

Family Supports and Services in Early Childhood Programs

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Focus Today

- Describe my involvement in a Community of Practice (CoP) in Family Supports and Services
- Describe the nature of the problem in providing supports and services to families
- Describe current research and policy directions

Community of Practice in Family Supports and Services

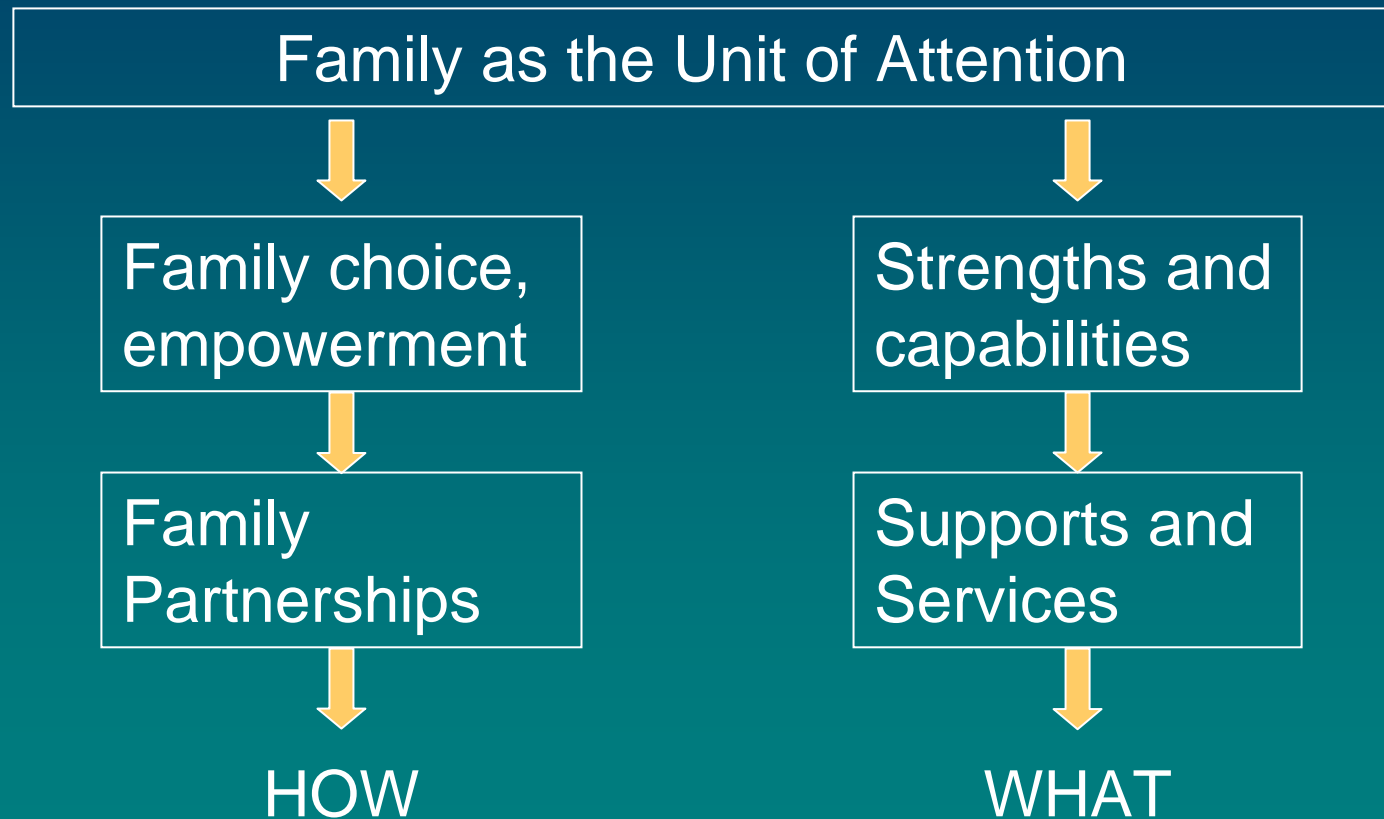
- CoP are groups who share a set of problems or passion about an issue and who deepen their knowledge and expertise by interacting
- Researchers, family leaders, service providers – about 45-50
- All share a commitment to enhance family supports and services through research, professional development, and improved practices

What is the Nature of the Problem?

- A convergence of four knowledge sources to understand and characterize the current gap in research and policy related to serving families in early intervention programs.
 - Empirical analysis
 - Conceptual analysis
 - Statutory analysis
 - Narrative analysis

Turnbull, A, Summers, J. A., Turnbull, R., Brotherson, M. J., Winton, P., Roberts, R., et al. (in press). Family Supports and Services: A Bold Vision. *Journal of Early Intervention*.

The Two-Pronged Concept in Family Centered Research and Practice



What's Happening to Family Supports?

State reports of services on the IFSP,
collected by NEC*TAC from 1994 to 2001

- Percents of OT, PT, and speech/language services have increased
- Percents of various family supports have decreased (e.g. family training & counseling 35.5% to 20.2%; social work 15.7% to 10.2%)

Early Childhood Outcomes Center (ECO)

ECO's Recommendations	OSEP's Recommendations
<ul style="list-style-type: none">■ Understand their child's strengths, abilities, and special needs■ Know their rights and advocate effectively for their children■ Help their children develop and learn■ Have support systems■ Access desired services, programs, and activities in their community	<ul style="list-style-type: none">■ Percent of families participating in Part C who report that EI services have helped the family<ul style="list-style-type: none">✓ Know their rights✓ Effectively communicate their children's needs✓ Help their children develop and learn

(Bailey et al., 2006)

Federal Mandate

- Purpose of Part C, IDEA: “To enhance the capacity *of families* to meet the developmental needs of their child.”
- DD Act – “To enable families to nurture and enjoy their children at home; maintain family unity; and preserve, strengthen, and maintain the family.”
- Statutes advance family-professional partnerships in ensuring key decision-making role for families and to protect their rights as a decision-maker

Summary of Statutory Analysis

- Statutory analysis
 - ✓ Focus primarily on child with disability rather than family
 - ✓ Lack of explicit requirements for family supports and services
 - ✓ Lack of accountability provisions for family outcomes
 - ✓ Statutes strong on *how* (partnerships) but weak on *what* (family supports and services)

Research and Policy Directions

- Conduct research on the outcomes of family supports and services for families - What do families really get from early intervention? (Current study)
- Conduct research on the impact of enhancing family outcomes on child outcomes
- Synthesize research within new conceptual framework of supports and services
- Partner with funding agencies to create priorities for research consortia on family supports / services
- Prepare for the next rounds of reauthorization of major legislation.

Family supports and services: What do families REALLY get from early intervention?

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Research Questions

1. What are the actual impacts/outcomes for *families*?
2. How do early intervention professionals implement family-centered practices to provide family supports and services?
3. What are the administrative structures professionals need to provide support to families?

Focus: Emotional Well-Being

- EI programs are accountable for outcomes for families – BUT lack knowledge on what supports and services lead to outcomes
- Emotional well-being is the area that parents were most vulnerable and professionals least comfortable in addressing
- Family emotional needs get in the way of reaching other outcomes – an important priority
- Emotional well being and emotional supports are hard to identify and measure – need to explore qualitatively as a first step

Our research design

- Ethnography - Exploring how family support is understood by people in context of the culture of early intervention:
 - Behaviors
 - Beliefs
 - Language – interactions and communication
 - Administrative structures

Our Data Sources

- Three sites – all serving 0-3, all home visiting models
- Interviews with 4 administrators
- Interviews with 18 professionals
- Interviews with 14 families: Agencies asked to select at least 2 families: “typical” and “challenged”
- Observations of home visits with 15 families

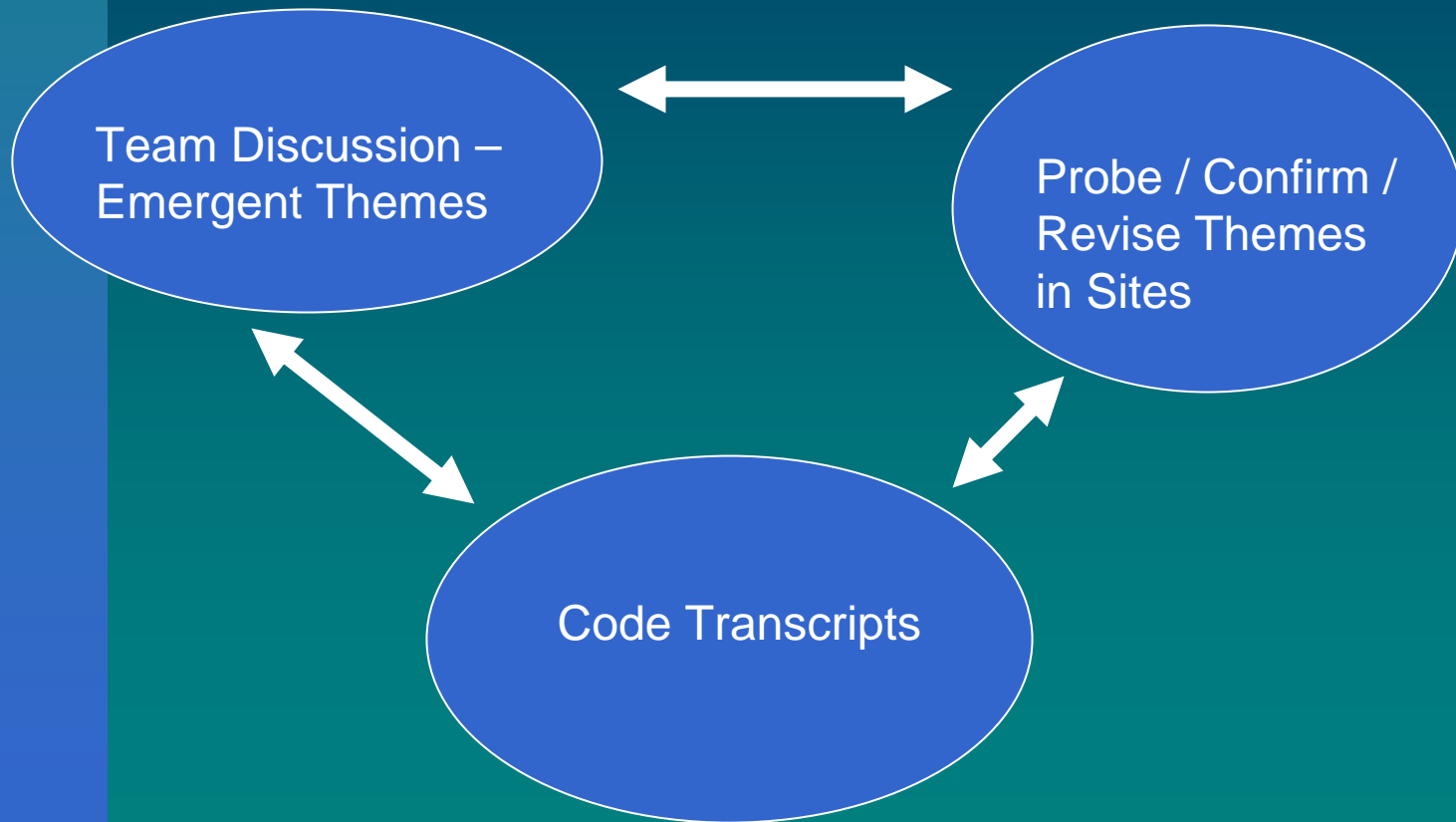
Emergent Analysis

- Site teams in each site conducted interviews, observations
- Full team meetings to discuss emerging themes
- Cross-checking in subsequent interviews with observations from other site team
- Continuous coding and theme development

Codebook Categories – QRS N6

- Administrative supports and structures
- Quality of life issues
- Program approaches/service models
- Levels of program involvement in service
- Impact and outcomes experienced by families
- Professional beliefs about partnerships
- Role of extended family and community
- Family background

Converging Theme Development with Coding Process



Research Rigor

- Multiple data sources
- Triangulation of researchers across sites
- Peer debriefings
- Credibility (member) checks
- Constant comparative approach to theme generation
- Audit trail

Results: Themes – Focus on Emotional Supports

Q. 1: What are emotional outcomes for families of early intervention?

- Emotional well-being – few services and unrecognized

Q. 2: How does emotional support “happen” in EI?

- Families cling to “normalcy”
- Challenged by challenging families

Q. 3: Administrative structures

- Professional time and energy for emotional support
- Administrators lead the way

Emotional well-being: Few services and unrecognized



Emotional well-being

- Few Services and unrecognized -
 - Parents described feeling emotional support – but few services to support emotional well being
 - Emotional outcomes are difficult to capture – professionals did not recognize or report

Emotional well-being

Parents described emotional support:

- Feeling less stress as a result of someone listening
- Feeling hope when they were told their child was doing well
- Feeling more confident when the provider said they were doing a good job

Emotional well-being

Yet emotional services were infrequent -

“They said don’t worry she’ll catch up – she’s just going to do it in her own time, you’ll see...I’m a bit more confident as a mom...But maybe if I could talk to some other parents that would help. I’ve been trying to find some sort of a support group with other kids that are like her so that I can get a feel for what I should expect – to maybe know what her future would be...”

Emotional well-being

Emotional services and outcomes rarely recognized or reported –

- Professionals focused on child outcomes and missed emotional support given
- As one EI provider said “Why write it down – it is already done. You may walk in and help them through a difficult emotional situation – then it’s done. I am not going to go back to the office and write a family outcome.”

Implications – Emotional Well-Being: Few services and unrecognized

- Policy that places greater emphasis on recognizing and responding to emotional well-being in families
- A measure of emotional well-being to capture these outcomes
- A continuum of emotional support and services as a guide to help professionals recognize and respond to emotional well being

Families seek “normalcy”



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Families seek “normalcy”

- Early intervention – a lifeline or early intrusion?
- This is my job as a mother – mothers take on the pressure to “make it work”
- Mothers experience sorrow:
Comparisons with other children

Families seek “normalcy”

■ Definition

- Families sought normalcy in terms of
 - ❖ Previous family roles, responsibilities, relationships
 - ❖ Social norms

■ Professionals’ roles

- Providers become a “lifeline” for seeking normalcy and a belief in the “power” of early intervention
- Early intervention becomes an intrusion on normalcy

■ Mothers’ roles

- “This is my job as a mother (parent)”

Families seek “normalcy”

- Early intervention as lifeline:

“...in helping [our son, the providers] try to give us as many resources as possible to help [with] parenting skills or adaptations...for his special needs. [They]...educate us to become better parents while they’re helping him be the best that he can be...we don't know what type of disabilities...all the [work]...now may help us to conquer an obstacle that shows up later. That's why we're doing everything to [give] him...a head start...now...”

-Father

Families seek “normalcy”

- Early intervention as intrusion:

“...[some] families...are really nervous about not accepting services...so they [consent to] services but in fact they really....don't [want] services. It's not a priority to them...I've had several families [who were] really nervous about what [would] happen if they didn't allow us to come.”

-Provider

Families seek “normalcy”

This is my job as a mother:

“I don’t think I really ask anything for myself, other than something to do with [my son]. Always, I think it’s about [him]. What he needs...or what we need to do for him to get him better.” -Mother

“...my routine is keeping my daughter’s routine and...the things I need...are secondary...it’s all about [her], you know, it really is...so, if it’s good for her, then she’ll have it.” -Mother

Implications – Families Seek Normalcy

- Greater awareness of emotional consequences and costs to mothers
- Provide parent to parent matches for mothers who want them
- Greater efforts to bring fathers or extended family into the program

Challenged by Challenging families



Challenged by Challenged Families

- Balancing the need to serve the child or the family
 - Professionals discuss being advocates for families, but turn away from more difficult emotional issues
 - To what extent do emotional issues fall within EI?
- Family strengths are elusive to providers
 - Lack of connection with challenged families; easier to work with those that are “more like us”
 - Providers focus on problems versus more holistic view
 - Use of language - “Frequent fliers” and “low functioning moms”

Challenged families

Professionals avoid difficult emotional issues

“The one thing I would have wished... [with] kids like our grandkids in a situation as to ours, that they would be able to speak up and speak out. And get a hold of the necessary authorities because I think that we wouldn't have lost the kids then. I mean, it's not their fault. It would have helped. I did talk to [provider]... She couldn't help.”

Is this in the realm of EI?

“[Mom] would call and say I have no money. I have no electricity, her house burned down . . . we were providing so much support, you know with money . . . She took advantage of it . . . Because she knew she could do it. .. we had lost our focus on the family.”

Challenged families: Elusive strengths

“You walk in and there is stuff on the floor ... you have no idea what it is and you still have to sit down ... it’s not the lifestyle that we’re used to and it can be very difficult ...that’s what their reality is and so I have to accept their reality as well if I expect them to be able to accept what I’m doing with their child.”

“I think the more difficult families are probably single parent families that maybe don’t carry over the strategies that I teach them. So I don’t see that much progress. They’re also the families that you know aren’t consistent . . . And the families that are usually a little bit easier are typical families where you have both mom and dad that are following the strategies. . . .”

Implications – Challenged families

- Re-examine the challenges of serving families in poverty in EI – what supports and services can we provide
- Have a greater understanding of the “values” of cultures and lifestyles unlike our own
- Look for strengths in all families

Professional Time and Energy for Emotional Support



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Professional Time and Energy for Emotional Support

- Definitions
 - Families, particularly mothers feel supported by parent/professional partnerships in which professionals spend time and listen to families
- Professionals' reality
 - Takes time to provide emphatic support
 - Large caseloads limit available time
 - Emotional effort/energy—"don't want to go there"
 - Providers struggle with setting boundaries
- Agency innovations
 - Use of weighted cases for more—"equitable and supportive" caseloads

Emotional Supports – Too much time and energy

- “...you can get hung up on families not doing things...and you can really get into a negative cycle about that family as opposed to realizing that my gosh, the fact is they got out of bed and they brushed their teeth today.”
- ‘...for those parents it becomes so emotional when you’re doing it with more than one...I don’t have the energy for that...but when you have two...and you know parents who have disabilities, you’re dealing with a whole different mind set...’

Implications – Professional time and energy for emotional support

- Recognize time and resources needed for listening and supporting families
- Address emotional effort and energy expenditure of professionals
- Families services such as parent support groups need greater usage

Administrators lead the way



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Administrative Structures

- In order to do their jobs well, the staff of agencies and schools need a variety of agency-wide structural supports.
- High-quality structural supports are a critical link in the chain that leads from policies at the national and state levels to the quality of life and opportunities for people with disabilities and their families.

Administrative Structures for Emotional Supports

- Families get what, when, and where? How much support and what kinds of support given to families is unclear.
- Administrative supports are the foundation – clear leadership, values, and language about support to families

Administrative Structures: Administrative Supports are the Foundation

- **EI Professional talking about supports:** Well one thing that they do very well is make learning opportunities available to us, if there's an area that you're interested in, they will find a way to send you to learn more and then when you come back, you teach your co-workers ... So they're very supportive in that regards.
- **EI Professional describing needed supports:** So I would like for somebody...to help me become a better employee, if somebody would say, "Okay, show me a chart of all the families that you've visited. Which ones are you struggling with, do you need help with someone, do you need ideas with this other family. I see that you have a standstill here, there's no progression." Just somebody that would sit down and...

Implications: Administrative Supports

- Renew and clarify our what, when, where, and how we deliver services to children with disabilities and their families.
- Renew and clarify policies regarding administrative support for non-typical services EI professionals end up providing.
- Continue to provide supports that enable EI Professional to implement DEC recommended practices.

Emerging Family Support Framework

(Turnbull et al., 2007, Beach Center on Families and Disabilities)

