
LEND-Genetics Planning Meeting Report

**December 13, 2006
Washington, DC**

Prepared by:

Ann W. Cox, PhD, RN, FAAN

February 2007

Executive Summary

LEND-Genetics Planning Meeting

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PURPOSE

The purpose of this first in an anticipated series of genetics planning meetings was two-fold:

1. to share what has been accomplished to enhance genetic content and learning opportunities for genetic counseling and other trainees across the Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) programs, and
2. to identify ways to build a sustainable genetic component within all LEND programs, with application to other Maternal and Child Health Bureau (MCHB) training programs.

FORMAT

A diverse group of individuals were invited to present and to participate in the discussion during this one-day meeting. Included were representatives from (a) the three LEND programs that received additional funding for genetic initiatives, (b) other examples of LEND programs with genetic or genetic counseling training components, (c) the Research, Training and Education Division and the Genetics Branch of the Maternal and Child Health Bureau (MCHB), (d) the Association of University Centers on Disabilities (AUCD), and (e) other national genetic organizations. Reports from the programs were given and discussed with particular emphasis on what can be applied across the network. Structured small and large group discussions addressed questions related to resources required within the LEND network to address the need for a viable genetic component and to extend beyond LEND to other federal, state, and local partners.

FINDINGS

1. Programs are challenged by rapidly increasing knowledge and competency in genetics at a time when there are workforce shortages in medical genetics and genetic counseling.
2. LEND programs, generally, are incorporating genetics information within their training programs, although the degree and methods vary.
3. Interdisciplinary education and leadership training for genetic counselors is important, although not included in most genetic counseling programs.
4. Genetic and genetic counseling faculty and trainees are important contributors to LEND interdisciplinary training programs, yet core LEND

- funding is inadequate to add faculty or to recruit diverse genetic counseling trainees.
5. Additionally, recruitment of diverse genetic counseling trainees into LEND programs is difficult due to the limited pool of diverse genetic counseling trainees from which to recruit.
 6. Through the special awards, the LEND/Genetics Special Projects have been able to support genetic counseling faculty time, to fund genetic counseling students in the LEND program, and to develop training materials in genetics that have benefited all LEND trainees.
 7. Some excellent tools and materials have been developed by the programs that need to be shared among all training programs.
 8. The National Institutes of Health (NIH) and the Centers for Disease Control (CDC) are interested in diffusing genetic knowledge and awareness, although professional training has not been their mandate.
 9. Funding for newborn screening and interest in training and education in genetics has emerged within Congress. Advocates for expanded services and research for single diagnoses recently have been effective in securing additional funding, although training has not been a part of the requests.

RECOMMENDATIONS

A list of potential activities/strategies were developed, yet were not prioritized. Some of those that were seen as possible starting points included the following:

- ❖ Use the AUCD website as a vehicle for the dissemination of information and materials to others within the LEND network. Explore the needs of other training programs.
- ❖ Connect with others such as the regional newborn screening centers and state Title V agencies for trainee learning opportunities and to assist with staff training.
- ❖ Use existing LEND trainee stipends flexibly to support genetic counseling trainees.
- ❖ Create/expand distance learning modules that are available to all training programs. Avoid “recreating the wheel”.
- ❖ Explore innovative mechanisms for participation of genetic counseling trainees in LEND.

The above were identified as activities that could be started without significant additional funding. Other strategies would require additional funding and include creative approaches for funding genetic counseling students, faculty, and combined research. Some broader policy initiatives included partnering with other governmental and advocacy agencies with similar, yet more narrowly

defined constituencies; creating a broad resource support center that would provide technical assistance across the training programs; and developing joint pipeline outreach initiatives for careers in disabilities and with an emphasis on increasing diversity of the workforce.

NEXT STEPS

- ◆ Continue the dialogue beginning with a follow-up meeting of this group to develop a specific plan and action steps.
- ◆ Develop a map indicating the current sources of training support for genetic counseling and the availability of funding by source.
- ◆ Identify the steps needed to move from “zero dollars” in support of genetics within LEND to adequate funding.
- ◆ Bring other key people to the table (other MCHB training program representatives, NIH, CDC, other genetic organizations, and genetics leaders) for a future meeting.
- ◆ Address the issue of training within the missions of agencies/organizations that typically do not emphasize training (NIH, CDC, etc.).
- ◆ Continue to pursue pipeline activities geared toward increasing diversity within all LEND disciplines in addition to genetic counseling.

LEND Genetics Planning Meeting

December 13, 2006

Phoenix Park Hotel

Washington, DC

Facilitator: Ann Cox, PhD, RN

Purpose

This meeting was the first in an anticipated series of meetings. The meeting was convened to share approaches from within the Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) network to enhance genetics and genetic counseling content and trainee experiences. Over the past year and one-half, three LEND programs were selected to receive approximately \$ 50,000 each, yearly for three years, to develop and implement strategies to increase genetics content within their LEND programs and to support inclusion of genetic counseling trainees, particularly those from under-represented groups. These three programs presented their accomplishments and future plans. Other presentations were made by selected LEND programs. By bringing together these programs, the purpose was to share what has been accomplished to enhance genetic content and learning opportunities for genetic counseling and all LEND trainees and to identify ways to build a sustainable genetic component within all LEND programs. It is anticipated that what is learned can be broadly applied to other Maternal-Child Health Bureau (MCHB) training programs.

Attendees

(A complete participant list can be found in Appendix A of this document and is accessible at www.aucd.org, click LEND, click genetics)

Marion T. Baer, PhD, RD	Judith Benkendorf, MS, CGC
Daniel Bier, MPA	Joann Bodurtha, MD, MPH
Darla Cohen	Herbert Cohen, MD
Ann W. Cox, PhD, FAAN	Christopher DeGraw, MD, MPH
Karen Edwards, MD, MPH	Cindy Ellis, MD
Erynn Gordon	Anne Heintzelman
George Jesien, PhD	Laura Kavanagh, MPP
Audrey Koertvelyessy, MSN, MA, FNP	Penny Kyler, MA, OTR
Michelle Lloyd-Puryear, MD	Marie Mann, MD, MPH
Sheryl Mathis	Roz Parish, MSN
Crystal Pariseau, MSSW	CAPT. Nanette H. Pepper
Madhavi Reddy, MSPH	Casey Reiser
G. Bradley Schaefer, MD, FAAP, FACMG	Jill Shuger, MS
Denise Sofka, MPH, RD	Martha Thomas
Lann Thompson, EdD, MSSW	Christine M. Trahms, MS, RD
Lauren Vanner Nicely, GENETIC COUNSELING	

Agenda

(A copy of the full agenda can be found in Appendix A of this document and is accessible at www.aucd.org, click LEND, click genetics)

The agenda for the meeting was developed by a planning committee consisting of Ann Cox, Crystal Pariseau, George Jesien, Laura Kavanagh, Penny Kyler, Madhavi Reddy, and Denise Sofka. The agenda and supplemental information were sent to participants prior to the meeting. The programs were requested to prepare written comments that addressed specific questions of interest to the planning committee. These reports are included in Appendix C. Both small and large group discussions were planned to assist in moving the group toward synthesis of priorities and initial implementation steps.

Introductions and Welcome

Following a review of the Agenda and introductions, the facilitator, Ann Cox, underscored the purposes of the meeting: to identify ways to expand genetic content within LEND programs and to provide leadership learning experiences for Genetic Counseling trainees. Presentations highlighted programs that have embedded genetic content; attempted to recruit genetic counseling trainees from diverse backgrounds for leadership education opportunities; and partnered with other universities, programs, and key stakeholders to bridge the genetics and LEND communities. Welcoming comments from a few of the primary architects of the LEND/genetics initiative were given.

Laura Kavanagh, MPP, Chief, MCHB Training Branch, acknowledged the people who worked 4 years ago to infuse genetics back into the training programs. The Medical Genetics Program began in the 1960s and because of financial issues was dropped as a priority. Because of the work of Joann Bodurtha, Michelle Lloyd-Puryear, Marie Mann, and Denise Sofka creative funding mechanisms were found to support some efforts to bring genetic counseling training and LEND back together. The group was encouraged to think about how genetics could be infused into training beyond LEND.

Michelle Lloyd-Puryear, MD, Chief, Genetics Branch, credited the inspiration and conceptualization of this new initiative to the faculty from the Virginia LEND program. There is a chance now with the new legislation introduced by Sen. Obama (IL) to revisit this issue. Senator Obama is going to reintroduce this particular piece of legislation to include education and training. Because of the budgetary continuing resolution, no one knows the level of funding tied to this legislation.

George Jesien, PhD., Executive Director, Association of University Centers on Disabilities (AUCD) saw this meeting as an opportunity to reflect, compile experiences, hear about lessons learned, and identify the challenges that need to

be addressed to propel this group into the future. In 2005 there were three grants of \$ 50,000 per year (for three years) competitively available to LEND programs to demonstrate approaches that would bring genetic counseling and LEND training together. Seventeen (17) applications were received. Out of 35 LEND programs, half were interested enough to set aside what they were doing and to submit a proposal. This was the most popular response to any funding proposal the AUCD network has had. It is hoped that the cost effectiveness of this approach is considered today. While the program is costly, there may be alternatives to augment it so that more LEND programs can be involved. He praised the idea of bringing the grantees to today's meeting and challenged the grantees to exert leadership aimed at generating new ideas.

The Genetics group is at the beginning of a fast-moving field. The National Institutes of Health (NIH) recently sponsored a Mid-East and North African conference on genetic screening. State programs are evolving. With science changing at a tremendous pace, implications for everyone's work will be great. Mechanisms need to be found to identify the science. The 2008 legislation eliminates earmarks; this will be a fairly lean year through the fall of 2008.

Overview of the LEND/Genetics Special Projects

The three special LEND projects addressed the following questions in their presentations:

- Of your original plan, what have you been able to accomplish?
- What resources were developed and used?
- How have you addressed your trainee diversity goal?
- What has been the return on investment (ROI)?
- What lessons have you learned along the way?
- What would you recommend for the future?

Copies of the complete PowerPoint presentations made by these three programs and the AUCD-MCHB LEND Genetics Grant Progress Reports can be found in Appendix B of this report and are accessible at www.aucd.org, click LEND, click genetics.

Herb Cohen, MD, Rose Kennedy Center, NY

Accomplishments. Dr. Cohen reviewed the nature of the collaborative project emphasizing the following accomplishments:

1. UCEDD/Children's Evaluation and Rehabilitation Center (CERC), Sarah Lawrence College, Genetic Counseling MS Program (SLC), Children's Hospital at Montefiore (CHAM), and Albert Einstein College of Medicine, Reproductive Genetics Program (AECOM) formed the collaborative relationships necessary to implement this project.

2. Genetic Counseling LEND Interdisciplinary Fellows participate in the following training components along with the other long-term LEND trainees:
 - Interdisciplinary Clinical Team Experience at CERC
 - Core Lecture Series on DD
 - Genetic Counseling Experience at CERC and CHAM
 - Research Project
3. CERC faculty provide training at SLC to all genetic counseling students. Topics include pediatric genetic syndromes and reproductive genetics. Other DD and Health Policy lectures are provided.
4. The results from the first 18 months of this training include:
 - Five full genetic counseling LEND fellows enrolled
 - Ten intermediate trainees from genetic counseling (clinical placement)
 - Sixty-one genetic counseling students in courses and seminars (short-term)
 - All LEND trainees receive increased exposure to genetic content and role of the genetic counselor
 - Genetic counseling fellows receive exposure to interdisciplinary leadership training and understand roles of other disciplines.
 - Research involvement of trainees in genetics-related topics expands.
5. This compares favorably to the original plan.

Resources developed and used.

- Increased availability of genetic counseling services at the Rose Kennedy Center
- Expanded emphasis on diagnosis and managing genetic disorders

Diversity of Genetic Counseling Trainees

- Complicated in that the Sarah Lawrence Genetic Counseling Program has few students from minority groups.
- Has one student with a hearing impairment for which the lectures have been accommodated.
- Stipend may not be enough to attract the few eligible diverse students due to competing priorities.

Return on Investment (ROI)

- Additional Interdisciplinary Training Activities, benefiting all LEND trainees.

- Expanded interdisciplinary and leadership training for five genetic counseling fellows.
- Training program has been modified based on genetic counseling trainee feedback.
- Three first year fellows are working in the field, one at another UCEDD/LEND program.
- Expansion to include another genetic counseling program in the region.

Lessons Learned

- Need to begin recruitment of trainees earlier by marketing the program to 1st year Sarah Lawrence genetic counseling students.
- More structure and hands-on activities are needed.

Recommendations for the Future

- Incorporate genetic counseling as a discipline within the LEND program.
- Increase funding in the core LEND grant to support genetic counseling trainees.
- Follow-up to see how trainees are using their experience.

Casey Reiser, Anne Heintzelmann, Dan Bier, Waisman Center LEND Program, Madison, WI

Accomplishments

1. Over half of the funding was used for direct trainee expenses, including LEND Genetics Trainee Stipends (5) and tuition reimbursement and travel expenses for one genetic counseling 2nd year trainee who serves as the project assistant.
2. A Genetics Discipline Training coordinator was hired at .25 FTE.
3. Genetic content within the LEND curriculum was expanded. Six on-line genetics case based discussions were designed and implemented. Genetic clinic and counseling sessions were available for non-genetics trainees.
4. Leadership and Policy content from the LEND curriculum became a component of LEND genetics.

Resources Developed

- Six genetic case based discussions, using [Learn@UW](#) for online discussions, were developed and used.

- DVDs of these discussions are available for non-genetic trainees.

Diversity

- Recruitment letters sent through UW system student groups
- No diverse students were admitted to the genetic counseling training program.
- Genetic counseling training program director joined the diversity special interest group of the National Society of Genetic Counselors.
- University of Washington diversity contacts were expanded.
- Five genetic counseling trainees participated in an intensive summer cultural immersion experience with other LEND trainees.

Return on Investment

- National Coalition for Health Professional Education in Genetics (NCHPEG) competencies are part of the overall LEND curriculum.
- Genetic Counseling trainees perceive themselves as part of the interdisciplinary team, and LEND trainees and faculty view the genetic counselor as an integral member of the interdisciplinary team.
- Influence of the genetics curriculum enhancements on the research activities of a Psychology LEND trainee's dissertation.
- LEND genetic trainee scholarship an outgrowth of the LEND Leadership project.
- Speech-Language Pathology LEND trainee reported higher performance on National Board Exam, in part attributed to genetic content.

Lessons Learned

- Genetic counseling trainees must be part of the interdisciplinary clinical experiences in which all LEND trainees participate.
- Must fully integrate LEND genetic counseling trainees into Wisconsin LEND curriculum.
- New content can be integrated without overwhelming trainees or faculty.
- Enhanced potential for genetics influence on future research of non-genetics disciplines.

Recommendations for the Future

- Maintain and expand continued commitment to LEND genetics.
- Make trainee stipend money available.
- Support for Faculty Discipline Training Coordinator important.

Joann Bodurtha, MD, SYNERGY, Virginia LEND, Richmond, VA

The goals of SYNERGY are to (1) integrate genetics into LEND training, (2) train genetic counseling students in interdisciplinary leadership excellence, (3) increase genetic awareness through checklists and modules, (4) enhance diversity in genetic counseling.

Accomplishments

1. Genetic awareness checklist developed and distributed to all LEND programs.
2. All Virginia LEND students have some genetics training.
3. One of three web-based learning modules (genetic awareness) has been developed and is awaiting IRB approval for evaluation; two others (family history and newborn screening) are in development.
4. All genetic counseling students take the LEND leadership seminar series.
5. National Society for Genetic Counselors' Disabilities Special Interest Group established.
6. Multicultural Advisory Committee established and functioning well.
7. Two-three genetic counseling students/year enrolled as long-term LEND trainees.
8. Two Historically Black Colleges and University (HBCU) undergraduate students selected as interns and completed summer internship.
9. SYNERGY presented at Association of Maternal-Child Health Programs (AMCHP), AUCD, and NCHPEG meetings.

Resources Developed and Used

- Genetic awareness checklist developed and disseminated.
- HBCU summer internship planned and implemented with focused recruitment strategies.
- Autism clinic genetic screening tool and family history tool developed and used with the Virginia Department of Health, March of Dimes funding for State Genetics Education Plan.

Diversity

- Partnered in LEND recruitment with HBCU (Virginia Union University, Virginia State University).
- LEND faculty have given lectures at HBCUs.
- Partnered with other diversity Life Science and summer initiatives at Virginia Commonwealth University (VCU) to introduce all LEND disciplines.
- Drafted organizational cultural competency plan.
- Formed Multicultural Advisory Committee.

Return on Investment

- One HBCU intern presented at National meeting, both are ongoing advocates at their schools for the LEND program and summer internship.
- Five long term LEND genetic counseling trainees are considering pediatric genetic counseling careers.
- Genetic counseling students connected with HBCUs.
- Genetic counseling faculty dollars and support important to PhD Chair, school leadership.
- Module development estimated 1/10th the cost of doing them commercially. Modules and checklist made available for use across LEND network.

Lessons Learned

When the glass is half empty:

- No dollars, no diversity
- No extramural NIH funding available, no diversity
- No outside dollars/overhead available, no institutional support.
- No insurance, no genetic testing accessible.

When the glass is half full:

“Effective leadership unfolds from the common good.” DePaola

Recommendations for the Future

- Partnerships across all training programs, performance measure.
- Create a genetic counseling research network
- Consider extramural training grants through National Human Genome Research Institute
- Recommend use of genetic awareness checklist
- Include genetic counseling/LEND training in autism funding portfolio.
- Secure funding to continue stipends for genetic counselors in LEND programs.
- Maintain funding for a genetics faculty for LEND programs.
- Consider lifespan partnering on projects.

Large Group Discussion and Summation

Currently, everyone has some genetic content in their LEND programs. Genetics and neuroscience is the future direction that is being infused into the training programs. However, funding is critical to sustain the momentum. Funding opportunities need to be sought to further enhance the LEND Interdisciplinary training with genetic content and practitioners. This is an evolving process for roles to be developed and worked into the teams. Faculties are learning more from watching the trainees with the genetic counselor as part of the team.

The diversity goal in each of these projects has been the most difficult to achieve. That is because the genetic counseling programs with which the LEND programs are partnering do not attract a diverse student group (and this is the trend nationwide). There are many reasons for this, one of which includes lack of funding. We need to expand the pipeline dollars for minority recruitment.

The genetic awareness checklist, developed by SYNERGY, was praised for the family focus of the first four items.

Other LEND Program Genetic Efforts

Other LEND programs in the network with genetic training components were invited to participate in this meeting. Each responding program was asked to prepare a written report of their genetic counseling/LEND activities and was given a brief amount of time to present. Each program was asked to respond to the following four questions:

- What strategies have you used to infuse genetics information into your training program?
- What funding/resources did you use to support these activities?
- What relationships were developed or expanded?
- What lessons have you learned and what would you suggest for the future?

Copies of the written reports from these six programs (University of Southern California LEND, University of Washington LEND, Nebraska LEND, Westchester LEND, Indiana LEND, Cincinnati LEND) can be found in Appendix C of this document and are accessible at www.aucd.org, click on LEND, click genetics.

The following points were made during these six presentations.

1. Genetics content was being offered in these LEND programs and there was an expressed need and desire to further expand this content.
2. Genetic counseling students are available to most of these programs but typically not as long term leadership trainees. Unless stipends are

- available, genetic counseling students receive a “less” than full LEND training experience.
3. Some of these programs have genetic faculty on staff, few have genetic counseling faculty.
 4. If stipends are available to genetic counseling trainees, it typically comes from the core LEND funding. This means that the same number of funded trainee slots are spread among a larger group of disciplines.
 5. Genetic Counseling faculty involvement in the LEND program was often voluntary because of limited funds via the core LEND grants. Both genetics faculty and genetic counseling faculty are needed to develop and to sustain an integrated genetics component within LEND.
 6. All programs have developed collaborative relationships among departments within their universities and centers or with departments in affiliated universities (especially genetic counseling programs) to accomplish their goals around integration of genetic content and experiences.
 7. These programs continue to expand content and experiences for LEND trainees in genetics, even without funding. What they are less able to do is to hire faculty in genetics/genetic counseling for their LEND programs to coordinate this expansion and recruitment of trainees or to competitively recruit genetic counseling trainees.
 8. A common theme was that the programs have been able to advance their efforts by coming up with creative ideas to increase funding to advance the LEND Programs.

Update on New Issues, Efforts, Resources, Diversity Recruitment, and Retention in the Field of Genetics

Three individuals were invited to give an overview of what is happening nationally around these issues. Joseph McInerney, Director, National Coalition for Health Professional Education in Genetics, refers participants to the NCHPEG website @ www.nchpeg.org for presentation materials and other useful information.

Judith Benkendorf, MS, CGC, Project Manager, American College of Medical Genetics.

(A copy of Ms. Benkendorf's PowerPoints is available in Appendix D of this document and is accessible at www.aucd.org , click on LEND, click genetics).

Judith Benkendorf presented a review of activities related to genetics and genetic counseling around workforce issues and diversity, from multiple organizations including the American College of Medical Geneticists (ACMG), the American Board of Medical Genetics (ABMG), the National Society of Genetic Counselors (NSGC), and the National Coordinating Center (NCC) for Genetics and Newborn

Screening Regional Collaborative Groups. Findings from recent surveys regarding workforce issues related to medical genetic and genetic counseling personnel underscore several trends including:

- Genetic advances will impact the healthcare for people and families with neurodevelopmental disabilities.
- The genetics workforce situation is critical, requiring coordinated, multi-pronged approaches (1 board certified MD clinical geneticist for every 301,900 Americans; 1 genetic counselor for every 166,900 Americans. Data from August 2005 survey)
- The lack of workforce diversity needs to be addressed. (According to 2003 data, 13% of board certified medical geneticist belong to minority groups. In a more recent survey (2006), 91% of genetic counselors are Caucasian and 94% are women)
- Both the ACMG and NSGC are engaged in activities directed toward increasing the workforce and advancing diversity.
- The Regional Centers are a venue for LEND trainees to gain experience in public health genetics, and they provide a vehicle for dissemination of LEND materials and messages.

Penny Kyler, MA, OTR, MCHB, Genetic Services Branch, HRSA/MCHB

Penny Kyler reviewed a number of resources that were supported with MCHB funding and are appropriate resources to support training. An array of low health literacy materials have been developed and disseminated and some materials are in both English and Spanish. Several DVDs and CDs are available including a DVD template of newborn screening material, AAFP DVD – Annual Clinical Focus on Genomics 2005, and a CD – Medical Home Family Stories; Genetics and Common Disorders: Implications for Primary Care and Public Health Providers. The following sites can be used to access many of these resources:

www.geneticalliance.org (A Guide to Family Health History)

www.genes-r-us.uthscsa.edu (Newborn Screening Tests and promotional flyers in multiple languages)

<http://www.genetists.org/> (click on Genetics Tools)

<https://familyhistory.hhs.gov/> - Family Health Portrait profile online

Discussion and Comments from Session

The issue of payment for genetic counseling services was raised. In response, the vast majority of genetic counselors are working in hospital settings and universities. With the growth of genetic counselors, less traditional settings such as labs, private practice, public health, and health maintenance organizations

have emerged as work settings. The following table summarizes work sites identified from a recent survey conducted by the National Association of Genetic Counselors (2006).

Table 5. Primary Employment Setting

	N	%
<i>University Medical Center</i>	474	38%
<i>Private Hospital/Medical Facility</i>	252	20%
<i>Public Hospital/Medical Facility</i>	134	11%
<i>Diagnostic Laboratory</i>	95	8%
<i>Physician's Private Practice</i>	58	5%
<i>Health Maintenance Organization</i>	43	3%
<i>University/Non-Medical Center</i>	39	3%
<i>Other</i>	38	3%
<i>Federal/ State/County Office</i>	27	2%
<i>Self-Employed/Private Practice</i>	12	0.9%
<i>Research Development/Biotechnology Company</i>	10	0.8%
<i>Pharmaceutical Company</i>	7	0.6%
<i>Outreach/Satellite/Field Clinic</i>	4	0.3%
<i>Internet/Website Company</i>	2	0.2%
<i>Bioinformatics Company/Health Advocacy Organization</i>	1	0.1%

Very few geneticists work in a private setting. Salaries are not based on counseling services. Previously, training grants, medical procedures, and diagnostic laboratories and procedures paid for genetic services. Medical clinical geneticists have to generate their income, thus time for training is limited. Residency slots are available, and are variably funded. While most are funded, they are hard to fill. Some Title V grant money is used to develop infrastructure. Resources are in different parts of the system. This challenges all to be creative in locating roles within existing programs and diminishes the likelihood of genetic services operating as independent programs.

Work Group Assignments

A number of excellent strategies to address the goal of integration of genetics and genetic counseling with the LEND programs were discussed. A review of the workforce issues from a national perspective as well as the availability of national resources was presented. For the afternoon, the participants broke into four smaller work groups. Given that it is not known whether there will be continued funding for genetics within LEND, the groups discussed the following:

- (1) Discuss and place those activities that have been or could be fruitful to enhancing genetic information and experiences within the LEND programs into one of three categories:

- activities that can be done if no additional funding is earmarked for genetics in LEND,
 - activities that can be done by a program if a supplement of up to \$ 50,000 is available, and
 - activities that require substantial increases or additional funding sources can be found.
- (2) Prioritize the activities in each category from most attainable to least attainable.
- (3) Then determine whose priority is it (MCHB, AUCD/network, LEND program-level), and who are appropriate partners?

(Copies of this assignment and recording format can be found in Appendix E of this document)

The information discussed and gleaned is organized by category on the following tables.

Activities we can do if <u>no</u> additional funding sources is earmarked for genetics in LEND:	
1: Organize existing materials, post on AUCD web, disseminate	A: who? MCHB,AUCD B: partners? LEND programs, NCHPEG
2: Maintain/expand current level of genetics content	A: who? LEND programs B: partners? AUCD,MCHB,Genetics Br, PPC, SPH LEAH,
3: Connect with regional NBS centers and partner with them in training	A: who? LEND programs, genetic counseling programs B: partners? NCC/RCC, MCHB, Genetics Br
4: Cultivate relationship with genetic counseling faculty	A: who? LEND programs B: partners? Genetic counseling programs, Genetics Br, NSGC MCHB, NCC/RCC
5: Use existing LEND stipends flexibly	A: who? LEND programs B: partners? MCHB
6: Exchange among LEND mentor/mentee/clinical exposure with some student sharing among LEND programs	A: who? LEND programs B: partners? Genetic counseling programs, regional centers, State/local genetics programs
7: Work with existing pipeline initiatives, multicultural committees	A: who? B: partners?
8: Advocate for needs broadly and at multiple levels	A: who? B: partners?
9. Encourage the use of Title V Block Grant money for genetic counseling and other training	A: who? MCHB, genetic counseling programs B: partners? State Title V, UCEDD/LEND

10. Add genetic and LEND competency questions to national accreditation requirement for schools of medicine	A: who? B: partners?
11. Add family-centeredness/family focus to all genetic counseling training	A: who? B: partners?
12. Make the guidance clear that genetic counselors are considered "official, approved" LEND trainees	A: who? MCHB B: partners? Genetic counseling programs LEND, NSGC
13. Provide regular updates to network on GENETIC COUNSELING and LEND initiatives	A: who? MCHB/AUCD B: partners? Special Projects, Planning Group
14. Develop a performance measure that embraces genetics within LEND	A: who? MCHB, Genetics Branch B: partners? LEND Programs, genetic counseling programs

Activities we can do if a supplement of up to \$50,000, in addition to current funds earmarked for genetics in LEND, is available:

1: Hire faculty to serve as genetic counseling coordinator for LEND programs	A: who? LEND B: partners? Genetic counseling programs, faculty
2: Earmark part of faculty time to work with minority granting institutions or in pipeline-type activities aimed at recruiting	A: who? LEND, genetic counseling programs B: partners?
3: Award stipend money for long-term genetic counseling trainees on par with amount allocated for other LEND disciplines	A: who? LEND B: partners? Genetic counseling programs, MCHB, other funders
4: Create unconventional mechanisms for participation in LEND (part through distance learning, part on site)	A: who? LEND B: partners?
5: Creation or expansion of distance learning modules that are available to all programs	A: who? Funded programs, LEND B: partners? Genetic counseling programs, MCHB, AUCD
6: Advocate for a student loan repayment program for GenLEND trainees with mechanisms for loan forgiveness if working in underserved area	A: who? NSGC, genetic counseling programs B: partners? LEND, Genetics Br., MCHB, AUCD
7: Include LEND trainees in National Health Service Corps	A: who? B: partners?
8: Create collaborative LEND/genetics research program	A: who? B: partners?

9. Develop internships, with genetic counseling mentoring, to increase diversity	A: who? LEND, genetic counseling programs B: partners? HBCU's, other minority institutions
10. Award \$ 500- \$ 1000 to LEND trainees for projects on genetic topics	A: who? LEND, AUCD B: partners? Trainees, faculty
11. Involve LEND trainees (genetic counseling as well) in community membership activities	A: who? B: partners?

Activities we can do if increased funding and additional funding sources are found:	
1: Support genetic counseling/genetics faculty time in clinician/educator role	A: who? LEND B: partners?
2: Develop joint pipeline outreach to high schools re: careers in disabilities (focus on all LEND disciplines and all Bureau of Health Professions training)	A: who? MCHB, Bureau of Health Professions B: partners?
3: Develop a coordinating resource support center (technical assistance) on infusing genetics into LEND-National Center on LEND-etics	A: who? MCHB, Genetics Br. B: partners? AUCD
4: Advocate for all NBS legislation to include interdisciplinary training and workforce development component	A: who? AUCD, National Organizations B: partners? LEND, genetic counseling programs, LEAH, PPC, Schools of Public Health
5: Develop national, high profile Fellowships in genetics and genetic counseling	A: who? B: partners?
6: Develop training consortia across state lines	A: who? B: partners?
7: Explore avenues to advocate for jobs, adequate salary, and reimbursement for genetic counselors	A: who? National Organizations B: partners? Genetic counseling programs, Genetics Branch
8: Develop summer internships for practicing professionals who will complete part of LEND (certificate in leadership)	A: who? LENDs with interest Health departments B: partners? State/local professionals
9. Embrace a translational approach to training (research to practice to policy)	A: who? B: partners? NIH, CDC, AHRQ, MCHB

Large Group Discussion and Consensus

Following the group reports, the larger group was challenged to address the following:

- Collectively select several priorities and develop implementation strategies.
- Identify what needs to be done, who will do it, and what resources are required.
- Decide next steps.

A lively, although abbreviated (due to limited time), discussion followed. Several points were made that will influence the direction that is taken. One participant talked about how advocacy groups and genetic support groups spend their time getting dollars for research, not the translation of information or training. While alliances with these groups is important, the missions are different. Congress is typically approached with a single gene group (autism, fragile X are examples). To leverage additional dollars, a case needs to be made for an interdisciplinary approach, requiring many disciplines. Thus the need is substantial for workforce development through training.

As part of the care infrastructure, genetics is an important component, yet is under-funded (lower reimbursement avenues) and under-staffed. Further, there is a distribution problem in the number and location of genetic counseling programs. For instance, there are only five genetic counseling programs west of the Rockies.

While most LEND programs have incorporated some genetic content within their programs, fewer have genetic clinical experiences. Several strategies were discussed to heighten the visibility of genetics across the network. For example, some group could sponsor a monthly genetic topic (Genetics for the Month) offered as a webcast to the entire MCHB training network. Resources like those that were presented during this meeting could be shared broadly across the Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND), University Centers for Education in Developmental Disabilities (UCEDD), Leadership Education in Adolescent Health (LEAH), Pediatric Pulmonary Centers (PPC), Bureau of Health Professions (BHPr), Schools of Public Health (SPH) programs. Resources will be needed to support the development of infrastructure, research, training, and current structures. Thus, supplemental funding will be needed to add a viable genetics program. And while there is support for reaching beyond the LEND network, it will be critical to identify some coordinating entity that can use technology to disseminate information.

Finally, there is the need to stretch across federal agencies. National Institute for Child Health Development (NICHD) and Centers for Disease Control (CDC) also are invested in newborn screening. A way needs to be found to share and/or develop resources among Federal partners. Perhaps it is time to set a high-level meeting to look at what collectively can be done and to identify partnership responsibilities in this regard.

Next Steps

In conclusion, the LEND-Genetics planning meeting participants suggested the following:

- (1). Continue the dialogue beginning with a follow-up meeting of this group to develop a specific plan and action steps.
- (2). Develop a map indicating the sources of genetic counseling training support and availability funding by source.
- (3). Identify the steps needed to move from “zero dollars” in support of genetics within LEND to adequate funding.
- (4). Bring other key people to the table (other MCHB training program representatives, NIH, CDC, other genetic organizations, and genetics leaders) for a future meeting.
- (5). Address the issue of training within the missions of agencies/organizations that typically do not emphasize training (NIH, CDC, etc.).
- (6). Continue to pursue pipeline activities geared toward increasing diversity within all LEND disciplines in addition to genetic counseling.

Appendices

(Because of the size, the complete appendices are contained in a separate file.
The title of and content included in these appendices is as follows)

Appendix A Participant List
Agenda

Appendix B Presentations from AUCD/Genetics Special Projects
Rose Kennedy Center, NY
Waisman Center, WI
Virginia LEND, VA
Progress Reports – June 2006

Appendix C Reports from Other LEND Programs
University of Southern California, CA
University of Washington, WA
Monroe-Meyer Institute, NE
Westchester Institute for Human Development, NY
Riley Child Development Center, IN
Cincinnati Center for Developmental Disabilities, OH

Appendix D Update on National Issues, Efforts, Recruitment, Diversity, and
Resources
Presentation by Judith Benkendorf, MS, CGC

Appendix E Work Group Assignment and Recording Format