DISCUSSION SUMMARY
FAMILY SUPPORT COMMUNITY OF PRACTICE MEETING:
EMERGING FAMILY SUPPORT CONSENSUS FRAMEWORK

DEC Conference
Little Rock, AR
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Presenters: Don Bailey, Mary Beth Bruder, Carl Dunst, Linda Gilkerson, Robin McWilliam, Richard Roberts, and Jean Ann Summers,

Parent Commentators: Sookyung Shin and Amy Khare

Participants: Mary Jane Brotherson, Daniel Dinnell, Pam Epley, Susan Fowler, Anna Friend, Andy Gomm, George Gotto, Lisa Greenwald, Gail Houle, Mary Kramer, Linda Mitchell, Susan Palmer, Jamie Ruppman, Lisa Sharp, Judy Swett, Pam Winton

Facilitator: Ann Turnbull

WHAT SUPPORTS SHOULD BE PROVIDED?

- **For issues concerning emotional well-being; support for:**
  - ✓ Experiencing, regulating, and expressing emotions
  - ✓ Dealing with upsets, pain, and negativity
  - ✓ Receiving professional counseling
  - ✓ Addressing mental health concerns (e.g., depression, schizophrenia)
  - ✓ Preventing mental health problems
  - ✓ Dealing with grief after child dies

- **For issues concerning material supports; support for:**
  - ✓ Accessing needed equipment and materials
  - ✓ Accessing needed financial resources
  - ✓ Having adequate insurance and dealing with insurance issues

- **For issues concerning health; support for:**
  - ✓ Having a medical home
  - ✓ Preventing health problems
  - ✓ Fostering parent and child wellness
  - ✓ Screening for health problems
  - ✓ Carrying out ongoing surveillance of health and development
  - ✓ "Forecasting" and screening related to genetics
  - ✓ Having adequate insurance and dealing with insurance issues
  - ✓ Getting sufficient sleep
  - ✓ Preventing, delaying, or reducing the severity of secondary conditions

- **For issues concerning the family's interactions (both within and outside of the family unit); support for:**
  - ✓ Addressing needs of other children
  - ✓ Having time for self
  - ✓ Having social opportunities
  - ✓ Establishing close and secure interpersonal relationships
  - ✓ Addressing the needs of the whole family, as well as the child with special needs
  - ✓ Making decisions about whether to have additional children in light of reproductive risks or concerns about the scope of needs of the child with a disability/pre-symptomatic conditions
  - ✓ Knowing when and how to tell family members, friends, and others about the child's actual or pre-symptomatic disability

- **For issues concerning parenting; support for:**
  - ✓ Minimizing or preventing behavior problems
  - ✓ Accessing parenting resources
  - ✓ Learning techniques to foster child's development
  - ✓ Accessing community resources
  - ✓ Having clear understanding of child development

- **For issues concerning disability-related services; support for:**
  - ✓ Understanding and acting on legal rights
  - ✓ Receiving state-of-art service coordination
  - ✓ Addressing issues of future concerns related to the child's disability
  - ✓ Accessing Early Care and other education services
  - ✓ Having clear understanding of child's disability
  - ✓ Having clear understanding of intervention treatment options
  - ✓ Preparing parents to participate in policy-making related to disability
  - ✓ Accessing child care in light of special needs

HOW SHOULD FAMILY SUPPORTS AND SERVICES BE PROVIDED?

- **Use family-centered practices**
  - ✓ Be positive, responsive, friendly, and sensitive in interacting with the family
  - ✓ Listen longer than what is typical
  - ✓ Use participatory helpgiving practices
  - ✓ Build on strengths/assets
  - ✓ Build family capacity
  - ✓ Use positive communication
  - ✓ Accommodate to family's culture, agenda, priorities, and routines in the delivery of all supports and services (including parent's work schedule)
  - ✓ Foster equal family-professional partnerships throughout all delivery systems
  - ✓ Use a team approach (including virtual teams)
  - ✓ Deliver support to enhance self-reliance and attribution of progress to families
  - ✓ Use "4 Es" approach – ears (listen), elicit (ask), empathize, encourage

- **Use evidence-based practice**

- **Use reflective supervision**
  - ✓ Enable staff to address their own emotions
  - ✓ Provide appropriate consultation at all levels

WHERE ARE SERVICES DELIVERED?

- Through home visits and in family's activity settings (experiences, events, situations)
- In community activity settings (experiences, events, situations)

WHO DELIVERS SERVICES?

- Other parents who have a child with a similar need
- Formal support
- Informal support
- Early intervention program (program should have a staff member with expertise in providing family support)
- Specialists (related to both child and family needs)

WITH WHAT AMOUNT OF INTENSITY SHOULD SUPPORTS AND SERVICES BE OFFERED TO CHILDREN AND FAMILIES?

- Implement a response-to-intervention approach in terms of starting with less intense services and only increasing the intensity of services when less intense services are not sufficient, in light of systematic data-collection
- Avoid pile-on of too many services
- Keep service delivery simple
- Support families to mobilize resources on their own
- Provide 6-10 outcomes as a general guide for an appropriate amount of intensity
- Consider multi-systemic therapy which provides highly intensive services over a shorter period of time (www.mstservices.com)
- Avoid providing too little intervention (such as the 2-3 hours per month that many children and families receive)
- Avoid expecting families to do all of the follow-up on services that are not sufficiently intense

WHAT ARE APPROPRIATE FAMILY OUTCOMES FOR WHICH EARLY INTERVENTION SHOULD STRIVE TO OBTAIN?

- Family quality of life; increased confidence; increased competence
- Parental confidence and competence; family cohesion
- Family well-being; parental confidence and competence
- Family quality of life
- Family adaptation
- Quality of life to enhance well-being

- Family quality of life
- Family and community inclusion

SYSTEMS ISSUES

- Fund teams to have time to meet
- Fund reflective supervision
- Provide mental health consultation
- Add social/emotional supports and services to Part C
- Establish national EI guidelines and include children who are at-risk
- Link EI with interventions/services in domestic violence, substance abuse, and adult mental health
- Visualize a renewed Part C system that is universal, asset-based, effective, and simple
- Ensure that OSERS emphasizes family-professional partnerships
- Conduct research to learn more about the child and family outcomes associated with different service delivery models