

## Westchester Institute for Human Development

### FAMILY PARTNERSHIP

LEND 2005-06

#### **Faculty, Fellows and WIHD Staff:**

Barbara Levitz, M.S., Rosario Areizaga, Patricia Aguayo, M.D.,M.P.H., Laura Carfi, Diane Montero-Heyert, Barbara Stein M.A.T., Marilyn Vitale, M.A.

#### **Guest/sAffiliated Faculty:**

Linda Caruso, Diane Greble, M.S Cynthia Lanza, Stephanie Rifkinson-Mann, M.D., J.D. Adriana Suvaiala,, M.B.A., M.S.

#### **Overview:**

Families have a natural and pivotal role as the major influence in the lives of children with disabilities and special health care needs. Families continue to identify the need for assistance in accessing, obtaining and coordinating services and supports for their children and themselves. Contemporary models of service delivery emphasize family-centered care and family empowerment in which families act and are viewed as active decision-makers and team members who have the potential to influence policy and planning with the outcome of creating systems change.

The goal for these LEND sessions is to define and explore exemplary practices in family-centered care, family support, service coordination, cultural competence, and parent/professional collaboration. This will include information on community resources and partnerships in family empowerment, advocacy and policymaking, and systems change. Legal, moral and ethical issues related to children with special health care needs and their families will be discussed within the context of parent/professional collaboration in health care decision-making. Presentations will utilize lecture, discussion, videotape, parent panels, self-assessment tools and informational material.

#### **Objectives/Competencies:**

After participating in these sessions, LEND trainees will:

- ◆ List key issues of families and health care professionals in caring for a child with disabilities and special health care needs.
- ◆ Demonstrate family-centered practices including cultural competence and “people-first” language.
- ◆ Demonstrate the value of parent-to-parent and other informal natural supports for families.
- ◆ Be aware of the use of family-centered self-assessment tools.
- ◆ Describe service coordination and how to assist families in accessing community resources.
- ◆ Define family support and family quality of life, and describe the role of parent advocacy and empowerment in policy, planning, and systems change.
- ◆ Appreciate and respect the importance of parent/professional collaboration.
- ◆ Describe challenges of legal, moral and ethical issues involving health care decision-making for children with complex medical needs.

## **Session 1- 11/03/05**

**9:00-12:00**            **Family-Centered Care, Family Quality of Life, and Parent/Professional Collaboration**

Aguayo, Greble, Levitz, Suvaiala

**1:00-2:30**

### **Leadership Seminar:**

**Legal, Moral and Ethical Issues in Health Care Decision Making**

Rifkinson-Mann, Vitale

## **Session 2- 11/10/05**

**9:00-12:00**

### **Access to Systems of Care:**

**Advocacy, Family Support, Service Coordination and Community Resources**

Areizago, Carfi, Caruso, Heyert, Lanza, Levitz, Stein

### **Selected LEND Course Manual Resource Material:**

- Agosta, John. (2004). "Family support is dead...long live family support!!" In Family Support Policy Brief #7 Portland, OR: National Center for Family Support.
- Brengman, Sylvia. (2005). "Caring for Sarah: a mother's story". In Impact: feature issue on enhancing quality and coordination of health care for persons with chronic illness and/or disabilities, Vol.18-No.1. Minneapolis, MN: Institute on Community Integration (UCEDD).
- The Association of Maternal and Child Health Programs (August 2000). "Care coordination for children with special health care needs and their families in the new millennium". Washington, D.C.: Author.
- Beach Center. (1991). "Family-centered program rating scale: user's manual". Lawrence, KS: Author.
- Blue-Banning, M., Summers, J., Frankland, H.C., Nelson, L.L., Beegle, G. (2004). "Dimensions of family and professional partnerships: constructive guidelines for collaboration". In Exceptional Children, Vol. 70-No. 2: 167-184. Arlington, VA: Council for Exceptional Children.
- Developmental Disabilities Assistance Bill of Rights Act of 2000, Title II, Family Support.
- Gaylord, V., (Ed.) (2000). Impact: feature issue on partnering to improve health care for children with disabilities. Vol.13-No. 2. Minneapolis, MN: Institute on Community Integration (UAP).
- Higgins, C. (Ed.) (1997). "Family-centered service delivery". In Families and Disability Newsletter, Vol. 8-No.2. Lawrence, KS: Beach Center on Families and Disability at The University of Kansas.
- Mitchell, L.& Philibert, D.B. (2002). "Family, professional, and political advocacy: rights and responsibilities". In Young Exceptional Children, Vol. 5- No. 4. Missoula, MT: Division for Early Childhood Education & Sopris West.
- Oklahoma Family Support Partnership Project (2003), "Individual and family support principles to practice indicators. Oklahoma City, Oklahoma: Center for Learning and Leadership/UCEDD-College of Medicine, OUHSC and Oklahoma Family Support Partnership.
- Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J. and Wang, M. (2003). "Family quality of life: a qualitative inquiry". In Mental Retardation, Vol. 41-No.5: 313-328. Washington, D.C.: American Association on Mental Retardation.
- Trivette, C. and Dunst, C. (2004) "Parenting experiences scale". In Young Exceptional Children, Vol.7-No.3 Missoula, MT: Division for Early Childhood Education & Sopris West.

### **Other Recommended Reading (available for review in The Family Connection)**

- Exceptional Parent Resource Guide (2005). Vol.35, Issue 1. Marion, OH: Psy-Ed Corp.
- Goode, T.D. (2000). "Promoting cultural diversity and cultural competency: self-assessment checklist for personnel providing services and supports in early intervention and early childhood settings". Washington, D.C.: Georgetown University Child Development Center/UCED.
- Harry, B. (1992). *Cultural diversity, families and the special education system: communication and empowerment*. New York: NY: Teachers College Press: Columbia University.
- Meyer, D. (1995). *Uncommon fathers: reflections on raising a child with a disability*. Bethesda, MD: Woodbine House.
- Marsh, J.D.B. (1995). *From the heart: on being the mother of a child with special needs*. Bethesda, MD: Woodbine House.
- Santelli, B. Turnbull, A., Lerner, E. & Marquis, J., (1993). "Parent-to-parent programs: a unique form of mutual support for families of persons with disabilities". In Singer, G.S. & Powers, L. (Eds.) *Families, disability and empowerment: Active coping strategies for family intervention*. Baltimore: Paul H. Brookes.
- Snow, K. (2001). *Disability is natural: revolutionary common sense for raising successful children with disabilities*. Woodland Park, CO: BraveHeart Press.
- Singer, G.S., Powers, L. & Olson, A., (Eds.) (1996). *Redefining family support*. Baltimore: Paul H. Brookes.

### **Course Outline**

#### **Session 1–11/03      Family-Centered Care, Advocacy and Parent/Professional Collaboration** Brenner, Greble, Levitz, Suvaiala,

9:00–9:30	<u>Introduction to Family Partnerships</u> Defining "Family", "People-First" language, "Disability is Natural" video
9:30-10:15	<u>Family-Centered Care</u> ➤ "Family-Centered Care", ACCH video ➤ Quality Indicators of Family-Centered Practices
10:30-10:30	Break
10:30-11:45	<u>Parenting Children with Disabilities and Special Health Care Needs:</u> A Panel Discussion with Family Specialist LEND Fellows ➤ Family Quality of Life, Parent/Professional Collaboration and Parent Advocacy
11:45-12:00	Summary and Assignment

### **Related Leadership Seminar**

1:00-2:30	<b>Legal, Moral and Ethical Issues in Health Care Decision-Making for Children with Complex Medical Needs, Their Families and Health Care Professionals</b> Rifkinson-Mann and Vitale
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**Session 2 – 11/10**

**Access to Systems of Care: Family Support, Service Coordination and  
Community Resources**

Areizaga, Caruso, Carfi, Heyert, Lanza, Levitz, Stein

9:00-9:45

Family Support

- Defining Family Support and Essential Features of Family Support Programs and Systems
- Overview of New York State’s OMRDD “Family-Directed” Family Support Services System Model:

9:45-11:45

Service Coordination and Families Accessing Community Resources

A Roundtable Discussion with Parents of Children with Disabilities and Special Health Care Need who are Service Coordinators for Other Families

11:45-12:00

Summary