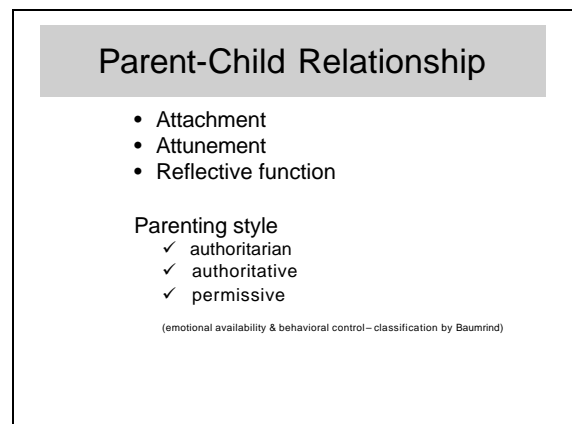
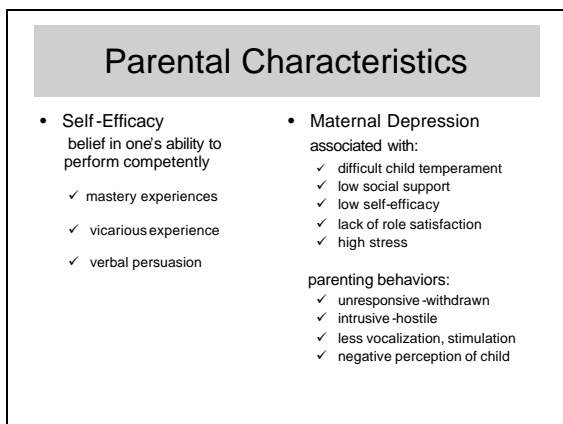
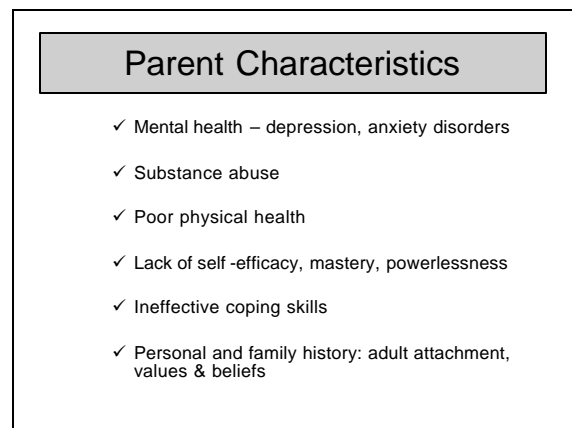
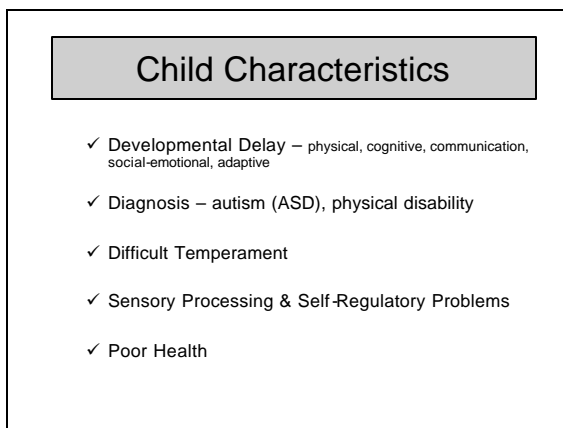
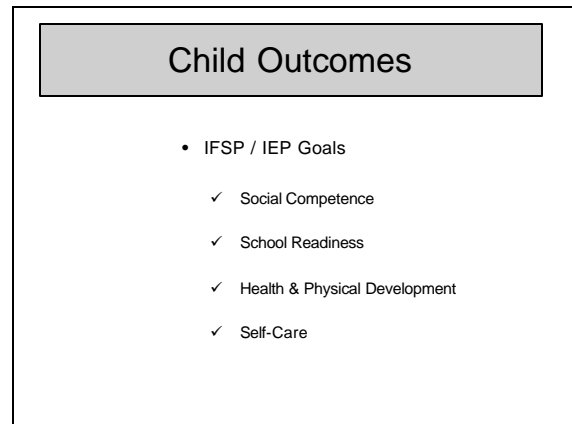
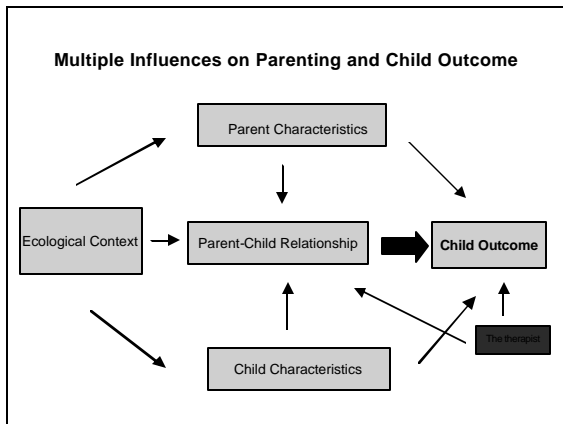


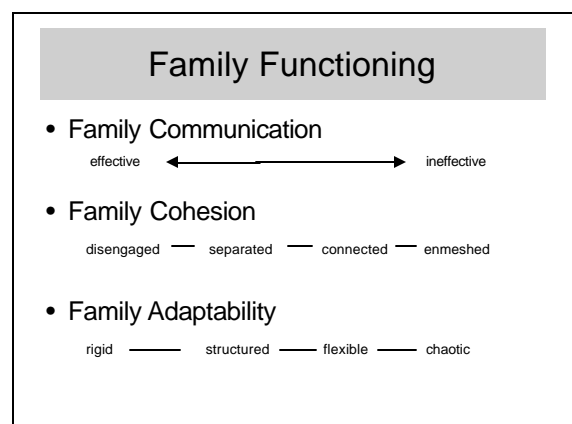
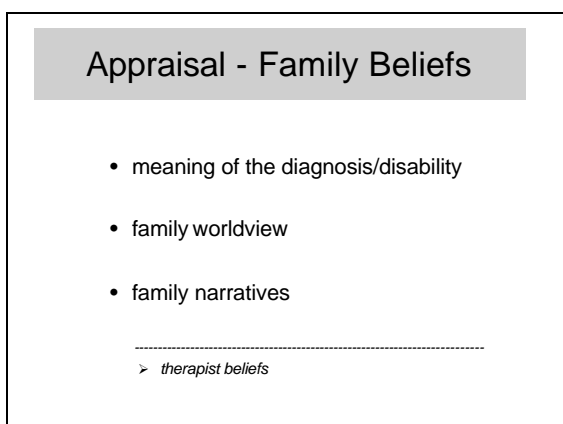
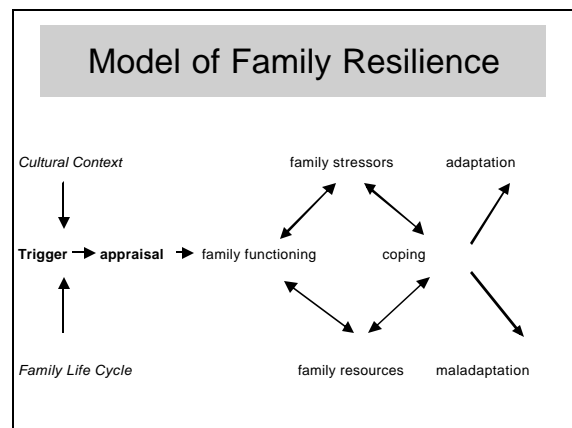
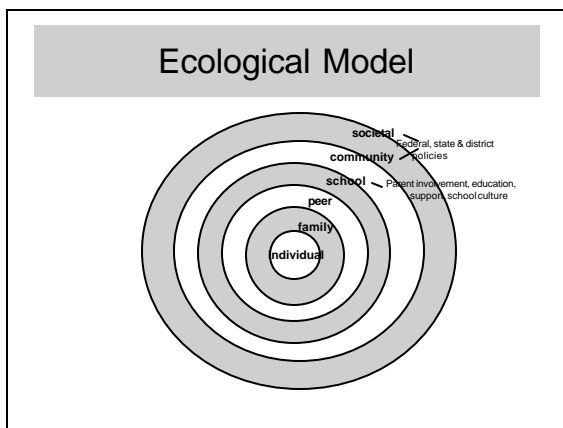
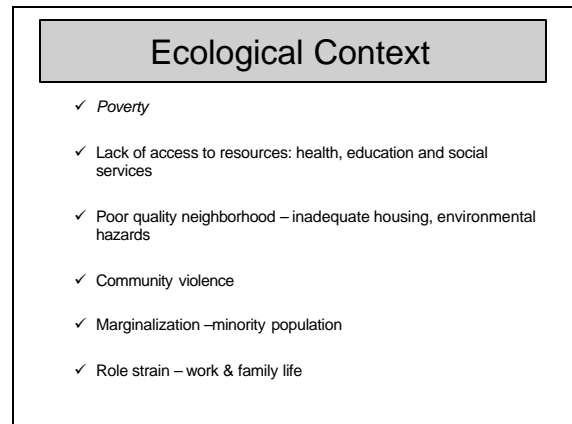
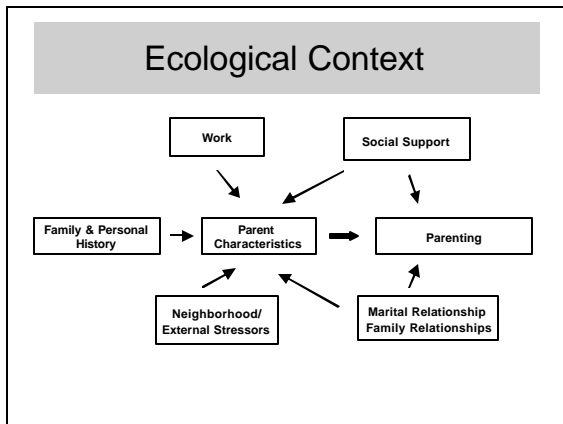
Parents as Partners Working with the Child in Context

Contemporary Practices in Early Intervention and
School-Based Practice: Fourth Annual Institute
April 7, 2006

Judy Grossman, DrPH, OTR, FAOTA

Ackerman Institute for the Family
Center for the Developing Child and Family

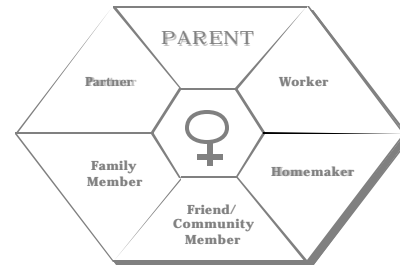




Family Stress

- Sources of stress
 - personal, couple, child, family, work & neighborhood
- Types of stressors
 - ✓ life events
 - ✓ daily hassles
 - ✓ chronic stress
 - ✓ role strain

Personal Best



Role Competence Curriculum
© Judy Gorman, DEdM, ODE

Family Resources

- Personal resources
- Social support
- Financial and material resources
- Spirituality and hope

Family Coping Responses

- Problem-focused coping
 - ✓ gain knowledge
 - ✓ problem-solving skills
 - ✓ reduce demands
 - ✓ acquire more resources

The activist / advocate
The researcher
- Emotional-focused coping
 - ✓ express feelings
 - ✓ manage tension, anxiety
 - ✓ reframe meaning
 - ✓ develop personal resources
 - ✓ seek social support/ spiritual guidance

The communicator
The cheerleader

Family Assessment

- Interview, conversation – understand the family's experience
- Observation – naturalistic, parent-child interaction, family process
- Self-report instruments
- Standardized instruments

Initial Conversation

- ❖ Tell me about your child – probe for strengths & abilities
- ❖ What does he/she like to do? What do you like to do together?
- ❖ When did you first notice a problem? Was your child different than you expected? Take time to get the family narrative – history of the problem (prenatal & birth history up to current time); empathize with the parent's experience.
- ❖ When did your child first get his/her diagnosis?
- ❖ What do you think caused the problem?
- ❖ Does anyone in the family have similar problems or characteristics? Does your child remind you of someone?

Initial Conversation

- ❖ Tell me about your family. Take time to ask about all family members.
- ❖ What kinds of things does your family enjoy doing together?
- ❖ How have things changed since your child's diagnosis? How does your child's disability affect the family? Your day to day experience? Family routines?
- ❖ Are there other significant stressors/concerns in your family?
- ❖ How has the family pulled together?
- ❖ What has worked for you? What hasn't worked? What else have you tried?
- ❖ Where do you get support? Practical help? Advice? Are you satisfied?

Initial Conversation

- ❖ Are you satisfied with the services that your child and family have received?
- ❖ Do you have any other concerns that we haven't talked about?
- ❖ What are your goals for your child? Ask about priorities.
- ❖ How can we work together to achieve your goals?

Phone Conversation

My life is so altered, my life is led by my son. If he has a good day, I have a good day; if he has a bad day.....

When your child has many therapies your privacy goes out the window, forget about it!

In team meetings, I still feel like they can say things like I am invisible or say negative things about my son.

Therapists are training me to take care of my child – can you imagine, I need someone to teach me how to be with my 8-year-old son.

I know my child best but I don't always know what is best for my child.

Emotional Adaptation of the Parent

- Stages of the grief process
 - ✓ Shock
 - ✓ Denial
 - ✓ Self-blame (over-identification)
 - ✓ Anger
 - ✓ Depression
 - ✓ Acceptance
 - ✓ Hope
- Each transition can activate the grief process

Impact on Relationships

- The marital relationship
- Siblings
- Extended family
- Family routines

Family resources, priorities and concerns

Family-directed assessment to identify supports and services necessary to enhance the family's capacity to meet the developmental needs of the infant or toddler

IFSP

- Family training, counseling, home visits and parent support groups
Assist the family in understanding the special needs of the child and enhancing the child's development
- Providers of EI services shall be responsible for providing support, education and guidance to parents and other caretakers regarding the provision of those services
- Service model options:
 - ✓ provision of EI services to child and/or parent
 - ✓ parent-child groups
 - ✓ family/caregiver support group

Parent Counseling & Training

- Assist parents in understanding the special needs of their child
 - provide parents with information about child development
 - help parents acquire skills to support the implementation of their child's IEP
- while parent counseling & training may be recommended for any student, the regulations require that provision be made to enable parents to perform appropriate follow-up intervention activities at home for parents of:
- students in special classes
 - students with autism
 - preschool students

Public Law 108-446

- Parent training and information activities assist parents of a child with a disability in dealing with the multiple pressures of parenting such a child
- Assist parents in the development of skills to participate effectively in the education and development of their children
- Foster positive relationships with parents

Autism Program Quality Indicators

- the program makes available *parent counseling and training services*, which
 - ✓ provide parents with information about child development
 - ✓ assist parents to understand the needs of their child
 - ✓ foster coordination efforts between home and school
 - ✓ support the family in behavior management

NYSED APQI for children 3-21

Service Delivery

- ❖ joining – importance of relationship, authentic partnership
- ❖ shared observation – parent's reflective function, look for normalcy
- ❖ focus on the parent-child relationship
- ❖ consider the parents' concerns and priorities
- ❖ incorporate interventions into naturally occurring daily life activities
- ❖ help parents manage family rituals and routines
- ❖ help parents prepare for transitions and all special education meetings

parents should be actively involved in all aspects of ongoing assessment & intervention to the extent of their interest, resources and abilities

Service Delivery

- ❖ function as a team; coordinate plans & services among providers & parents
- ❖ avoid competition between therapist and parent
- ❖ don't increase family stress through your expectations or excessive demands
- ❖ interventions should not be all work, nurture the relationship
- ❖ build on individual and family strengths
- ❖ empower parents, support their sense of self-efficacy, competence and self-confidence
- ❖ balance hope and practical reality
- ❖ support the families overall well-being
- ❖ continually ask for feedback about what is working

Service Delivery

- Reflective Practice – what do you bring to the interaction?
 - how do you feel about working with this family?
 - recognize issues of countertransference
 - are you reacting to the parent's emotional state?

Family-Centered Practice

- ❖ Family is the expert in the child's life
- ❖ Treat families with respect & dignity
- ❖ Honor cultural diversity
- ❖ Identify and build on family strengths
- ❖ Focus on family's identified needs & priorities; explore expectations
- ❖ Develop partnerships & collaborate with families

Family-Centered Practice

- ❖ Exchange information so families can make informed decisions
- ❖ Recognize different methods of coping; improve problem-solving skills
- ❖ Strengthen family supports
- ❖ Provide flexible, comprehensive, coordinated services
- ❖ Emphasize prevention & early intervention

My Family Beliefs

- ◆ **Family Beliefs About Discipline** – What is the best way to get children to behave? [How were you disciplined?]
- ◆ **Family Beliefs About How Children Should Behave** – Do you worry about spoiling your child? [Did your family have realistic expectations of you as a child?]
- ◆ **Family Beliefs About Rules** – What kind of rules should a family enforce to raise a good child? [What were the rules at home when you were a child?]
- ◆ **Family Beliefs About Play** – How much and what kind of play should be encouraged? [How did you and your family play and have fun together?]
- ◆ **Family Beliefs About Gender** – How should boys act and how should girls act? Should they be raised the same? Should you expect the same things? [Were you treated differently because you were a girl?]
- ◆ **Family Beliefs About Fathers** – What role do fathers play in their child's development? What is the influence of the father on his child? [Did your father have an influence on you growing up?]
- ◆ **Family Beliefs About Mothers** – Do you have realistic expectations for yourself as a mother? [What were the family expectations of your mother?]
- ◆ **Family Beliefs About Success** – What values do you want to promote in your family? Values can include personal characteristics or actions that give life meaning such as the importance of education, obedience and respect for elders or hard work. [What values did your family encourage when you were growing up?]
- ◆ **Cultural Beliefs About Childrearing, Parenting & Family Life** – How much are your values and beliefs influenced by your cultural group? Are they consistent with the cultural practices of families from similar backgrounds, e.g., approaches to discipline, routines such as bedtime and family meals, family rituals and celebrations, or male and female role expectations. [Did your family share similar practices and beliefs with other families from the same cultural background?]

REFERENCES: FAMILY RESILIENCE

Judy Grossman DrPH, OTR, FAOTA

- Belsky, J. (1984). The determinants of parenting. *Child Development*, 55, 83-95.
- Campbell, T.L. (2003). The effectiveness of family interventions for physical disorders. *Journal of Marital and Family Therapy*, 29, 263-281.
- Carter, B., & McGoldrick, M. (Eds.). (1998). *The expanded family life cycle: Individual, family, community*. Needham Heights, MA: Allyn & Bacon.
- Danielson, C.B., Hamel-Bissell, B. & Winstead-Fry, P. (1993). *Families, health and illness: Perspectives on coping and intervention*. St. Louis, MO: Mosby.
- Dunst, C., Trivette, C., & Deal, A. (1988). *Enabling and empowering families*. Brookline, MA: Brookline Books.
- Dunst, C.J., Trivette, C.M., Deal, A.G. (1994). *Supporting and strengthening families: Vol. 1: Methods, strategies and outcomes*. Cambridge, MA: Brookline Books.
- Ell, K., & Northen, H. (1990). *Families and health care: Psychosocial practice*. New York: Walter de Gruyter, Inc.
- Erickson, M.F., & Kurz-Riemer, K. (1999). *Infants, toddlers, and families: A framework for support and intervention*. New York: The Guilford Press.
- Garbarino, J. (1995). *Raising children in a socially toxic environment*. San Francisco, CA: Jossey Bass Publishers.
- Gilkerson, L., & Stott, F. (2000). Parent-child relationships in early intervention with infants and toddlers with disabilities and their families. In C.H. Zeanah (Ed.). *Handbook of infant mental health* (pp.457-471). New York: The Guilford Press.
- Habin, G.L., McWilliam, R.A., & Gallagher, J.J. (2000). Services for young children with disabilities and their families. In J.P. Shonkoff & S.J. Meisels (Ed.). *Handbook of early childhood intervention* (pp. 387-415). New York: Cambridge University Press.
- Imber-Black, E. (1988). *Families and larger systems*. New York: Guilford Press.
- Luster, T., & Okagaski, L. (1993). *Parenting: An ecological perspective*. Hillsdale, NJ: Lawrence Earlbaum Associates, Publishers.
- McCubbin, H.I., & Cauble, A., & Patterson, J. (Eds.). (1982). *Family stress, coping, and social support*. Springfield Ill: Charles C. Thomas.
- McCubbin, H.I., & Figley, C.R. (Eds.). (1983). *Stress and the family: Coping with normative transitions*. New York: Bruner/Mazel.

McCubbin, H.I., & Thompson, A.I. (Eds.). (1987). *Family assessment: Interventions for research and practice*. Madison WI: University of Wisconsin- Madison Press.

McGoldrick, M. (Ed.). (1998). *Re-visioning family therapy: Race, culture, and gender in clinical practice*. New York: The Guilford Press.

McGoldrick, M., Giordano, J., & Pearce, J. (Eds.). (1996). *Ethnicity and family therapy*. New York: Guilford Press.

Molina, C.W., & Aguirre-Molina, M. (1994). *Latino health in the US: A growing challenge*. Washington, DC: American Public Health Association.

Patterson, J.M., & McCubbin, H.I. (1983). Chronic illness: Family stress and coping. In C.R. Figley & H.I. McCubbin (Eds.). *Stress and the family II: Coping with catastrophe* (pp. 21-36). New York: Bruner Mazel.

Rolland, J.S. (1994). *Families, illness & disability: An integrative treatment model*. New York: Basic Books.

Saracho, O.N., & Spodek, B. (1983). *Understanding the multicultural experience in early childhood education*. Washington, DC: National Association for the Education of Young Children.

Shelton, T.L., & Stepanek, J.S. (1994). *Family-centered care for children needing specialized health and developmental services*. Bethesda, MD: Association for the Care of Children's Health.

Smith, T.B., Oliver, M., & Innocenti, M.S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry*, 71, 257-261.

Walsh, F. (2003). Family Resilience: A framework for clinical practice. *Family Process*, 42, 1-18.

Walsh, F. (1998). *Strengthening family resilience*. New York: The Guilford Press.

Wehman, T. (1998). Family-centered early intervention services: Factors contributing to increased parent involvement. *Focus on Autism and Other Developmental Disabilities*, 13, 80-87.

Select Journals: *Family Systems and Health*; *Family Process*; *Journal of Marital and Family Therapy*; Collaborative HealthCare Coalition - www.infor@cfhc.org
The Institute for Family-Centered Care, Bethesda, MD