**REPORT ON**

**FY2004**

**NATIONAL INFORMATION AND REPORTING SYSTEM (NIRS)**

**DATA**

Prepared for

The Association of University Centers on Disabilities (AUCD)
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by

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# Contents

## Background

The web-based National Information and Reporting System (NIRS) is a collective effort by the Association of University Centers on Disabilities (AUCD), its member programs, and their federal partners. NIRS is designed to describe the outputs and outcomes of the network and to assist the University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) and the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs to comply with their federal data reporting requirements. UCEDDs receive their core funding from the Administration on Developmental Disabilities (ADD) and the LEND Programs receive their core funding from the Maternal and Child Health Bureau (MCH).

Network-wide data collection dates back to 1987. In 1987, amendments to the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) included a provision requiring ongoing collection of comparative data that would reflect the national impact of the UCEDD network. A plan was proposed and endorsed at the October 1987 Annual Meeting (AUCD was known at that time as the American Association of University Affiliated Programs) for implementing the network's first national data collection standards; the proposed plan resulted in the 1990 publication, *National Information Reporting System for University Affiliated Programs*.

Since its inception, NIRS has undergone several iterations, most recently with the introduction of a fully web-based NIRS on August 1, 2002. This most recent substantive revision of NIRS not only employed web-based data collection and management strategies, it incorporated (a) the new UCEDD data collection requirements outlined in the DD Act of 2000 and (b) the integration of data elements required by MCH for its LEND Program grantees. The fiscal year (FY) 2003 dataset was the first NIRS dataset to reflect these changes. Centers and Programs now enter their data directly into a national database and the data is cleansed using data review routines; the database allows network members to manage their own Center or Program data while enabling AUCD to present a picture of the network's activities using aggregate data.

This report on FY2004 NIRS data presents aggregate network data for FY 2004 (July 1, 2003– June 30, 2004) organized within four datasets: Trainees, Projects, Activities, and Products. AUCD developed the following tables and graphs using the information submitted by these programs for the FY2004 reporting period. The data presented illustrates that the network, together with their partners, impact the lives of people with disabilities.

## Acknowledgements

This report could not have been completed without the contributions of many people. The staff of AUCD gratefully acknowledges the contributions of the many individuals who have worked to develop, maintain, and improve NIRS, including Ray Gurganus and the staff of Community IT Innovators (CITI), Dr. Kelly Myles, the AUCD Board of Directors, and the Center and Program Data Coordinators and staff who assure the quality of the data entered. In addition, we wish to acknowledge the guidance provided by the project officers of AUCD's federal technical assistance contracts, Jennifer Johnson (ADD) and Denise Sofka (MCH).

## Interdisciplinary Training

Centers and Programs provide interdisciplinary training to professionals, paraprofessionals, students, family members and caregivers, people with disabilities, children with special health care needs, and the general public. The MCH LEND Program however, has a particular goal to improve the health of children who have, or at risk for, neurodevelopmental or related disabilities by training individuals identified with 11 targeted disciplines (pediatrics, nursing, public health, social work, nutrition, speech-language pathology, audiology, pediatric dentistry, psychology, occupational therapy, physical therapy, and health administration) as well as parents of children with neurodevelopmental disabilities.

Although NIRS and this report on FY2004 NIRS data are structured to be consistent with the requirements of the most recent authorization of the DD Act, the Trainee Dataset within NIRS is designed to be particularly responsive to the MCH reporting requirements for the LEND Program.

As authorized under Title V of the Social Security Act, MCH funds training programs, including the LEND Program, that are focused primarily on long-term training at the graduate and post-graduate levels with the goal of developing high levels of skill, competence, and leadership in maternal and child health.

All MCH programs support a shared strategic plan for meeting the needs of the maternal and child health populations of the United States. The strategic plan has three overarching goals:
- To eliminate barriers and health disparities in health status outcomes through the removal of economic, social, and cultural barriers to receiving comprehensive, timely, and appropriate health care;
- To assure the highest quality of care through the development of practice guidelines, data monitoring, and evaluation tools; the utilization of evidence-based research; and the availability of a well-trained, culturally diverse workforce; and
- To facilitate access to care through the development and improvement of the MCH health infrastructure and systems of care to enhance the provision of necessary, coordinated, quality health care.

**Core Functions and Areas of Emphasis**

NIRS supports individual Centers and Programs in their data management, program evaluation, long-range planning, and information sharing activities. The Trainee Dataset within NIRS is used to generate reports that support LEND Programs in meeting their MCH reporting requirements; however NIRS in general, as well as this report on FY2004 NIRS data, is structured consistently with the requirements of the most recent authorization of the DD Act.

The DD Act establishes the UCEDD grant program "in order to provide leadership in, advise federal, state, and community policymakers about, and promote opportunities for individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life." The UCEDDs are described to be entities associated with universities that engage in core functions addressing, directly or indirectly, one or more of the areas of emphasis.

The DD Act identifies that the UCEDDs' **core functions** shall include the provision of interdisciplinary pre-service preparation and continuing education of students and fellows, which may include the:

- Preparation and continuing education of leadership, direct service, clinical, or other personnel to strengthen and increase the capacity of states and communities.
- Provision of community services that provide training or technical assistance for individuals with developmental disabilities, their families, professionals, paraprofessionals, policy-makers, students, and other members of the community and that may provide services, supports, and assistance for the persons through demonstration and model activities.
- Conduct of research, which may include basic or applied research, evaluation, and the analysis of public policy in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families.
- Dissemination of information related to activities undertaken to address the purpose of this title, especially dissemination of information that demonstrates that the network authorized under this subtitle is a national and international resource that includes specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances.

The DD Act defines **areas of emphasis** to mean the areas related to quality assurance activities, education and early intervention activities, child care-related activities, health-related activities, employment-related activities, housing-related activities, transportation-related activities, recreation-related activities, and other services available or offered to individuals in a community, including formal and informal community supports that affect their quality of life.

The following NIRS data provides an overview of the network's FY2004 outputs and outcomes, organized by core function.

**Training and Technical Assistance**
Training includes *Pre-Service Preparation*, *Continuing Education*, and *Community Training*. *Pre-Service Preparation*, which usually takes place in an academic setting, leads to the award of a certificate or degree. *Continuing Education* is post-professional training for which continuing education units (or their equivalent) are granted. *Community Training* encompasses all other types of training. Within this core function:

- 3,959 trainees trained
- 572,564 people educated through pre-service preparation, continuing education, and community outreach training
- 155,692 hours of pre-service preparation, continuing education, and community outreach training provided
- 14.65% of total effort dedicated to training

Technical Assistance is the direct problem-solving services that are provided to assist individuals, programs, and agencies in improving their services, management, policies, and/or outcomes. Examples of technical assistance include needs assessment, program planning, curriculum or materials development, administrative consultation, program evaluation, advisory group participation, policy development, coalition development, and consultation to service providers about clients. Within this core function:

- 1,472,562 people received technical assistance
- 575,117 hours of technical assistance provided
- 54.13% of total effort dedicated to TA

**Service**
Service may include a variety of services, supports, and assistance for individuals with disabilities or special health care needs, their families, professionals, paraprofessionals, policy-makers, students, and other members of the community. These services may be related to a number of areas, including but not limited to education, child care, health, employment, housing, transportation, and recreation. Within this core function:

- 74,303 people received direct clinical or community contact services
- 195,376 hours of service provided
- 18.39% of total effort dedicated to service

**Research**

Research may include basic or applied research, evaluation, and the analysis of public policy in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families. Research and evaluation may entail such functions as the development and vetting of project proposals, implementation of research designs, data collection and analysis, report writing, and other types of functions. Research and evaluation functions may support measurement of progress, such as in the areas of consumer satisfaction, collaboration, and improvement. Within this core function:

- 87,480 hours dedicated to research
- 8.23% of total effort dedicated to research

**Information Dissemination**

Information development and dissemination equip programs to serve as a resource to various constituents on a local, regional, state, national, and international level, and might include product dissemination, public awareness projects, and other types of initiatives. Within this core function:

- 1,055 new products developed
- 4,949 distinct products available for dissemination
- 2,297 distinct products disseminated
- 1,641,371 copies of products disseminated and a substantial number of web-based material distributed via the internet
- 4.59% of total effort dedicated to information dissemination

In addition to the eight areas of emphasis identified in the DD Act, NIRS allows Centers and Programs to manage their data using two additional areas of emphasis: a general *Quality of Life* option and an *Other* option. The following NIRS data provides an overview of the network's FY2004 outputs and outcomes, organized by area of emphasis.

**Quality Assurance**
*Quality Assurance* is concerned with interagency coordination and systems integration that result in improved and enhanced services, supports, and other assistance that contribute to and protect the self-determination, independence, productivity, and integration and inclusion in all facets of community life of individuals with developmental disabilities. In this area of emphasis:

- 488,420 people acquired knowledge and skills
- 605 products were made available
- 9.22% of total effort
- 10.26% of total funding was obtained

**Education and Early Intervention**
*Education and Early Intervention* is concerned with (a) facilitating students' efforts to maximize their educational potential, benefit from educational activities, and participate in all facets of student life and (b) working with younger children and their families to enhance the child's development and the capacity of families to meet the special needs of the child. In this area of emphasis:

- 1,956,385 people acquired knowledge and skills
- 1,457 products were made available
- 20.87 % of total effort
- 16.82% of total funding was obtained

**Child Care**
*Child Care* is concerned with promoting access to and use of child care services by families of children with disabilities, including before-school, after-school, and out-of-school services, in their communities. In this area of emphasis:

- 359,273 people acquired knowledge and skills
- 498 products were made available
- 5.18% of total effort
- 6.8% of total funding was obtained

**Health**
*Health* is concerned with assuring equal, integrated access to health, dental, mental health, and other human and social services, including prevention activities, in the community. In this area of emphasis:

- 933,178 people acquired knowledge and skills

- 940 products were made available
- 12.27% of total effort
- 14.37% of total funding was obtained

## Employment
*Employment* is concerned with ensuring the ability of individuals with developmental disabilities to acquire, retain, and advance in paid employment in an integrated community setting. In this area of emphasis:

- 578,219 people acquired knowledge and skills
- 909 products were made available
- 7.84% of total effort
- 7.59% of total funding was obtained

## Housing
*Housing* is concerned with promoting equal access to and use of community housing and housing supports and services, including assistance related to renting, owning, or modifying an apartment or home. In this area of emphasis:

- 156,978 people acquired knowledge and skills
- 320 products were made available
- 3.93% of total effort
- 4.2% of total funding was obtained

## Transportation
*Transportation* is concerned with promoting equal access to and use of public transportation systems. In this area of emphasis:

- 216,484 people acquired knowledge and skills
- 279 products were made available
- 2.76% of total effort
- 3.65% of total funding was obtained

## Recreation
*Recreation* is concerned with assisting individuals with developmental disabilities gain access to and use of recreational, leisure, and social activities in their communities. In this area of emphasis:

- 419,501 people acquired knowledge and skills
- 391 products were made available
- 3.42% of total effort
- 4.52% of total funding was obtained

## Quality of Life
This additional *Quality of Life* area of emphasis is concerned with supporting individuals with

developmental disabilities in their efforts to practice greater self-determination and consumer- and family-focused planning, exerting greater choice and control in their lives, effecting their full inclusion and participation in the community, and increasing their general satisfaction with and access to services and supports.  In this area of emphasis:

- 929,424 people acquired knowledge and skills
- 1,203 products were made available
- 11.5% of total effort
- 15.42% of total funding was obtained

**Other–Assistive Technology**
The additional "Other" area of emphasis allows for further refinement of the category.  *Other–Assistive Technology* is concerned with any project that assists an individual with a disability and their family/caregivers in the selection, acquisition, or use of an assistive technology device.  In this area of emphasis:

- 335,726 people acquired knowledge and skills
- 469 products were made available
- 2.92% of total effort
- 2.44% of total funding was obtained

**Other–Cultural Diversity**
*Other–Cultural Diversity* is concerned with any project that provides or focuses on the provision of services, supports, or other assistance that is conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports, or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved.  In this area of emphasis:

- 971,760 people acquired knowledge and skills
- 174 products were made available
- 1.71% of total effort
- 1.92% of total funding was obtained

**Other–Leadership**
*Other–Leadership* is concerned with any project that enhances the potential of health care, allied health or related personnel to improve the health, developmental or functional status of children and adults with disabilities and equips personnel with the knowledge and skills required to enhance the systems of care and support for people with disabilities and their families.  In this area of emphasis:

- 252,267 people acquired knowledge and skills
- 246 products were made available
- 2.81% of total effort
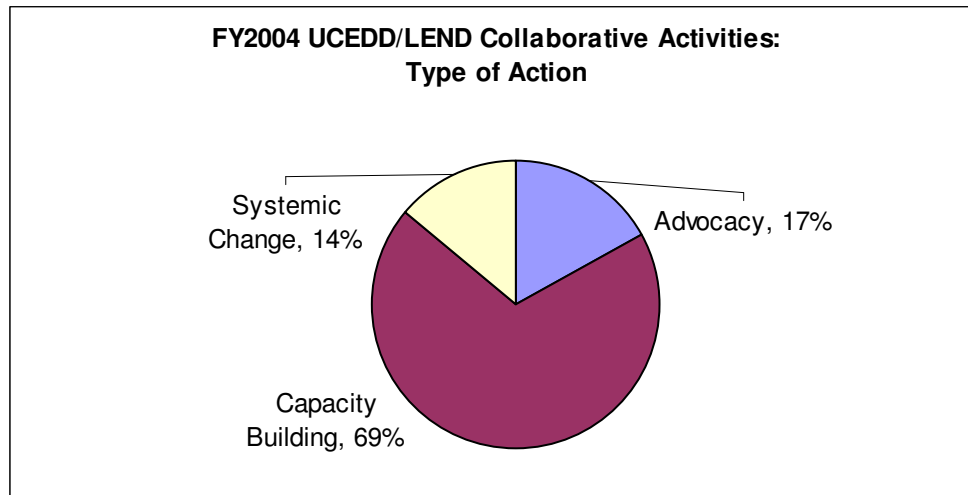- 1.58% of total funding was obtained

The DD Act calls for interagency coordination and collaboration between entities funded under its auspices. In FY2004, substantial numbers of the Centers and Programs engaged in funded collaborative projects with the other two programs funded under the DD Act—Protection & Advocacy Agencies and the Developmental Disabilities Councils—as well as the other national, state, and local programs.

### Collaborative Projects

| FY2004 Collaborative Efforts with Other DD Act Programs | | |
|---|---|---|
| # UCEDDs/ LENDs | Collaborated With | # Collaborative Projects |
| 56 | **Protection & Advocacy (P&A) Agency** | 401 |
| 58 | **Developmental Disabilities Council** | 348 |
| | **Total** | **749** |

| FY2004 Collaborative Efforts with Other National, State, & Local Programs | | |
|---|---|---|
| # UCEDDs/ LENDs | Collaborated With | # Collaborative Projects |
| 36 | Transportation Agency | 662 |
| 62 | Post Secondary Educational Institution | 593 |
| 59 | State/Local Social Services | 471 |
| 60 | State/Local MR/DD Agency or Provider | 432 |
| 62 | Health Agency - Public/Private | 426 |
| 62 | State/Local Special Education (3-21) | 423 |
| 58 | Consumer/Advocacy Organization | 385 |
| 62 | Child Care/Early Childhood/Part C Infants and Toddlers | 369 |
| 57 | Other | 351 |
| 54 | Employment/Voc Rehab | 297 |
| 56 | State/Local Coalition | 296 |
| 55 | Mental Health/Substance Abuse Agency | 272 |
| 53 | Head Start/Early Head Start | 250 |
| 34 | Recreation Agency | 246 |
| 59 | State/Local General Education | 224 |
| 50 | Community or Faith-Based Organization | 177 |
| 44 | Other MCHB Funded Program | 147 |
| 44 | Aging Organization | 129 |
| 40 | Housing Agency/Provider | 104 |
| 43 | Legislative Body | 99 |
| 39 | Justice/Legal Organization | 90 |
| 60 | Other UCEDD | 80 |
| 60 | State Title V Agency | 79 |
| 23 | National Association | 38 |
| | **Total** | **6,640** |

**Collaborative Strategies**

**FY2004 UCEDD/LEND Collaborative Activities:
Type of Action**

Systemic
Change, 14%

Advocacy, 17%

Capacity
Building, 69%

The vast majority of the collaborative work undertaken by the network in FY2004 was designed to increase the capacity of systems to meet the needs of individuals with disabilities and/or their families (capacity building–69%). Centers and Programs also engaged in substantial collaborative advocacy work (17%) and efforts to effect systems change (14%).

The following are definitions of action types:

*Advocacy*: support for a program, initiative, or change, often generated from increased awareness of issues or dissatisfaction with current practices and policies. Self-advocacy is support on the part of the individual directly affected by the issues, and may include capacity-building skills in effective expression, strategy development and implementation, and leadership and is closely related to self-determination with regard to choice and planning in the areas of living arrangements, medical care, personal assistance, employment, and community participation.

*Capacity Building*: a variety of approaches used to strengthen their own and local, Ssate, regional, and national communities. Such activities may include enriching program depth and breadth, acquiring additional resources, and fostering an increase in effective activities. Performance measures are used to indicate progress toward enhanced capacity.

*Systemic Change*: the attainment of an outcome or goal and/or the alteration of programs, policies, funding streams, and/or services for persons with disabilities.

**Trainee Dataset Highlights**

The Trainee Dataset is designed to capture information on network trainees. The NIRS Trainee Dataset enables Centers and Programs to create and manage multi-year records for all trainees.

Trainees are categorized in NIRS by the number of contact hours required to complete their training program. Trainees are designated as short-term (40–149 contact hours), intermediate (150–299 contact hours), or long-term trainees (300+ contact hours). In FY 2004, the network trained nearly 4,000 individuals comprised of 2,275 short- and intermediate-term trainees and 1,717 long-term trainees. LEND trainees numbered 1,190.

The following table compares the ethnicity of network trainees to the nation's demographics. The relative percentages of network trainees in several ethnic categories are greater than what might be expected given the nation's demographics.

**Trainee Ethnicity**

| FY2004 UCEDD/LEND Trainees by Ethnicity with US Demographics | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Geographic area | Total population | % White alone, not His-panic or Latino[1] | % Black or African Amer-ican | % Amer-ican Indian and Alaska Native | % Asian | % Native Hawai-ian and Other Pacific Islander | % Some other race | % Two or more races | % His-panic or Latino (of any race)[2] |
| United States | 281,421,906 | 69.1 | 12.3 | 0.9 | 3.6 | 0.1 | 5.5 | 2.4 | 12.5 |
| **Network Trainee Totals[3]** | **3,992** | **68.9** | **9.2** | **0.5** | **8** | **0.8** | **5.9** | **2.4** | **5.7** |
| percentage point difference | | -0.2 | -3.1 | -0.4 | 4.4 | 0.7 | 0.4 | 0 | -6.8 |

[1]The US Census 2000 uses the designation "White alone" as well as "White" because individuals who are Latino may be of any race. In contrast, the NIRS database only allows the selection of only one ethnic category, so individuals who are both White and Latino must only select one designation. For this comparison, we are using the US Census "White alone" data to compare with NIRS "White" data.

[2]For this comparison, the US Census 2000 "Hispanic or Latino" designation data is used in comparison with the NIRS database "Hispanic" designation data.

[3]The network trainee total represents a sample of .0014% of the nation's population.

**Trainee Ethnicity and Level of Training**

| FY2004 UCEDD/LEND Trainees by Ethnicity and Level of Training | | | | |
|---|---|---|---|---|
| | Type of Trainee | | | % of Total Ethnicity |
| Ethnicity | Long-Term | Intermediate | Short-Term | |
| White | 1,150 | 595 | 1,009 | 69% |
| Black/African-American | 183 | 37 | 146 | 9% |
| American-Indian/ Alaska Native | 12 | 5 | 4 | 1% |
| Asian | 145 | 59 | 114 | 8% |
| Native Hawaiian/ Pacific Islander | 27 | 5 | 1 | 1% |
| Hispanic/Latino | 107 | 52 | 68 | 6% |
| Multiracial | 17 | 6 | 13 | 1% |
| Other | 76 | 102 | 59 | 6% |
| % of Total Trainee Type | 43% | 22% | 35% | 100% |

In FY2004, the network had more long-term trainees (43%) than short-term (35%) or intermediate (22%) trainees.

**Trainees by Gender and Age**

| FY2004 UCEDD/LEND Trainees by Gender and Age | | | |
|---|---|---|---|
| | Gender | | % Age Range |
| Age Ranges | Male | Female | |
| 18-20 years | 21 | 113 | 5.3% |
| 21-25 years | 97 | 722 | 32.5% |
| 26-30 years | 207 | 619 | 32.8% |
| 31-35 years | 96 | 254 | 13.9% |
| 36-40 years | 31 | 128 | 6.3% |
| 41-45 years | 14 | 87 | 4.0% |
| 46-50 years | 9 | 72 | 3.2% |
| 51-55 years | 8 | 32 | 1.6% |
| 56+ years | 1 | 11 | 0.5% |
| **% for Gender** | 19% | 81% | 100% |

65.3% { (spanning 21-25 years and 26-30 years rows)

The majority of trainees (65.3%) in FY2004 were between the ages of 21–30; female trainees outnumbered males 4:1 in FY2004.

## Trainees by Academic Level and Identified Training Program

| FY2004 UCEDD/LEND Trainees by Academic Level and Curriculum | | | | | | |
|---|---|---|---|---|---|---|
| Academic Level | MCH | ADD | OSEP | Pediatric Residency | Other | % Academic Level |
| Non Degree | 26% | 6% | 16% | 1% | 25% | 4% |
| Undergraduate | 8% | 23% | 20% | 0% | 21% | 24% |
| Masters | 33% | 17% | 11% | 0% | 22% | 29% |
| Doctoral | 32% | 20% | 4% | 2% | 27% | 16% |
| Post Doctoral | 36% | 17% | 0% | 23% | 16% | 23% |
| Other/Unknown | 33% | 9% | 6% | 9% | 25% | 3% |
| % Curricula | 27% | 18% | 10% | 6% | 21% | 100.0% |

This table depicts the distribution, by curricula, of the network's FY2004 trainees whose training programs require at least 40 contact hours for completion. The "curriculum" is the training program as generally defined by its funding source.

## Current Employment Settings of Former Trainees

| Former (pre-2004) UCEDD/LEND Trainee Employment | |
|---|---|
| Current Employment Setting | % Former Trainees |
| Hospital | 25% |
| Academic | 21% |
| Schools | 15% |
| Private Sector | 13% |
| Nonprofit | 10% |
| Other | 6% |
| Government | 5% |
| UCEDD/LEND | 4% |
| Public Health | 1% |

Follow-up surveys of individuals who completed their training programs prior to FY2004 reveal that former trainees work most predominately in hospital and academic settings, but are also prevalent in school (non-university), private sector, and nonprofit settings.

**Trainee Discipline**

| FY2004 UCEDD/LEND Trainees by Discipline | | |
|---|---|---|
| **DISCIPLINE** | **TOTAL #** | **TOTAL %** |
| Audiology | 75 | 2% |
| Dentistry/Pediatric Dentistry | 90 | 2% |
| Education: Early Intervention/Early Childhood | 270 | 7% |
| Education: General Education | 72 | 2% |
| Education: Other | 78 | 2% |
| Education: Special Education | 495 | 12% |
| General Medicine | 46 | 1% |
| Genetics | 81 | 2% |
| Health Administration | 49 | 1% |
| Human Development/Child Development | 66 | 2% |
| Interdisciplinary | 37 | 1% |
| Nursing | 116 | 3% |
| Nutrition | 98 | 2% |
| Occupational Therapy | 113 | 3% |
| Other/Unknown | 559 | 14% |
| Pediatrics | 668 | 17% |
| Physical Therapy | 140 | 4% |
| Psychiatry | 38 | 1% |
| Psychology: Clinical | 295 | 7% |
| Psychology: General | 123 | 3% |
| Social Work: Administration | 22 | 1% |
| Social Work: Clinical | 142 | 4% |
| Speech-Language Pathology | 303 | 8% |
| % of Total | 3,992 | 100% |

23% { (Education: Early Intervention/Early Childhood through Education: Special Education)

10% { (Psychology: Clinical through Psychology: General)

This table depicts the distribution, by discipline, those trainees in FY2004 whose training programs require at least 40 contact hours for completion. Twenty-three percent (23%) of the FY2004 trainees represented a variety of education disciplines, and 10% represented psychology disciplines. The single highest discipline represented by FY2004 trainees was pediatrics (17%).

The Projects Dataset is intended to record information on on-going major initiatives—which may span several years—that are likely to encompass multiple activities. In contrast, the Activities Dataset is intended to record information on individual, time-limited events (often measurable in hours) with a more targeted purpose. NIRS is designed so that projects in the Projects Dataset may be linked to a number of measurable activities.

Project-level reporting can further be distinguished from activity-level reporting in that project reporting focuses more on the project's infrastructure than the impact of their activities (e.g., number of students trained).

The network values the contribution of consumers to Center and Program projects. The DD Act mandates that UCEDDs have a consumer advisory committee "of which a majority of the members shall be individuals with developmental disabilities and family members of such individuals." A major goal of the MCH Service Block Grants, under which the LEND Program is funded, is to change attitudes and practices. The participation of family members is essential to move toward this goal of providing services for children with special health care needs that are family-centered, community-based and coordinated.

**Consumer Participation in Projects**



FY2004 Consumer Participation in Projects
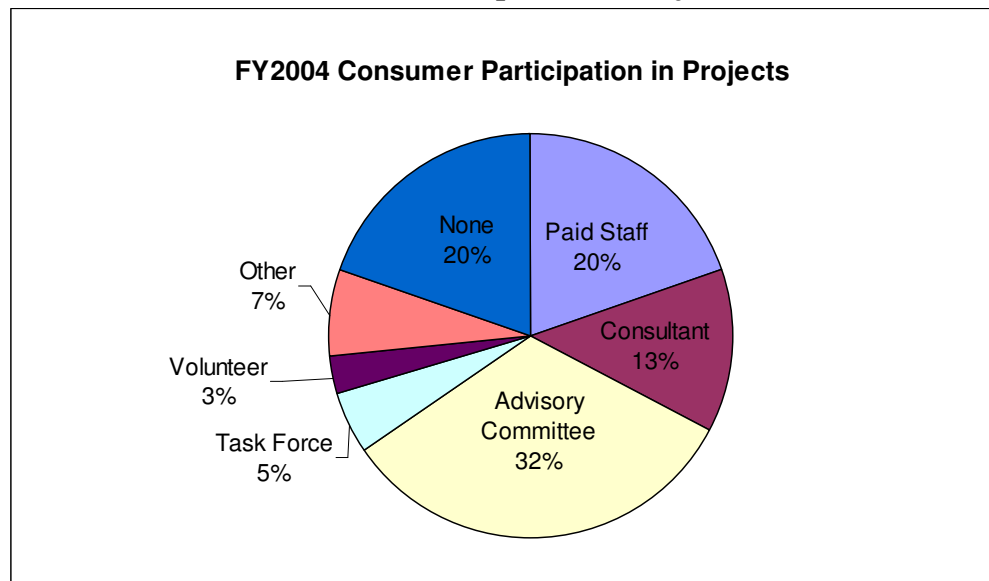
Fully 80% of the networks FY2004 projects involved meaningful participation by consumers. In addition, a total of 33% of projects reported paying consumers for their contributions to projects as either paid staff (20%) or consultants (13%). The typical types of projects that did not report consumer participation included fee for service projects and data analysis projects.

**Projects by Un- or Underserved Populations**

| FY2004 UCEDD/LEND Projects by Un or Underserved Populations | |
|---|---|
| Racial or Ethnic Minorities | 18.69% |
| Individuals from Disadvantaged Circumstances | 17.71% |
| Individuals from Underserved Geographic Areas – Rural/Remote | 13.66% |
| Individuals with Limited English Proficiency | 11.04% |
| Specific Groups within the Population of Individuals with Developmental Disabilities | 10.34% |
| Individuals from Underserved Geographic Areas – Urban | 10.25% |
| Individuals from Underserved Geographic Areas – Empowerment Zone | 4.39% |
| Unserved/Underserved Population Not Served | 3.66% |
| Other | 3.65% |
| Individuals from Underserved Geographic Areas – Reservation | 3.63% |
| Individuals from Underserved Geographic Areas – Renewal Community | 1.29% |
| Individuals from Underserved Geographic Areas – Territory | 0.95% |
| Individuals from Underserved Geographic Areas – Other | 0.74% |
| Total | 100.00% |

This table describes the target populations of the network's FY2004 projects. The projects of Centers and Programs work with the following groups within the target populations: students/trainees, professionals and paraprofessionals, family members and caregivers, people with disabilities, children with special health care needs, and the general public. Although each project may work with more than one target population, 96.33% of the network's projects targeted at least one un- or underserved population.

**Projects with an International Focus**

The network has taken an increasing interest in projects that have an international focus.  In FY2004, Centers and Programs operated **20 projects** within the following countries/regions: Australia, Canada, Commonwealth of the Northern Mariana Islands, Dominican Republic, England, Europe, Federated States of Micronesia, Guam, Haiti, Kuwait, Pacific Rim, Republic of Palau, Spain, and Turkey.

The Centers performed research and provided technical assistance, training, and service in their international projects.  Following is a brief list of the types of activities performed in FY2004:

- **Technical Assistance**
  Technical assistance provided in the areas of assistive technology, behavior skills, communication, early intervention, employment, hearing impairments/deaf, housing, mental health, motor sensory skills, nutrition, positioning, quality of life, special education, and vision impairments/blind.

- **Training**
  Training provided in the areas of assistive technology, graduate and undergraduate speech language pathology, quality improvement in special education, and special education.

- **Research**
  Research projects to determine the impact of infant massage on orphans; the cognitive, social, educational, and behavioral effects of clinical trials for the treatment of childhood cancer; and to test the efficacy of a new form of pediatric rehabilitation therapy for children with cerebral palsy.

- **Service**
  Service provided in the form of special education assessments.

The Activities Dataset is intended to record information on individual, time-limited events (often measurable in hours) with a more targeted purpose. In contrast, the Projects Dataset is intended to record information on on-going initiatives that may encompass multiple activities.

Activity-level reporting can further be distinguished from project-level reporting in that activity records focus more on impact (e.g., number of students trained) of the work than on the infrastructure of any project. NIRS allows Centers and Programs to manage information on the activities performed for each project. All the data collected in the Activities Dataset is linked to particular projects identified in the Projects Dataset.

**Activities by Area of Emphasis**
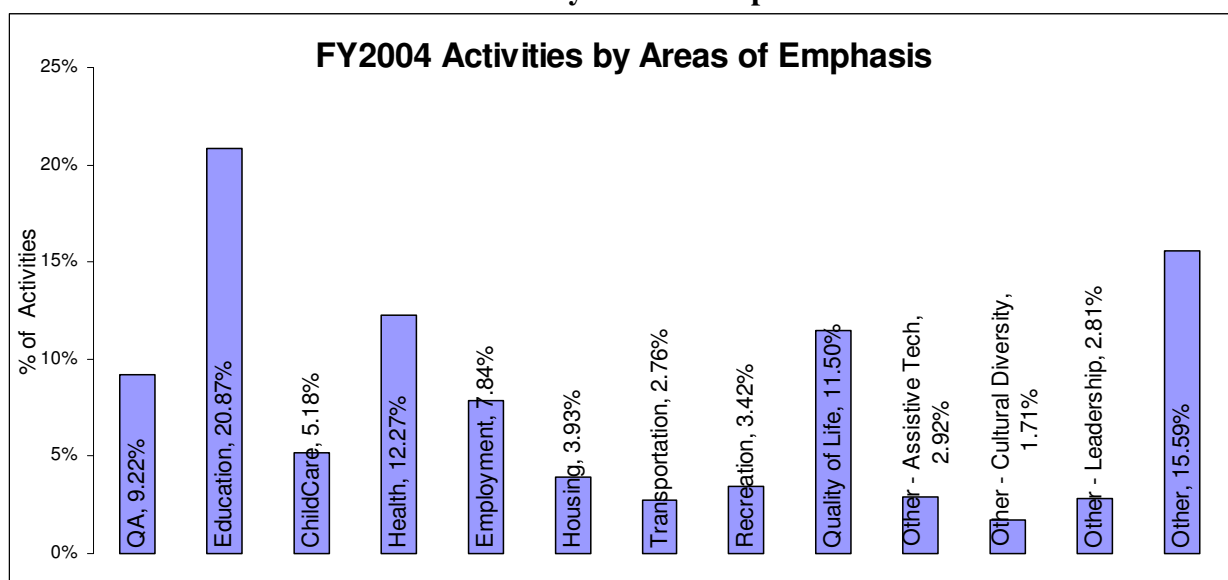


This table illustrates the percentage of network activities that were dedicated to the various areas of emphasis in FY2004. The amount of effort dedicated by area of emphasis is closely related to the level of funding obtained for each area of emphasis (see *Funds Obtained by Areas of Emphasis* on page 26).
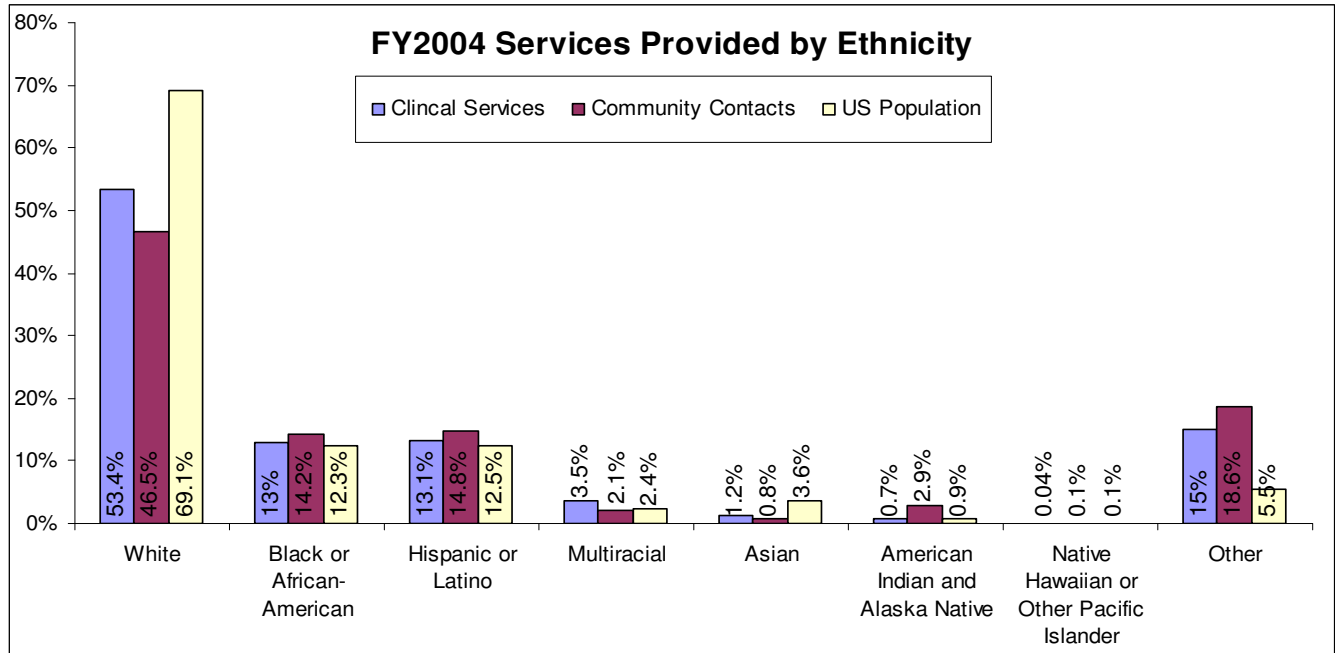
**FY2004 Services Provided by Age of Recpients**
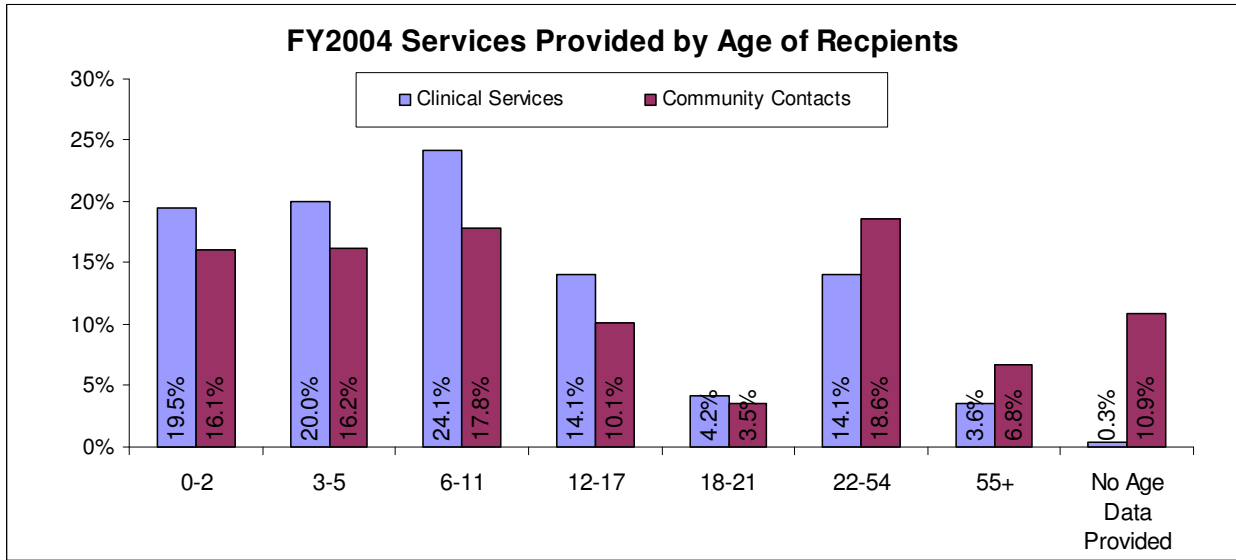


NIRS allows for the collection of *clinical services* data by the individual served in network clinics.  In contrast, NIRS collects *community contacts* data by consults provided or contacts made, rather than by the individuals served.

This figure displays, by age, the relative percentages of individuals served clinically and in the community by the network.  The figures shown reflect the percentage served, by age, for the type of service.  For example, 19.5% of all the clinical clients were aged 0–2, while 16.1% of all the community consults or contacts made were made for individuals in the 0–2 age range.  The majority of network clinical (77.7%) and community contacts (60.3%) in FY 2004 were provided to or on behalf of individuals aged 0–17 years.

**Services Provided by Ethnicity**

## FY2004 Services Provided by Ethnicity

Legend: ☐ Clincal Services   ■ Community Contacts   ☐ US Population

| Ethnicity | Clinical Services | Community Contacts | US Population |
|---|---|---|---|
| White | 53.4% | 46.5% | 69.1% |
| Black or African-American | 13% | 14.2% | 12.3% |
| Hispanic or Latino | 13.1% | 14.8% | 12.5% |
| Multiracial | 3.5% | 2.1% | 2.4% |
| Asian | 1.2% | 0.8% | 3.6% |
| American Indian and Alaska Native | 0.7% | 2.9% | 0.9% |
| Native Hawaiian or Other Pacific Islander | 0.04% | 0.1% | 0.1% |
| Other | 15% | 18.6% | 5.5% |

NIRS allows for the collection of *clinical services* data by the individual served in network clinics.  In contrast, NIRS allows for the collection of *community contacts* data by consults provided or contacts made, rather than by the individuals served.

This figure displays, by ethnicity, the relative percentages of individuals served by the network in FY2004 clinically and in the community.  The figures shown reflect the percentage served, by ethnicity, for the two types of service. To provide a context, national ethnic population figures (US Census 2000) are provided.

As this figure demonstrates, the relative percentages of the individuals served in network clinical services and community contacts in FY 2004 are greater than what might be expected given the nation's demographics in several ethnic categories.  Although only 30.9% of the US population is other than white, 46.6% of all the clinical clients and 53.5% of the community contacts made in FY2004 were made to individuals who are other than white.  In addition, the figure demonstrates that Centers and Programs serve individuals of minority populations at rates greater than their national prevalence, and serve individuals who are white at a rate lower than their national prevalence.

The Product Dataset is intended to capture information on various materials produced and disseminated by network. NIRS allows Centers and Programs to manage information on the products they develop and/or disseminate. The products may be linked to specific activities and projects.

## Products by Area of Emphasis

**FY2004 Products Disseminated by Area of Emphasis**
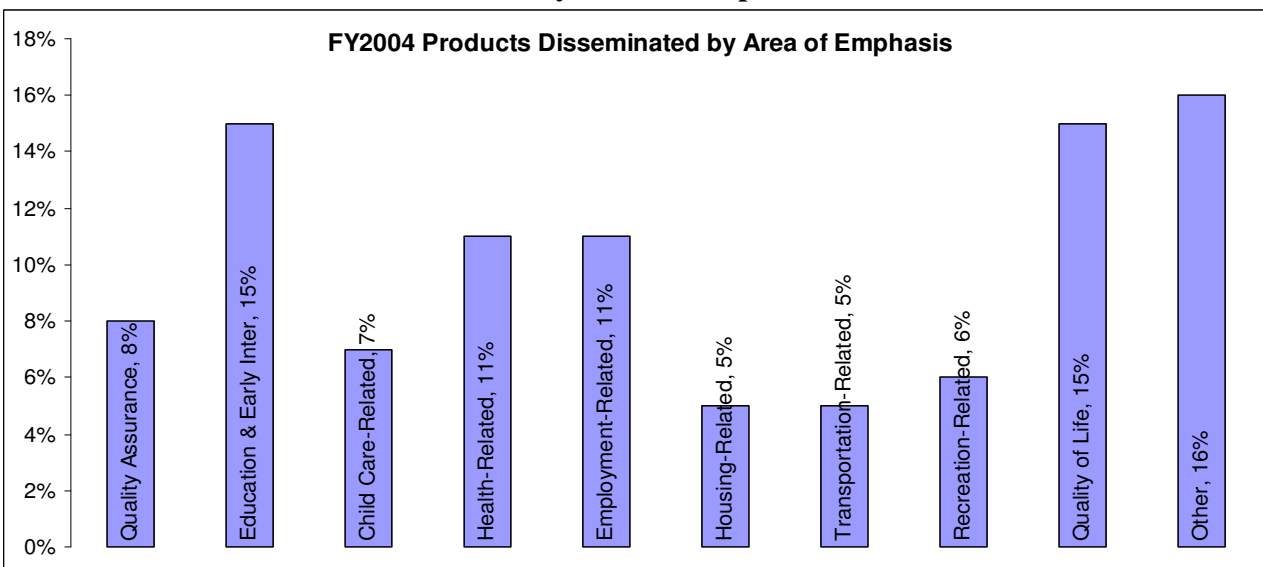


The relative percentages of material disseminated by area of emphasis provide a meaningful overview of the level of public interest in such material.

## Product Formats

| FY2004 Format of Products Disseminated by UCEDDs/LENDS | | |
|---|---|---|
| **Format of Disseminated Products** | **# of Copies Disseminated** | **% Disseminated** |
| Audio-Visual | 9,734 | 0.59% |
| Guide/Handbook | 73,270 | 4.46% |
| Curriculum | 9,319 | 0.57% |
| Monograph/Report | 26,787 | 1.63% |
| Non-refereed publication | 781,193 | 47.59% |
| Public awareness material, brochure, or newsletter | 681,287 | 41.51% |
| Refereed journal article | 35,944 | 2.19% |
| CD or Software | 12,387 | 0.75% |
| Book | 11,450 | 0.70% |
| Total | 1,641,371 | 100.00% |

In addition to the products listed above, Centers and Programs disseminated substantial amounts of web-based material over the internet.
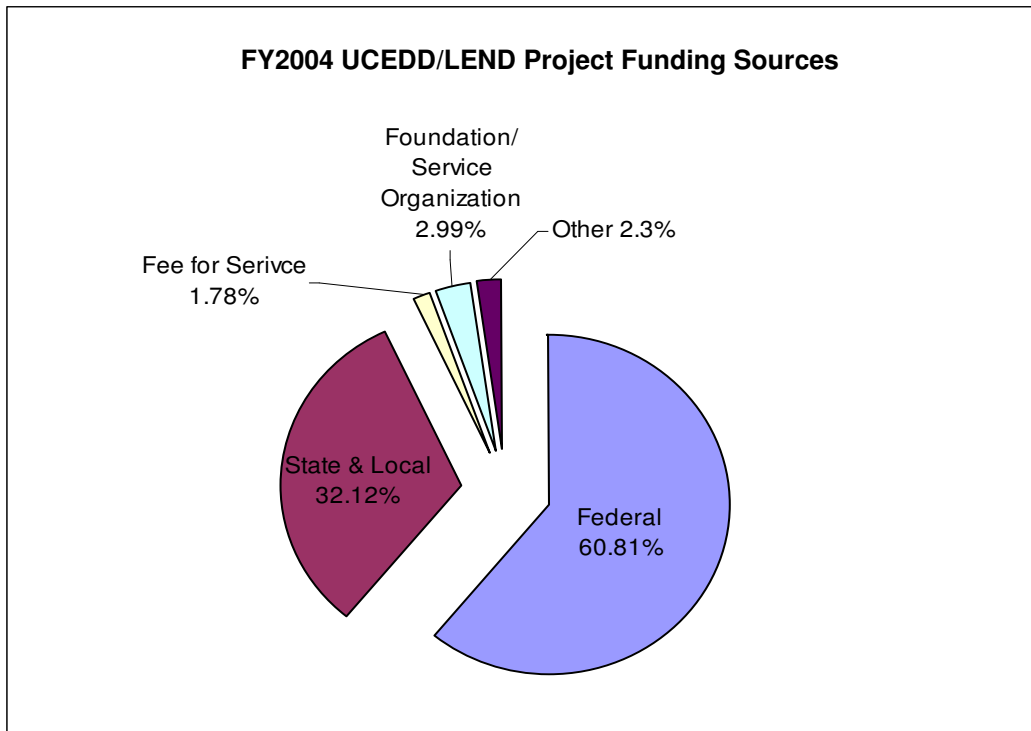
NIRS allows Centers and Programs to manage information on the funding of their projects.   The following charts and tables provide an overview of the network's funding for FY2004.

The DD Act provides the authorizing language for funding the UCEDDs, which mandates that UCEDD core grant funds be distributed in equal amounts to each Center.  Currently, the 61 UCEDDs each receive annual core funding in the amount of $382,888.

Title V of the Social Security Act authorizes discretionary Special Projects of Regional and National Significance (SPRANS) grants, which is the mechanism used by MCH for the LEND Program.  Thirty-five (35) LEND Program grants are awarded with a range of budgets, however with one exception, annual grant budgets range from $355,000 to $881,000, with an average (excluding the one outlier) annual award of $503,621.

## Sources of Project Funding



FY2004 UCEDD/LEND Project Funding Sources

- Foundation/ Service Organization 2.99%
- Other 2.3%
- Fee for Serivce 1.78%
- State & Local 32.12%
- Federal 60.81%

The vast majority (92.93%) of FY2004 network funding came from federal, state, and local government sources.  Federal sources provided 60.81% of total network funding; state and local sources provided 32.12% of the total funding in FY2004.

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# Federal Funding

Federal sources provided the majority (60.81%) of the total funding for Centers and Programs in FY2004. The US Department of Health and Human Services (HHS) and Department of Education (DOE) agencies supplied nearly 90% of the federal funds that supported the network in FY2004.

| FY2004 UCEDD/LEND Federal Funding by Department | | |
|---|---|---|
| **Agency** | **Funding Amount** | **% of Support** |
| HHS | $94,022,630 | 48.47% |
| DOE | $79,810,290 | 41.14% |
| DOJ | $1,370,489 | 0.71% |
| DOL | $9,834,015 | 5.07% |
| SSA | $2,984,176 | 1.54% |
| NSF | $183,490 | 0.09% |
| HUD | $436,000 | 0.22% |
| Other | $5,340,591 | 2.75% |
| **Total Federal Funding** | **$193,981,681** | **100.00%** |

| FY2004 HHS Funding | |
|---|---|
| ADD | $26,399,188 |
| MCH | $22,006,246 |
| Other NIH | $10,585,962 |
| NICHD | $8,863,959 |
| CDC | $8,324,357 |
| CMS | $7,625,265 |
| Head Start | $3,018,703 |
| SAMHSA | $1,902,476 |
| Other HRSA | $1,674,884 |
| Other ACF | $1,645,565 |
| I H S | $975,793 |
| NIDCD | $591,199 |
| Other HHS | $383,393 |
| NIMH | $21,640 |
| AoA | $4,000 |
| **HHS Total** | **$94,022,630** |

| FY2004 DOE Funding | |
|---|---|
| OSEP | $36,325,001 |
| NIDRR | $30,619,581 |
| RSA | $7,532,911 |
| DOE other | $5,332,797 |
| **DOE Total** | **$79,810,290** |

## State and Local Funding

The second largest source of support (32.12%) for Centers and Programs in FY2004 was from state and local government sources.
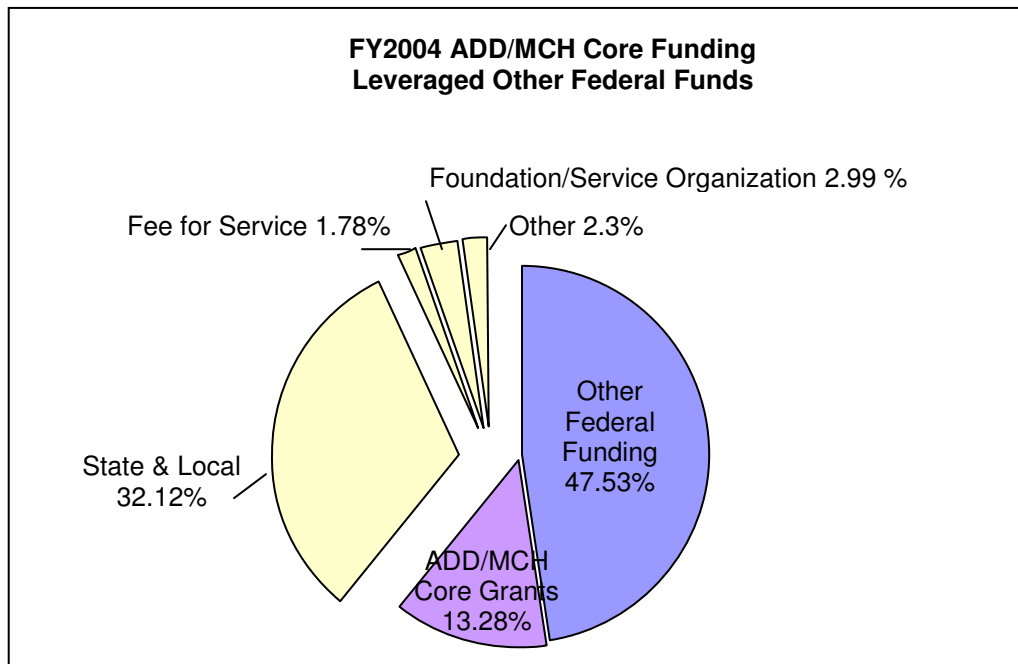
| FY2004 UCEDD/LEND State & Local Funding by Agency | | |
|---|---|---|
| **State or Local Agency** | **Funding Amount** | **% of Support** |
| Department of Education | $25,581,533 | 24.97% |
| Other State | $20,038,784 | 19.56% |
| Department of Health (including Title V) | $15,030,797 | 14.67% |
| Department of Social Services | $12,316,037 | 12.02% |
| Department of Mental Retardation/Developmental Disabilities | $10,957,749 | 10.70% |
| Vocational Rehabilitation | $4,668,994 | 4.56% |
| Local Health, Schools, Social Services, etc. | $4,433,531 | 4.33% |
| Medicaid/Medicare | $4,072,316 | 3.97% |
| Department of Mental Health | $3,163,773 | 3.09% |
| Developmental Disabilities Council | $2,184,867 | 2.13% |
| **Total State & Local Funding** | **$102,448,381** | 100.00% |

## Funds Obtained by Areas of Emphasis



FY2004 Project Funding by Area of Emphasis

QA 10.26%, Education 16.82%, Child Care 6.81%, Health 14.37%, Employment 7.59%, Housing 4.2%, Transportation 3.65%, Recreation 4.52%, Quality of Life 15.42%, Other-Assistive Tech 2.44%, Other-Cultural Diversity 1.92%, Other-Leadership 1.58%, Other 10.43%
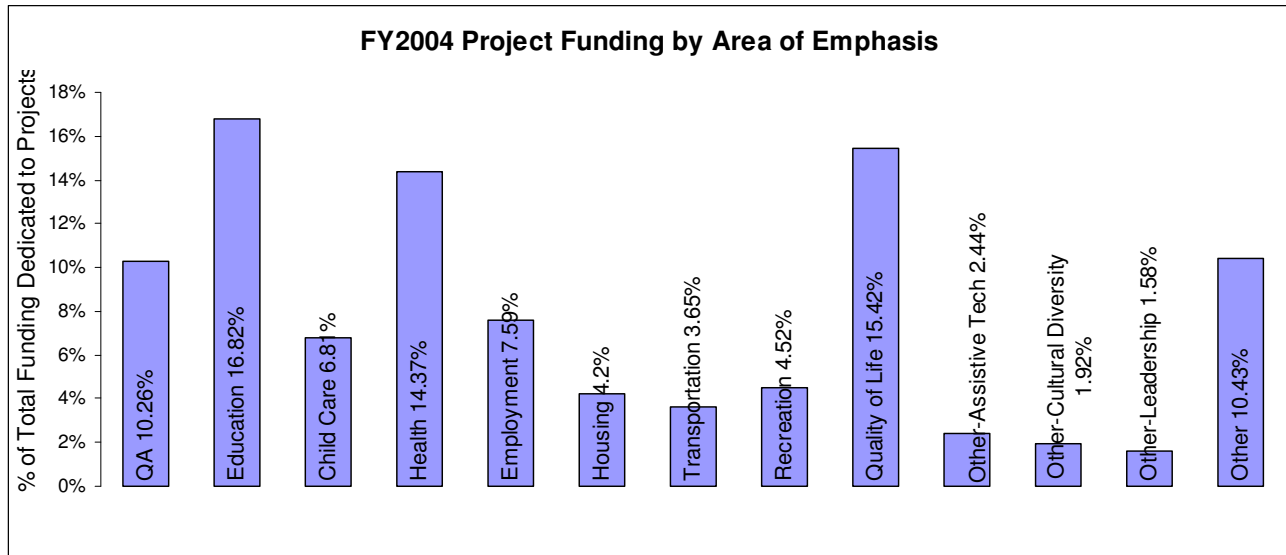
This table illustrates the percentage of network funding that was dedicated to the various areas of emphasis in. FY2004. The level of funding is closely related to the amount of effort dedicated to each area of emphasis (see *Activities by Area of Emphasis* on page 20).

**Leveraged Core Funding**



**FY2004 ADD/MCH Core Funding
Leveraged Other Federal Funds**

Foundation/Service Organization 2.99 %

Fee for Service 1.78%

Other 2.3%

Other Federal Funding 47.53%

State & Local 32.12%

ADD/MCH Core Grants 13.28%

The DD Act requires that UCEDDs, to the extent possible, utilize the infrastructure and resources obtained through funds made available under the grant to leverage additional public and private funds to successfully achieve project goals.  The leveraging of funds is not legislatively mandated for the LEND Programs under Title V of the Social Security Act; however to effectively operate, Programs must leverage support from other sources.  Centers and Programs reported:

- In FY2004, total network ADD/MCH core funding was $43,107,773, encompassing:
    - Total ADD core grant funding of $24,276,353
    - Total MCH core grant funding of $18,831,420

- In FY2004, the network leveraged an additional $275,878,349 in funding beyond their core grants.

- In FY2004, the network generated $6.40 for every core grant dollar from ADD/MCH, a slight increase (1.97%) over FY2003, in which the network generated $6.22 for each ADD/MCH core grant dollar.