe how parents’ employment is affected when caring for a child with a mental health disorder.

To identify employment strategies used by parents to manage employment and family responsibilities.

To identify workplace practices and policies that support employees who are caring for children with special mental health needs.
The Parent Employment Experiences Survey

Web-Based Survey
30 questions
- 27 quantitative
- 3 qualitative

Participant recruitment through national family support organizations, two national conferences, & RTC National Advisory Committee members
Research Questions

What are the employment characteristics from parents’ perspectives that maximize work/life integration for employed parents of children with serious emotional and behavioral disorders?

What do parents who are caring for children with serious emotional or behavioral disorders identify as workplace supports and barriers to obtaining and maintaining adequate employment?
Participant Eligibility

Self-identified parents of children with emotional and behavioral disorders

Currently caring for children in the home

Employed, seeking employment, or unemployed by choice to care for their children with emotional or behavioral disorders
Participant Characteristics
N=349

322 women (94%)
83% European-American, 10% African-American
Average age = 42.93, range 22-73
Education: 34% “some college”, 25% “college degree”, 27% “graduate study or degree”
60% full time, 21% part-time, 19% unemployed
40% professional/technical, 16% executive/managerial, 12% administrative support
Median income range = $30,000-34,999
Family Characteristics

Partner status: 61% partnered, 39% single
80% biological parent, 13% adoptive parent
95% caring for child 7 days per week
766 total children
Mean number per family = 2.2
Mean age of total children = 12.46
60% of total children have serious emotional or behavioral disorder
- 27% girls, Mean age = 13.1
- 73% boys, Mean age = 12.51
Effects on Employment

17% currently unemployed to care for child with serious emotional or behavioral disorder

11% unable to find work due to caregiving responsibilities for child with serious emotional or behavioral disorder

27% (of total) have had employment terminated because of work disruptions due to care responsibilities

48% (of total) have quit work to care for child with serious emotional or behavioral disorder
Participant Ratings: Work-Family Fit

Participants were asked, “How satisfied are you with your ability to meet both work and family responsibilities?

Overwhelmingly, parents reported dissatisfaction with the degree of work-family fit.

Overall, 67% dissatisfied, 33% satisfied
How Parents Feel About Work-Family Fit

- Very Satisfied
- Satisfied
- Dissatisfied
- Extremely Dissatisfied

Employed Parents
Unemployed

Supporting Families-W#29
Parents were asked, "What have you personally found to be the most significant challenges/barriers to finding and keeping employment because you are caring for a child with emotional or behavioral disorders?"

Four Categories:
- Inadequate Workplace Support
- Lacking Community Resources
- Limited Workplace Flexibility
- High-level Stress
What Parents Say About Employment Barriers

One parent explains that, “Supervisors who are unable and unwilling to understand the long term nature of caring for kids with serious mental health problems. [They] think that if you have taken the child to the doctor every week for six months then the child should be ok. Generally, they are less supportive as time goes on.”

Another parent states, “While officially there are policies like the FMLA, it’s still hard for supervisors and co-workers to deal with my sudden absence. There is resentment, but also the question of whether I can do my job.”

This parent voices, “Finding sources to help care for your child that are qualified, dependable, and affordable is difficult. Without those services, one cannot work.”
What Parents Say About Employment Barriers

One parent writes, "Difficulty with school. They are not supportive and always calling about problems with school and do not follow through with handling or they do not notify me right away when something happens."

A parent comments, "This company was not flexible as a whole. I did have a supervisor who covered for me regularly and most of my co-workers were very supportive. However, before I left the company my supervisor was getting an enormous amount of pressure from higher-up. I felt his job may be threatened because of my performance and the amount he covered for me."

One parent expresses the stress of "the mental, emotional, and physical exhaustion I must continually deal with and still try to work."
Work/life integration strategies are ideas, plans, actions, resources, services, programs, or policies that when utilized by parents improve their ability to meet employment and family responsibilities; therefore enhancing satisfaction with multiple roles in the family, workplace, and community.
Participants were asked: “What strategies have you used to find and keep employment while you are caring for a child with emotional or behavioral disorders?”

Four major employment strategies identified:

1) Finding a job in a family-friendly workplace
2) Restructuring of employment
3) Disclosure in the workplace about child’s mental health status
4) Reciprocity and negotiation
Strategy: Finding A Family-Friendly Workplace

A *family-friendly workplace* is one that acknowledges and responds to the work and family responsibilities of its employees. There are four interrelated components:

- Benefits, policies, and programs
- Workplace culture and climate
- Workplace relationships
- Work processes, systems, and structures that sustain family-friendly practices (Pitt-Catsouphes, 2002)

**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).
What Parents Say About Finding A Family Friendly Workplace

"The strategy that I now have is to find an employer who is family friendly. I work for an airline and it provides me with great flexibility. I am able to trade shifts with other people to accommodate my needs. I also communicate more with my supervisor. Also, at the airline I don’t feel stigmatized."

Another parent explains, “Having been in retail for the majority of my career, I mentally kept track of those companies that pay the best and offer the best benefits for the fewest hours.”
Strategy: Restructuring Employment

Faced with inflexibility of job demands or schedules and lack of child care resources, parents frequently must alter their employment or leave the workforce completely. Gaining job flexibility is a central focus in the restructuring strategy.

Restructuring strategies include:
- Relocation to another community to enhance job opportunities, child care options, or school programs
- Shift in career focus or type of employment, including self-employment
- Reduce number of hours employed, full-time to part-time
- Reschedule when and/or where hours are worked, including: flex-schedule, telecommuting, job sharing
What Parents Say About Restructuring Employment

One parent comments, "I have had to leave a 12 month full-time job and take a lower paying position at school to be able to get his hours."

Many parents are forced to alter their careers altogether. This parent states, "My current strategy has been to quit my job and go back to school for medical transcription so I will increase my odds of being able to have a much more flexible employment situation."

Another parent shares, "I work in a less demanding job. I work less hours than I otherwise would...at a job that allows me to choose which days I will work."
Disclosure is very individual and personal. Only the parent knows the scope of the family situation and the job situation. A parent’s decision about whether or not to tell the supervisor or coworkers about a child’s mental health disability is complicated and has associated risks and benefits.

Benefits from disclosing may include increased support, improved work-family fit, increased use of benefits. Costs from disclosing may include: stigmatization, job insecurity, or job loss. Disclosure may be made by choice or by necessity.
The Process of Disclosure

Disclosure is a process that requires careful consideration of several factors such as:

To whom to disclose and how--supervisor, coworkers, human resources personnel, EAP?

Timing of disclosure--during hiring process, when child situation arises?

Amount and type of information disclosed--nature of disability, behaviors involved, anticipated frequency of interruptions?

Issues of confidentiality
Participants’ Disclosure

83.2% of the sample disclosed their child’s mental health status to the supervisor.
86.2% of the sample disclosed their child’s mental health status to coworkers.
What Parents Say About Disclosure

One parent explains, "Honesty with my employer. That has been the main strategy and working very, very hard when life is going well to make up for the times when I have to be out from work."

Another parents notes, "I do try to be up front with selective people about this. Some people I tell about my son's emotional disorder; to others I just say that my son has a chronic illness that sometimes requires hospitalization."

This parent calls attention to the chance that employers may not understand when she says, "All I've been able to do is explain to my employer the reality of my life with an autistic child. Some have understood and others have absolutely not!"
Strategy: Reciprocity and Negotiation

Workplace reciprocity refers to the relational process of mutual exchange between the parent/employee and the immediate supervisor or coworkers resulting in costs and benefits to both the parent and the workplace.

Reciprocity involves negotiation and accountability from all persons involved.

Reciprocity and negotiation may be formal or informal.
Potential benefits to the parent/employee
- better able to fulfill care responsibilities
- reduced stress

Potential costs to the parent/employee
- overworking to show appreciation for flexibility
- coworker resentment

Potential benefits to workplace
- higher work productivity from the employee
- increased commitment and engagement

Potential costs to the workplace
- “backlash” for instituting family friendly practices
What Parents Say About Reciprocity

One parent describes reciprocity when she states, "I have been employed in small, family owned businesses that understand the need for parents to be accessible to their kids. They have more flexibility to their positions, especially when you prove how valuable you can be to their business and give 150% when you are there."

Another parent explains the relational process when she says, "It is a give and take relationships with flexibility and understanding during times of crisis and when things even out, I attempt to give back 150%.”

With respect to co-workers this parent notes that, "I also offer to help co-workers in hope they can help when I need it."
Workplace Support Survey

To understand family support efforts from the workplace perspective

Nominations for family-friendly supervisors/employers

Mailed and telephone survey
Work-Life Integration: Perspectives from Family-Friendly Employers & Supervisors

On the meaning of being a family-friendly employer:

One supervisor noted that, “I think it's important that this company is some sort of link in the social services chain...we should be a support to employees in ongoing difficult circumstances.”

On the benefit of being a family-friendly employer:

Another supervisor commented, “[You have] better employees if the workplace is supportive of their need...you will retain people and have happier employees.”
On the importance of communication:

Reflecting on things employees can do to make it easier to be flexible, one supervisor comments:
“... keep me informed so I know what to expect...[it] doesn’t mean I need to know every detail, [but] more keeping [the information] up to date so [I am] not blind sighted.”

On responses to flexibility decisions among coworkers one supervisors simply states,
“...communication is key. Coworkers generally respond positively if they know something about [the] situation.”
Conclusions

Employment strategies developed by parents are only one component of achieving work/family integration. Workplace supports through family-friendly culture, polices and practices that address the unique needs of parents caring for children with disabilities essential for work/life integration.

Community-based resources including inclusive child care providers and responsive schools are essential to enhance parents’ participation in the workplace and the community.
Please share your comments with us. Is what we have presented today, similar or different from your experience? What ideas will you take home with you? How can we be more helpful in advancing family support? Anything else?