

Leadership Education in Neurodevelopmental and Related Disabilities (LEND)



The role of medical genetics



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Genetics as a Natural Component of LEND

- Neurodevelopmental disabilities
- Interdisciplinary care
- Technical Assistance
- Outreach
- Capacity building
- Interface with Title V programs
- Genetics as a component of all disciplines of clinical medicine



Clinical Genetics as a LEND core discipline

- Audiology
- Developmental medicine
- Education and child development
- Health policy
- Genetic medicine
- Nursing
- Nutrition
- Occupational therapy
- Pediatric Dentistry
- Physical therapy
- Psychology
- Recreational Therapy
- Social work
- Speech pathology



Genetics and Nebraska LEND

- Clinical Genetics
 - Interdisciplinary education (Core curriculum)
 - Clinical experience
 - Disciplinary clinics
 - Interdisciplinary
- Human Genetics Laboratory / Molecular Genetics
 - Expanded curriculum
 - Lab experience (elective)



Genetic Counseling and LEND

- Incorporate Genetic Counseling as a core discipline in the LEND training experience
- Include LEND components into genetic counseling training
- Familiarize other disciplines with the practice of Genetic Counseling
- Increase diversity in Genetic Counseling trainees



LEND and Genetic Counseling Special RFP

- 17 applications
- 3 Accepted
 - Rose Kennedy Center, NY
 - Waisman Center, WI
 - Virginia LEND

Experience of the Projects (1)

Herb Cohen, MD, Rose Kennedy Center, NY

- 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 received exposure to interdisciplinary leadership training and understand roles of other disciplines.
 - Research involvement of trainees in genetics-related topics expanded.

Experience of the Projects (2)

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

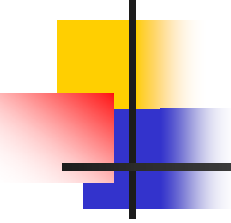
- Six genetic case based discussions, using Learn@UW for online discussions, were developed and used.
 - DVDs of these discussions are available for non-genetic trainees.
- New content can be integrated without overwhelming trainees or faculty.
- Enhanced potential for genetics influence on future research of non-genetics disciplines

Experience of the Projects (3)

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

■ Accomplishments

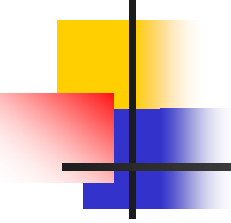
- Genetic awareness checklist developed and distributed to all LEND programs.
- All Virginia LEND students had some genetics training.
- One of three web-based learning modules (genetic awareness) has been developed and is awaiting IRB approval for evaluation; two others (family history and newborn screening) are in development.
- All genetic counseling students take the LEND leadership seminar series.
- National Society for Genetic Counselors' Disabilities Special Interest Group established.
- Multicultural Advisory Committee established and functioning well.
- SYNERGY presented at Association of Maternal-Child



LEND Genetics Planning Meeting (12/13/2006)

■ Findings

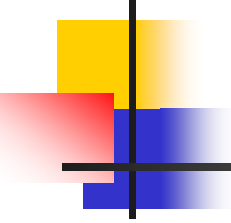
- Programs are challenged by rapidly increasing knowledge and competency in genetics at a time when there are workforce shortages in medical genetics and genetic counseling.
- LEND programs, generally, are incorporating genetics information within their training programs, although the degree and methods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



LEND Genetics Planning Meeting (12/13/2006)

■ Findings

- Funding is inadequate to add faculty or to recruit diverse genetic counseling trainees. 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.
- 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.
- Some excellent tools and materials have been developed by the programs that need to be shared among all training programs.
- 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.
- 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.

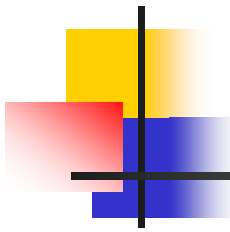


LEND Genetics Planning Meeting (12/13/2006)

- Recommendations

- 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.

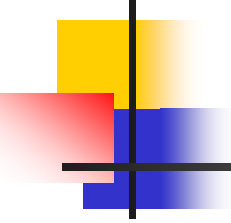
[The above were identified as activities that could be started without significant additional funding.]



LEND Genetics Planning Meeting (12/13/2006)

- Recommendations

- 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;
 - developing joint pipeline outreach initiatives for careers in disabilities and with an emphasis on increasing diversity of the workforce.



LEND Genetics Planning Meeting (12/13/2006)

- 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 sources of genetic counseling training support and availability 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