

LEND: Future Directions & Opportunities

LEND Directors Meeting
March 4, 2007
Washington DC



Current AUCD Work Areas

- Technical Assistance Contracts for Network
 - ADD – UCEDDs – Network wide TA
 - MCHB – LENDs – Broad based TA
 - NICHD – DDRCs - Website
 - CNS – Network wide – NSIP- Service
- Brokering Network for Federal Agencies \
 - SSA – PMU Contracts – 8 currently
 - NCBDD of CDC – 17 RTOIs with 3 more this year



Characteristics of Current Work

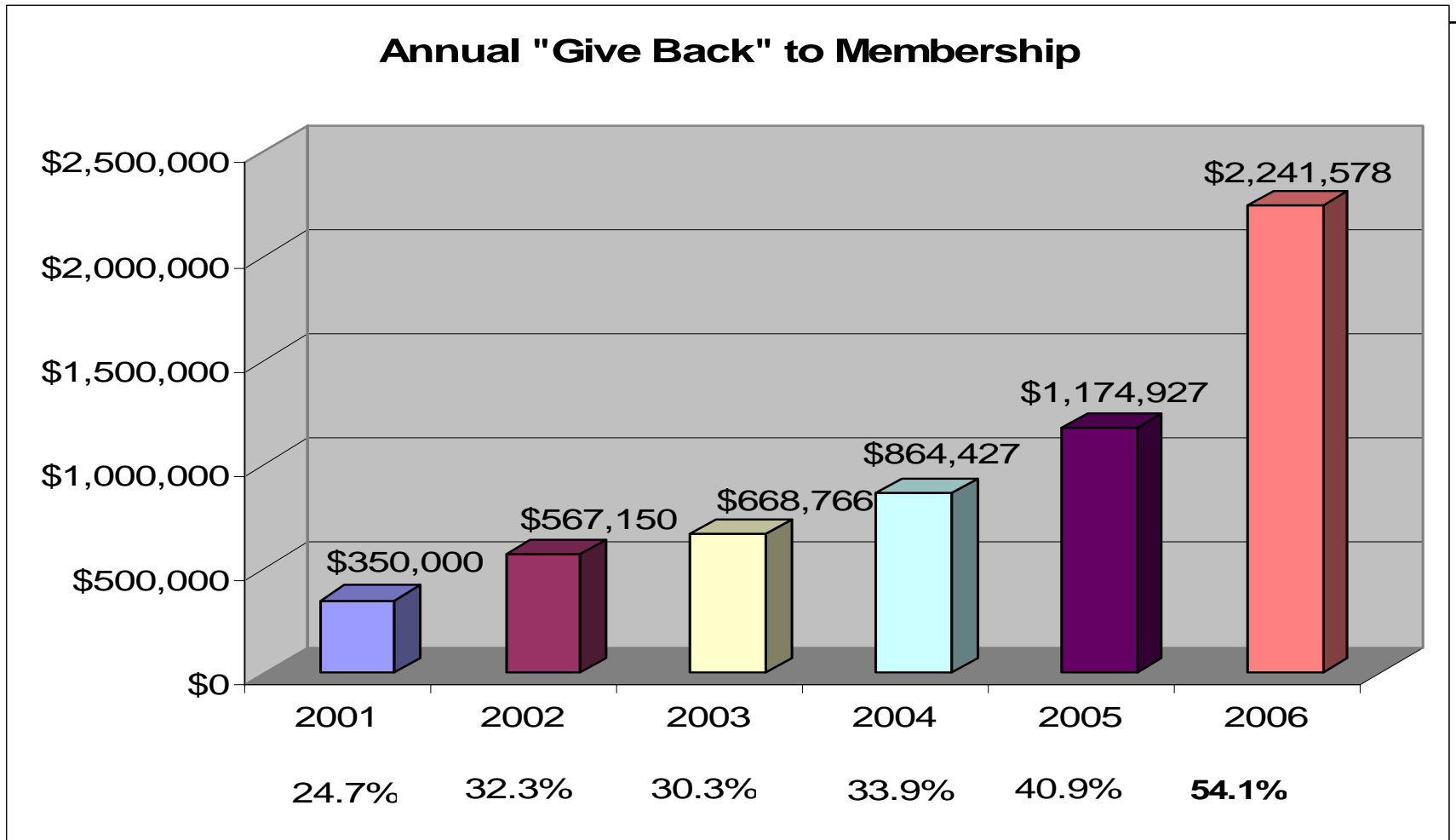
- Serve as Liaison between Federal Agency and network members
 - Network & individual centers & programs
- Puts AUCD in dual role
 - Association serving members who pay dues, and
 - Funding agent with associated responsibilities of to monitor and ensure quality of outcomes



Funding Implications

- Association budget has grown:
 - From \$750,000 to 5.2 million
- Outflow to members has increased 7 fold
 - From \$350,000 to \$2.2 million
- Additional financial resources for Association
 - 3-4% administrative fees charged on flow thru monies

AUCD's Annual "Give Back" To Member Centers & Programs



Outcomes for Members Centers and Programs

- Access to funding streams and federal agencies not previously widely available:
 - SSA, CDC, CNS
- Limited competition
- Building capacity in new areas



Potential Challenges

- Dual role of advocate for members and funder with associated responsibilities
- Centers become dependent on funding through AUCD
- Possible conflict between federal agency & legislative advocacy positions

Questions ?

- Do we continue with the existing arrangements?
- Do we expand and seek other such opportunities?
- If yes in what directions and what types of arrangements we should seek?-

Possible Criteria for Selecting Initiatives

- ❑ Can benefit a substantial part of the network either immediately or potentially in the future
- ❑ Builds on existing capacity and skills of Network or sub-network members
- ❑ Addresses serious needs of pwd
- ❑ Has potential for improving the lives of pwd
- ❑ Positions the network to make significant policy, research or model development impact
- ❑ Does not unduly over extend capacity of central office or network

Future New Opportunities – AUCD Wide for exploration

- Interdisciplinary Training – DD
- Services for Adults with disabilities
 - Transition from Pediatric to Adult Health Care
 - Training for adult health providers
- Impacting on Higher Education
- Single Disorders – e.g.
 - Autism
 - Down Syndrome
 - Fragile X
 - Spina Bifida

Interdisciplinary Training

- Current Contradiction
- Specific Expertise in range of disorders
- Need will expand with new born screening
- Individual disorder expertise coupled with knowledge of range of supports and services
- Need to build justification for ID approach
 - Research
 - Clear definition

Single Disorder Groups

- Clinical Services Specific to Disorders
 - Fragile X Clinics
 - Down Syndrome
 - Autism
 - Spina Bifida
- Registries
- Clinical Trials
- Identify common areas of interest including:
 - research questions,
 - pre-professional training- participation in training
 - service model development and
 - information
- Investigate legislative or budgetary areas of possible collaboration
- Work to expand single disorder focus to broader needs where appropriate



Adult Services

- Develop training models and programs to train interdisciplinary adult service providers
 - Transition to adult health care
 - Could be modeled or built upon existing LEND programs
 - Develop specialization in adults similar to pediatric specialization
 - Develop legislation that would meet the needs of adults with disabilities



Post Secondary Education

- Work with University Administration to expand and improve services and facilitate inclusion of student with disabilities
- Work with DOE to provide research, training, TA and models for postsecondary education
- Develop state system wide efforts to improve disability “friendly” campuses
- Develop resources for national dissemination
- Develop legislative agenda to move policy & supports forward



Transition & Employment

- Work with DOE to conduct research, model development, training
- Work with SSA to develop prototypes that increase odds of employment for beneficiaries
- Develop youth leadership & advocacy models
- Develop legislative agenda that address the needs of adolescents with disabilities

Questions

- Role of needs of Single Disorder Groups in Training
- Do we build Clinical Capacity?
- How to developing research capacity
- How do we develop mechanisms to work together
- State vs. regional vs. national needs?
- How do we build in existing strengths?
- What new areas do we need to develop?
 - Genetics
 - New Born Screening
 - Patient Registries
 - Other??