

## PROFESSIONAL FORMATION & TRAINING IN THE AUCD NETWORK: NOW AND INTO THE FUTURE

DDNA & AADMD Annual  
Conference  
Reno, NV

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AUCD  
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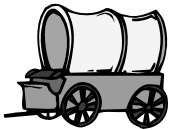


## Main Themes

- ❑ Provide Overview of the Development of an Interdisciplinary Training Model
- ❑ Discuss change of over time and current challenges
- ❑ Discuss Possible Future Opportunities
- ❑ Spark Debate about Next Steps



Historical Look → Present & Future



## Original Concept from John F. Kennedy's Panel on Mental Retardation

To Address:

- ❑ Critical shortage of personnel
- ❑ Need for research & statistical data
- ❑ Shortage of facilities
- ❑ Lack of coordination



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## Some of the early players

- ❑ Robert Cooke
- ❑ Elizabeth Boggs
- ❑ Allen Crocker
- ❑ Margaret Giannini
- ❑ George Tarjan
- ❑ Hugo Moser
- ❑ Richard Scheifelbusch
- ❑ Marvin Fifield
- ❑ Rick Heber

## Early Expected Characteristics

- ❑ University-based units that reached out to community
- ❑ Linked university resources with disability community
- ❑ Would provide:
  - Interdisciplinary training
  - Service
  - Clinical research



### First Generation UAFs 1963-1974

- ❑ Received construction funds from MCH
- ❑ Primary emphasis on health & allied health for children with mental retardation
- ❑ Emphasized clinical diagnosis & treatment
- ❑ Interdisciplinary leadership training
- ❑ Medically focused training
- ❑ Concentration of expertise in single location

### Second Generation UAFs 1975-1986

- ❑ Few received MCH training support
- ❑ Developed working relationships with State DD councils & service agencies
- ❑ Addressed full life span
- ❑ Emphasized community-based services & developmental concepts
- ❑ Move toward systems change
- ❑ Required to seek support from available opportunities- leveraging ADD support

### Third Generation UAFs 1987-1995

- ❑ Emphasized technical assistance, outreach training & dissemination
- ❑ Community-based programs as standard
- ❑ Consumer empowerment, participation & satisfaction
- ❑ Emphasis on inclusion, ADA and supports & services

### Fourth Generation UCEDDs 1996-?

- ❑ Further Expansion of network to 67
- ❑ Greater emphasis on generic systems affecting employment, housing, health, etc  
Attention to states with increased diversity and immigration
- ❑ Emphasis on evidence based practices and translation of research to practice
- ❑ Closer working relationships with state agencies: health, education, Medicaid, etc
- ❑ Shift to greater focus on needs of adults and aging populations in the community

### Three National Networks

- ❑ University Centers for Excellence in Developmental Disabilities (UCEDDs) - 67
- ❑ Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs - 39
- ❑ Developmental Disabilities Research Centers (DDRCs) - 15



### Conceptual Overview



- ❑ Serve as a Bridge between University and Community
- ❑ Bring the best of what science has to offer to real world problems
- ❑ Interplay between conceptual & practical
- ❑ Real world experience for trainees
- ❑ Opportunity for community to participate in formation of professionals
- ❑ Consumer advisory committees - 50% pwd

## Centers for Excellence in DD (UCEDDs)

- ☐ Authorized by Federal Law- Developmental Disabilities Assistance and Bill of Rights Act
- ☐ Federal funded for Core Functions: training, research, service and dissemination- building capacity
- ☐ Work with persons with disabilities, families, providers and government & advocacy agencies to conduct research, provide training & achieve positive changes



AUCD, 2006

## Leadership Education in Neurodevelopment and Related Disabilities (LEND) Programs

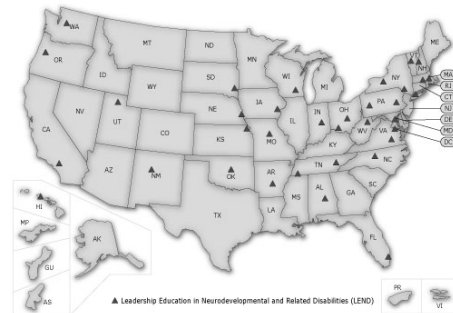
- ☐ Ensure health care professionals have necessary leadership skills and knowledge
- ☐ Provide interdisciplinary training in clinical and community settings
- ☐ Address the unique needs of children and youth with DD & special health care needs & their families
- ☐ Operate within a university system
- ☐ Provide training, technical assistance, community services, clinical services, leadership and collaboration in the field of developmental disabilities

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## LEND Programs Continued

- ☐ Funded by MCHB
- ☐ Emphasis on:
  - Leadership skills
  - Interdisciplinary practice
  - Cultural competency
  - Family-based care
- ☐ 39 Across the Country in 31 states

## LEND Network



## Faculty and students are drawn from 13 core disciplines

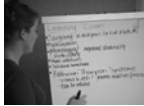
- |                       |                         |
|-----------------------|-------------------------|
| ☐ Pediatrics          | ☐ Speech & Language     |
| ☐ Nursing             | ☐ Health Administration |
| ☐ Social Work         | ☐ Occupational Therapy  |
| ☐ Audiology           | ☐ Physical Therapy      |
| ☐ Pediatric Dentistry | ☐ Special Education     |
| ☐ Nutrition           | ☐ Parents and consumers |
| ☐ Psychology          |                         |
| ☐ Genetics            |                         |

## LEND Training Curriculum

- ☐ Interdisciplinary Process
- ☐ Cultural Sensitivity, Family-centered care
- ☐ Developmental Disabilities: History
- ☐ Disabilities & Disorders: Genetic & Metabolic Causes, Clinical Aspects
- ☐ Evaluation & Treatment of Behavior Challenges
- ☐ Special Education Law, ADA
- ☐ Systems of Care
- ☐ Program Evaluation, Grant Writing
- ☐ MCH and Policy leadership

## Training Experiences

- ☐ Academic Work
- ☐ Clinical Experiences
- ☐ Community Based Experiences
- ☐ Team Projects
- ☐ Leadership Experience

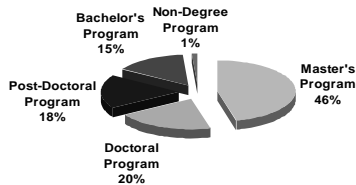


## LEND/UCEDD: Services & Training (FY09)



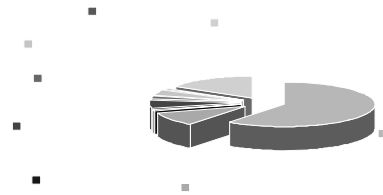
- ☐ 88,912 clients seen in clinics
  - 56% minorities
- ☐ 69,040 served in the community
  - 44% minorities
- ☐ Over 4,380 interdisciplinary long-term trainees
- ☐ Over 812,725 people participated in outreach & continuing education opportunities

## Academic level of long-term trainees



AALAP, 2001

## Percentage of Trainees & Fellows (Sample Size from NIRS: 4,129)



## Current and Expanding Services for Adults

- ☐ Adult Clinics especially for individuals with DS, Fragile X, Spina Bifida and Autism
- ☐ Rising interest in Transition
- ☐ Arrangements with Family Practice, Med Peds and Dental schools
- ☐ Some still in planning stage and searching for additional resources

## Training Examples

Center/Program	Activities	Participants
WIHD - LEND/UCEDD	Clinical Training with an emphasis on Patient-Centered Care; of adults with Disabilities Continuing Education and other Community Training on topics such as epilepsy, dental care for pwdd. Planning project to develop model curriculum for internal medicine and family medicine residents, <i>Providing Primary Care for Adults with Disabilities in a Patient Centered Medical</i>	ENT Residents Cardiology Fellows: Endocrinology Fellows: Neurology resident: 3 <sup>rd</sup> yr Medical Students: > 4700 Patients
Cincinnati LEND	Transition/adult clinic for residents to rotate thru. Also have adult Spina Bifida clinic	Med-Peds residents, family practice & pediatric residents

## More Examples

Centers/Program	Activities	Participants
Sonoran UCEDD, AZ	Disability resident training, educating primary care physicians on caring for pwdd, case problems for ID teams with individuals and family members	2 <sup>nd</sup> year medical students, nursing Pharmacy, sw, public health and law students; 3 <sup>rd</sup> year medical intercession students
JPK partners School of Medicine, Denver CO	Family practice fellowship in primary health care for pwdd, Adult DS clinic, medical home model, MCHB pediatric nursing leadership training includes transition & young adults	Family physicians, nurse practitioners & Doctor of nursing

## More Examples

Centers/Program	Activities	Participants
Georgetown UCEDD	Health Resources Partnership for DC to provide physician to physician consultation and TA; Continuity Clinic	Family medicine residents, senior nursing students, community primary care physicians
Nisonger UCEDD/LEND	Dental Program trains all 4 <sup>th</sup> year dental students with focus on clinical skills on children & adults with IDD	4 <sup>th</sup> Dental students and dental hygiene students
Elizabeth Boggs Center	Medical home for adults with DD at Family Practice ambulatory care site	Family practice residents

## Numerous other efforts at different stages

- ▣ Vanderbilt University – Behavioral Health & ID
  - Planning committee for extension of work
- ▣ Un of Alabama – Dentistry residents
- ▣ Un of Massachusetts – lifespan approach
- ▣ Iowa’s UCEDD – medical student training
- ▣ Wayne State UCEDD – working with hospitol
- ▣ Kansas State U – focus on transition
- ▣ Various other planning efforts

## Academic Activities of UCEDD/LEND Trainees Post Training

Academic Activities	One Year Post Training (560 responding)		Five Years Post Training (236 responding)	
	#	%	#	%
<b>Teaching/mentoring in my discipline or other MCH related field</b>	<b>267</b>	<b>48%</b>	<b>168</b>	<b>71%</b>
<b>Developing education materials or curriculum</b>	214	38%	131	56%
Conducting research in my clinical field or other MCH areas	176	31%	77	33%
<b>Providing consultation or technical assistance in MCH areas</b>	172	<b>31%</b>	112	<b>47%</b>
Publishing in my clinical field or other MCH areas	74	13%	46	19%
<b>Presenting in my clinical field or other MCH areas</b>	165	<b>29%</b>	100	<b>42%</b>
Success in procuring grant and other funding in MCH	23	4%	31	13%

## Policy Activities of UCEDD/LEND Trainees Post Training

Policy Activities	One Year Post Training (488 responding)		Five Years Post Training (232 responding)	
	#	%	#	%
Held <b>leadership position</b> in local, State or National public organization or government entity	21	<b>4%</b>	43	<b>19%</b>
Conducted <b>strategic planning</b>	22	<b>5%</b>	45	<b>19%</b>
Participated in <b>public policy development</b> or activities	46	<b>9%</b>	49	<b>21%</b>
<b>Procured grant, contract or other funding</b> (as author or co-author)	21	<b>4%</b>	40	<b>17%</b>
Influenced MCH related legislation	10	2%	15	6%
Published or presented in MCH-related policy issue areas	14	3%	18	8%
Written or reviewed policy statement	25	5%	11	5%
Represented your organization at a key MCH meeting	6	1%	10	4%

## Advocacy Activities of UCEDD/LEND Trainees Post Training

Advocacy Activities	One Year Post Training (538 responding)		Five Years Post Training (291 responding)	
	#	%	#	%
<b>Assisted individuals/families to overcome barriers</b> (e.g. access to service) or achieve goals	243	<b>45%</b>	229	<b>79%</b>
Participated in <b>advocacy group coalitions</b>	49	<b>9%</b>	55	<b>19%</b>
<b>Provided comment on regulations</b>	33	<b>6%</b>	35	<b>12%</b>
Provided written testimony for hearings	12	2%	17	6%
<b>Shared information with legislators/staff</b>	53	<b>10%</b>	68	<b>23%</b>
Developed or reviewed policy statements	29	5%	16	5%
Worked with media (media advocacy)	18	3%	19	7%
Testified at hearings	5	1%	17	6%

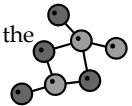
## Need in the Future



- ❑ Professionals trained to support health care transition to adulthood
- ❑ Professionals trained in adult care of pwdd
  - Interdisciplinary format
  - Clinical and Community experience
  - Knowledgeable & supportive of self determination
  - Conversant with community supports
  - Able to navigate adults systems of care
- ❑ Leadership in policy development & systems of care

## Possible Model

- ❑ Extend LEND programs across life-span approach
- ❑ Build on existent infrastructure
- ❑ Allow for exposure and then specialization:
  - Children
  - Adolescents
  - Adult
  - Elderly
- ❑ Begin with demonstrations in best of the LENDs



## Public Law 111-148



- Patient Protection and Affordable Health Care Act (H.R. 3590, P.L. 111-148)
- Health Care & Education Affordability Reconciliation Act (H.R. 4872, P.L. 111-152)
  - Included negotiated differences between the House and Senate bills and revised the student loan program

## Opportunities within HCR

- Prevention & Wellness: authorizes prevention & wellness programs with focus on disabilities
- Establishes National Prevention, Health Promotion and Public Health Council and Prevention and Public Health Fund (\$15+ B)
- Health Disparities: disability identified as health disparity
  - ❑ Supports and expands our Nation's health care workforce
- Funds scholarships and loan repayment programs
- Primary Care training Grants for Med. Schools
- Incentives to train primary care workforce for underserved population
  - ❑ Direct Support Workforce: \$ authorized to train those providing LTSS to develop training & certification
  - ❑ Requires accessible medical diagnostic equipment w/in 2 yrs
  - ❑ Redefinition of designation of Medically Underserved

## Overall Policy Opportunities

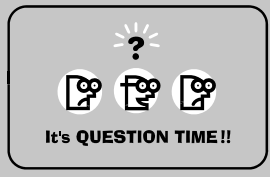
- ❑ Health Care Transition
- ❑ Adult Services – training, demonstration, research
- ❑ Workforce Development
  - Medical training related to disabilities
- ❑ Health Surveillance of people with IDD
- ❑ Autism – especially adult services
- ❑ Redefinition of Medically Underserved
- ❑ Health Promotion & Health Disparities



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