

Leadership Education in Neurodevelopmental and related Disabilities Training Program
at
Westchester Institute for Human Development (WIHD) and
The School of Public Health
at New York Medical College
and the
Joan H. Marks Graduate Program in Human Genetics
at Sarah Lawrence College (SLC)

Incorporating Genetics into the LEND Program at WIHD

- Choice of genetics topic for one LEND interdisciplinary research team projects per year
 - See posters concerning two such projects
- Sarah Lawrence College (SLC) Human Genetics Program Director presents LEND sessions on genetics topics
 - See “Participatory Care” case handout as one example
- Genetics considerations included in case discussions re interdisciplinary approach
 - See “A child with language delay” handout as an example
- Genetic counseling included as one of the LEND disciplines during “Disciplinary Presentation” series
 - See “Guidelines for Disciplinary Presentations”
- Sarah Lawrence Program Director is a panelist or co-discussant for interdisciplinary case discussion and disciplinary presentations during several LEND sessions and attends, with one or more other SLC faculty, the end-of-year LEND poster session at WIHD
- Three SLC genetic counseling students have been included in the WIHD LEND group since 2004, assuring that genetics issues arise and can be addressed to some extent during group discussions, even when a genetics faculty member is not present

Incorporating LEND curriculum into training of genetic counselors

- SLC students in LEND program write thesis based on, or as an outgrowth of, participation in WIHD LEND research teams
 - See three cover pages and abstracts from such theses
- LEND faculty serve as thesis advisors for SLC graduate students who are LEND trainees
- LEND program director is a member of SLC’s thesis project planning group
- LEND faculty/staff give presentations at SLC

Summary of SLC-WIHD LEND collaboration in research training:

- See handout of poster presented at AUCD meeting 11-06

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Participatory Care in Genetic Counseling: Case Discussion

Caroline Lieber MS, CGC
Director, Human Genetics Program, Sarah Lawrence College
Erin Carter, Ushtavaity Davar, Alice Hawkins, LEND fellows

1/06 Presentation to LEND Trainees
Westchester Institute for Human Development

The goals of this session are:

- 1) To use a multidisciplinary process to discuss the approach to a child presenting with certain history and physical examination findings which suggest a genetic or congenital etiology
- 2) During small group discussion, consider the cultural, family, economic, and social factors which must be addressed to best serve this child and her family
- 3) For trainees to gain insight into the approach used by genetic counselors to evaluate and counsel individuals referred to them.

A seven year old Hispanic female is referred to the genetics service for evaluation because of certain findings on history and physical examination. In brief: She is at the 75th percentile for height and weight, and her head circumference is at the 50th percentile. She has several café-au-lait spots on her torso, her hair is two different textures (soft over most of her head, but very coarse around a hair whorl on the right crown of her head). The right side of her face is larger than the left side. Developmentally, she is not keeping up with her classmates. The pediatrician who referred her is concerned that these findings might be consistent with a neurocutaneous disorder.

The genetic counselor seeing the child and her mother has learned that the child's family is from Colombia, South America, and they speak very little English. The father is not present at the meeting, as he is working. The child's health care is covered by a Medicaid managed care plan.

**LEND Program at WIHD
September 2006**

A child with language delay

Ms. B. is concerned that her two and a half year old son, L.B., is not speaking as much as his eight year old brother was speaking at 2 ½. In fact, L.B. can say only five or ten words, all of them familiar nouns. He can understand simple household commands. His mother notes that he often does not pay attention when people speak to him. She also notices that he does not seem as “coordinated” as his older brother was at this age and that he hasn’t gotten as far as she would expect in feeding himself. She is concerned enough that she made an appointment to take her son to his pediatrician.

The pediatrician agrees that L.B.’s language is delayed. Other important information shared by Ms. B is that her child has a habit of flapping his hands and biting his hands. Family history is significant for mother’s 40 year old brother having moderate cognitive disability (first noted at age three).

The pediatrician recommends a referral to Early Intervention (EI) and Ms. B agrees. The pediatrician also notes in the chart that in light of family history and the developmental and behavioral findings, the child should be referred to genetics / genetic counseling at a future date. She decides to wait until the child comes for a return visit after the EI core evaluation to discuss this recommendation with Ms. B.

Ms. B calls the Westchester County Department of Health EI office. An initial service coordinator (who is a social worker) is selected. The initial service coordinator contacts the parent, discusses concerns, and then suggests options for a core evaluation. They arrange to have the psychologist and speech/language pathologist do a core evaluation in the home.

A few weeks later, the pediatrician asks Ms. B to return for follow-up and discusses with her the recommendation that the child be evaluated by genetic counseling/medical genetics. The child is then seen by genetics/genetic counselor for evaluation.

As part of the Individualized Family Service Plan, the family is referred to a social worker for parenting training and to an occupational therapist because of “low tone” detected by the EI core evaluators and because of the history of feeding difficulties.

The LEND Training Program
at
**Westchester Institute for Human Development and
the School of Public Health at New York Medical College**

**Guidelines for Disciplinary Presentations
2006-2007**

In September, we discussed the interdisciplinary approach to evaluation of a child with language delay in order to begin to understand the role of various disciplines in this process. The **Disciplinary Presentations** provide an opportunity to share with LEND trainees from other disciplines more detail about how you work with children who have or are at risk for having developmental disabilities and their families.

With other LEND trainees from your discipline, and in consultation with faculty from your discipline, prepare a twenty minute presentation (do not use Powerpoint) which helps LEND trainees from other disciplines to understand your discipline and how you work with children and adolescents with, or at risk for, developmental disabilities and their families. Please limit your discussion to your discipline's work with children and adolescents.

On October 12, presentations will be made by the Occupational Therapy, Speech/Language Pathology, Psychology, and Psychiatry groups. **On October 19**, presentations will be made by the Social Work, Genetic Counseling, and Family Specialist groups (Family Specialist group should meet with Barbara Levitz before starting this assignment since there are special guidelines for your group).

Each team member should present a portion of the team's presentation.

Each team's presentation should include these elements:

- 1) Briefly state the educational and NYS licensure requirements (if any) for your discipline.
- 2) List the settings in which your discipline does clinical practice and is most likely to encounter children and adolescents with disabilities (or at risk for disabilities). For each setting, describe the most common reasons for them to come to your attention.
- 3) Briefly describe (in terms which can be understood by someone who is not from your own discipline!) standard elements of an evaluation by a member of your discipline of a child or adolescent with, or at risk for, developmental disability. Describe how family members would be involved in the evaluation.
- 4) State the professional organization which students in your discipline typically join and briefly state the benefits to students of joining the organization. Indicate

whether there is a regional or local chapter of the group which accepts students as members.

5) Ask if your colleagues from the other LEND disciplines have questions about what you have presented.

These resources may be helpful to you in preparing your presentation:

Annotated listing of LEND disciplines provided in the LEND Manual

Professional organization websites:

American Speech-Language Hearing Association
<http://www.asha.org>

American Psychological Association
<http://www.apa.org>

National Society of Genetic Counselors
<http://www.nsgc.org>

National Association of Social Workers
<http://www.naswdc.org>

American Occupational Therapy Association
<http://www.aota.org/>

The American Academy of Child and Adolescent Psychiatry
<http://www.aacap.org/index.wv>

New York State Education Department: Office of the Professions (Includes detailed information concerning NYS licensing requirements):

<http://www.op.nysed.gov/proflist.htm>

Several references available in the LEND office at WIHD:

Guralnick, Interdisciplinary Clinical Assessment of Young Children with Developmental Disabilities. Brooks, 2000.

Vargas and Prelock, eds. Caring for Children with Neurodevelopmental Disabilities and their Families. LEA, Inc., 2004.