

Administration on Developmental Disabilities

SPECIAL PROJECTS PROGRAM

ABSTRACTS OF FUNDED GRANTS, FISCAL YEARS 1988 - 1989

**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF HUMAN DEVELOPMENT SERVICES
ADMINISTRATION ON DEVELOPMENTAL DISABILITIES**

PROJECTS OF NATIONAL SIGNIFICANCE

**ABSTRACTS OF FUNDED GRANTS
FISCAL YEARS 1988-1989**

December, 1989

The Administration on Developmental Disabilities is pleased to share with you this compilation of abstracts on Projects of National Significance (PNS) funded from 1988 to 1989 under Part E of the Developmental Disabilities Assistance and Bill of Rights Act of 1984 (P.L. 100-146).

These abstracts describe the 26 projects and four interagency agreements that have been funded during this period to implement the PNS portion of P.L. 100-146 and meet the priorities of the Assistant Secretary for Human Development Services and the ADD Commissioner. They focus on topics such as: strengthening families, reducing dependency, pediatric AIDS, data collection, technical assistance, and information and referral systems.

These descriptions are representative of ADD's research, demonstration, evaluation, training and technical assistance efforts in support of the independence, productivity, and integration into the community of persons with developmental disabilities.

We hope that you find this information useful and take advantage of the resources presented.

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PROJECTS OF NATIONAL SIGNIFICANCE OVERVIEW FISCAL YEARS 1988 AND 1989

INTRODUCTION

Part E of the Developmental Disabilities Assistance and Bill of Rights Act of 1987 (P.L. 100-146) provides for the award of grants and contracts for projects of national significance to increase and support the independence, productivity, and integration into the community of people with developmental disabilities. The legislation mandates the funding of projects in the following categories:

- Projects to educate policymakers;
- Projects to develop an ongoing data collection system;
- Projects to determine the feasibility and desirability of developing a nationwide information and referral system;
- Projects that pursue Federal interagency initiatives and other projects of sufficient size and scope, and which hold promise of expanding or otherwise improving opportunities for people with developmental disabilities (especially those who are multi-handicapped or disadvantaged, or minority groups, including Native Americans, Native Hawaiians, and other underserved groups; and
- Technical assistance and demonstration projects (including research, training, and evaluation in connection with such projects) which hold promise of expanding or otherwise improving the advocacy functions of the State Developmental Disabilities (DD) Planning Councils, the functions performed by University Affiliated Programs and Satellite Centers, and Protection and Advocacy Agencies relating to the State projects for the evaluation and assessment of the quality of services provided people with developmental disabilities.

The purpose of this document is to provide you with information on the 26 grant awards and four interagency agreements that ADD has funded from fiscal years 1988-1989 in an effort to meet the mandates of Part E of P.L. 100-146.

The FY 1988 Projects of National Significance program focused on the following priority areas:

- The **Family Support** (Strengthening Families) priority area was targeted at evaluating projects and policies which have proven successful in making available to families essential services and other types of supportive mechanisms at the State, county or local level. Examples include: studies

of policies and practices that have been successful in making available supports, resources and services to families, educating policy makers to become aware of critical issues surrounding the care and support of families and providing technical assistance for implementing policy and practices that support and strengthen the family.

The **Integrated Employment** (Reducing Dependency) priority area was targeted at surveying the best practices in the current movement toward integrated employment for people with developmental disabilities. An example of this type of project would be one which gathers information about integrative employment services for persons with developmental disabilities.

The **Ongoing Data Collection Systems** priority area was targeted at the development of a system that will support the State Developmental Disabilities Planning Councils, Protection and Advocacy Agencies, and University Affiliated Programs (UAPs) in providing data to meet state and UAP reporting requirements as well as documenting the progress made to improve the independence, productivity and integration into the community of people with developmental disabilities. Examples include: residential services, expenditures, vocational services, education, public assistance, medical assistance, social services, maternal and child health, aging, and children with special health care needs.

The **Pediatric AIDS** priority area was targeted towards the non-medical service needs of infants and children infected with HIV and/or AIDS, and adolescents and adults with developmental disabilities who are at risk of acquiring HIV and/or AIDS. Examples include: research on the legal issues related to persons with developmental disabilities with AIDS for use in DD communities, resource and training materials on family support issues, and a curriculum package for persons with mental retardation and developmental disabilities.

The **Mental Retardation/Mental Illness** (MR/MI) priority area focused on the need to provide information and referral services, and dissemination of state-of-the-art information to families and consumers, DD network agencies, and other mental health and mental retardation agencies. The priority area was also targeted towards the development of advocacy models to improve the provision of services to persons with mental retardation and mental illness. Examples include: models to increase intervention services to persons with MR/MI and their families, and encouraging persons with MR/MI to receive mental health services in existing Community Mental Health Centers.

The **Culturally Sensitive** (Minority Populations) priority area was targeted towards collaborative and coordinated efforts to address the disparity between the minority and non-minority population in their effort to fully utilize the social services and health systems. This priority area also

focused on the identification of exemplary methods and programs that have been successful in recruiting, retaining, and increasing the number of minority students in educational programs leading to careers involved with people with developmental disabilities. Examples include: interdisciplinary training programs, conducting studies and producing materials for use with minority groups, and recruiting and training minorities into the University Affiliated Program system.

- The **Elderly Persons with Developmental Disabilities** priority area was targeted towards projects that would respond to a collaborative and coordinated effort of Area Agencies and State Agencies on Aging, and other public and private institutions in cooperation with Aging agencies in the development of educational materials and training programs, replication of community-based health care delivery models, and collaborative technical assistance with State and local agencies/organizations in planning and public policy development to integrate or otherwise assist the older person with developmental disabilities to obtain services. Examples include: physical fitness and expressive arts programs.
- The **Technical Assistance** priority area focused specifically on the identification, dissemination and training on indicators for use by the developmental disabilities network to measure the quality of life of persons with developmental disabilities; management training, continuing peer review, skill building, and legal training for Protection and Advocacy Agencies; arrangement and coordination of the provision of technical assistance to State Developmental Disabilities Councils in the development of policy analyses to be prepared by 1990; and assistance to University Affiliated Programs and Satellite Centers on planning and policy analysis across the DD network agencies and programs. Examples include: training on legal strategies, consumer surveys, analyzing technical assistance needs and resources, enabling participants to become advocates in influencing public policy, and developing training materials.

In FY 1989, the Projects of National Significance program targeted its efforts on the following priority areas:

- The **Family Support** priority area was targeted towards educating policy makers on the resolution of barriers to the delivery of home-based care. This priority area also focused on promoting cost effectiveness and quality in the provision of family support services and activities.
- The **Technical Assistance** priority area focused on the provision of technical assistance on program development, and planning and policy analysis in an effort to improve or otherwise expand the advocacy functions of the State Planning Councils; the functions performed by University Affiliated Programs and Satellite Centers; and the protection and advocacy services relating to the State protection and advocacy system.

- In addition, ADD participated in a cross-cutting priority area with the Administration for Children, Youth and Families entitled **Collaborative Training Efforts to Support Children with More Severe Handicaps in Head Start**. The purpose of this priority area was to assist Head Start in meeting the needs of the more severely handicapped children through Head Start's Resource Access Projects and ADD's University Affiliated Programs.

These priority areas ~ from fiscal years 1988 through 1989 - represent ADD's efforts to meet the mandates of Part E of P.L 100-146 and the needs of individuals with developmental disabilities. They also reflect input from national and local service organizations, provider and advocacy organizations, universities, health professionals and educators, private foundations, government offices, and private citizens.

We are indebted to these groups for their assistance in ADD being able to support the independence, productivity and integration into the community of individuals with developmental disabilities.

Title: Policy and Practices Analysis of Family Support Programs

Grantee: Western Carolina Foundation
Western Carolina Center
300 Enola Road
Morganton, North Carolina 28655

Grant Number: 90DD0144

Description:

This study will synthesize and analyze policies and practices that have been found to be successful in making services and other supports and resources available to families with disabled members. The project will combine policy evaluation, process evaluation, and outcome evaluation analyses. The findings are expected to shed light regarding the extent to and manner in which policies and practices support and strengthen family functioning.

Project Period: September 30, 1988 to September 29, 1990

Project Officer: Kay Smith
(202) 245-2984

Grantee Contact: Carl J. Dunst, Ph.D.
(704) 433-2661

Title: Educating Policy Makers and Empowering Families

Grantee: Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, Massachusetts 02140

Grant Number: 90DD0156

Description:

This project will address the need for educating policy makers and empowering families by achieving two broad goals. The first goal will be to identify and compile a means for assuring that "empowered families receive the circle of supports they deem necessary" to: (a) promote continued care at home; (b) enhance the family's capacity to provide care; (c) allow children to return home from an out-of-home placement if possible; and (d) assist people with developmental disabilities in maintaining their own homes and families. The second goal will be to design and implement a means for educating policy makers so that they: (a) are aware of the most critical issues surrounding family care and the best practices regarding how families may best be supported; and (b) are provided with technical assistance for implementing family support policy and practices.

Project Period: March 1, 1989 to February 28, 1991

Project Officer: Kay Smith
(202) 245-2984

Grantee Contact: Valerie J. Bradley
(617) 876-0426

Title: Building a Family Support Network in Hispanic Rural Communities

Grantee: Rosadrima, Inc.
Box 2434
Bayamon, Puerto Rico 00619

Grant Number: 90DD0159

Description:

The goal of this project is to provide a framework of family support in the rural Puerto Rico environment which is critically lacking in basic, direct services. This project will accomplish this through the development of a model for providing family support -- including parent training and respite care -- in Hispanic and rural environments for families with a member who has a developmental disability. The project is designed for communities which are generally unaccessible, have little or no services, and are confronted with severe cultural, language, geographic, and fiscal barriers. The project will function as a conduit for adapting innovative approaches in family supports from the States and subsequently yielding a model with implications for widespread adaptation and replication - not only in Puerto Rico, but also in the rest of the United States. The project goal is to demonstrate a model through interagency collaboration and to ensure its continuation by generic agencies.

Project Period: February 1, 1989 to January 31, 1990

Project Officer: Raymond Sanchez
(202) 245-1962

Grantee Contact: Christine Garcia
(809) 781-5292

II. ELDERLY PERSONS WITH DEVELOPMENTAL DISABILITIES

Title: A Quality of Life/Expressive Arts/Physical Fitness Innovative Training Service Program for Developmentally Disabled Elderly Persons in N.E. Georgia Senior Sites

Grantee: University of Georgia
Division of Education for Exceptional Children
570 Aderhold Hall
Athens, Georgia 30602

Grant Number: 90DD0148

Description:

The purpose of this project is to demonstrate that old age for persons with developmental disabilities can be a time of fulfilling activity and creativity. The project will develop, implement, research, and disseminate drama, art, dance, and fitness programs to improve these persons' quality of life and integration into the existing service system.

Project Period: September 30, 1988 to September 29, 1990

Project Officer: Judy F. Moore
(202) 245-1961

Grantee Contact: Claire B. Clements, Ed.D.
(404) 542-3960

Title: A Statewide Agenda for Enhancing the Quality of Life for People with Disabilities and Their Families

Grantee: World Institute on Disability
1720 Oregon Street, #4
Berkeley, California 94703

Grant Number: 90DD0158

Description:

This project will conduct a series of consumer conferences in California to develop a Statewide strategy for enhancing the quality of life (QOL) for persons with disabilities and their families. Its goal is to further the effort to create a human service system focused on empowering people to exercise choices in matters which affect their own lives -- both in our state and nationally. In addition, the project will further the effort to establish the quality of a person's life as the primary criteria for the quality of services. The project will also encourage people with disabilities to be self-advocates. The project builds upon the procedures and results of the recent Quality of Life for Persons with Disabilities Project, which was conducted by the Mental Retardation Institute, Valhalla, New York and funded by the Administration on Developmental Disabilities in 1987-88.

Project Period: January 1, 1989 to March 31, 1990

Project Officer: Wilhelmina Holton
(202) 245-1963

Grantee Contact: Joan Leon
(415) 486-8314

Title: Dakota Outreach: Training Native American Families Through Networking and Systems Development

Grantee: University of South Dakota
Center for Developmental Disabilities
School of Medicine, 208 Julian Hall
414 East Clark Street
Vermillion, South Dakota 57069-9999

Grant Number: 90DD0147

Description:

This project is a collaborative effort between the University of South Dakota UAP/Center for Developmental Disabilities, the South Dakota Advocacy Project, the Indian Health Service, and Parent Connection. Its purpose is to deliver interdisciplinary training to Native American families with children who have developmental disabilities. The project will also measure the parents' attitudes and knowledge as related to their children's disabilities. Products include a series of case studies dealing with Native American families and their children, and bilingual materials for use with Native American groups.

Project Period: September 30, 1988 to September 29, 1990

Project Officer: Kay Smith
(202) 245-2984

Grantee Contact: Cecilia Rokusek, Ed.D.
(605) 677-5311

Title: Recruitment and Retention of Minority Students in UAP Training Programs

Grantee: Waisman Center on Mental Retardation and Human Development
University of Wisconsin
750 University Avenue
Madison, Wisconsin 53706

Grant Number: 90DD0149

Description:

In order to improve the delivery of services to individuals of different ethnic backgrounds, there is a need to recruit and retain more minority trainees within the University Affiliated Program (UAP) system. The long-range vision is to develop training programs that are interdisciplinary and multicultural, so that UAP graduates will be culturally sensitive and able to provide services and appropriate leadership in the field of developmental disabilities. The specific needs being addressed by this project are: (a) the need for increased awareness of minority students regarding career opportunities in the field of developmental disabilities; and (b) the need for greater minority participation in UAP training programs throughout the nation. The primary locations of project activities will be: Nebraska (Afro-Americans), Oregon (Asian-Americans), South Dakota (Native American Indians), Texas (Hispanics), and Washington, D.C. (national dissemination). The project will be coordinated by the Chair of the Minority Affairs Committee for the American Association of University Affiliated Programs (AAUAP).

Project Period: December 1, 1988 to November 30, 1990

Project Officer: Raymond Sanchez
(202) 245-1962

Grantee Contact: Terrence R. Dolan, Ph.D.
(608) 263-5940

CULTURALLY SENSITIVE PROJECTS

Title: "Best Practice": Approaches to Integrative Employment

Grantee: University of North Carolina at Chapel Hill
Developmental Disability Training Institute
300 Bynum Hall, CB 4100
Chapel Hill, North Carolina 27599

Grant Number: 90DD0157

Description:

This project will gather detailed information about the development of integrative employment services for persons with developmental disabilities in fifty states, the existence of best practice approaches, the characteristics of the agencies operating best practice approaches, and the characteristics of the environment within which best practice approaches are provided. At the same time, this project will develop and disseminate two publications: a reference manual of "best practice" settings and a publication describing the outstanding "best practice" agencies in the United States.

Project Period: December 1, 1988 to November 30, 1990

Project Officer: Vern Evans
(202) 245-2980

Grantee Contact: George S. Baroff, Ph.D.
(919) 966-5463

Title: AIDS and Developmental Disabled Persons:
Legal Issues and Resources

Grantee: American Bar Association
Commission on the Mentally Disabled
1800 'M' Street, NW
Washington, D.C. 20036

Grant Number: 90DD0146

Description:

This project is intended to help overcome barriers (discrimination) to services for persons with developmental disabilities who have AIDS and to provide guidance on appropriate procedures for handling confidentiality issues. The project has a two-pronged approach. First, it will collect and analyze a wide range of federal and state laws, cases, and regulations related to persons with developmental disabilities with AIDS. Second, based on this extensive research, several work products will be created and widely disseminated for use by the developmental disabilities community. These include: "Report on Overcoming Barriers to Services for Persons with Developmental Disabilities with AIDS" (will address a variety of services, e.g., child welfare, health, education, housing and employment) and "Guidelines and Model Procedures on Confidentiality" (for DD service providers). The massive amount of legal information collected, including extensive secondary resources, will be abstracted and incorporated into the Commission on the Mentally Disabled Legal Research Services and Data Base. This information will be updated monthly and made available to users on the on-line service even after the conclusion of the project.

Project Period: September 30, 1988 to September 29, 1990

Project Officer: Kay Smith
(202) 245-2984

Grantee Contact: Sharon Rennert, Esq.
(202) 331-2282

PEDIATRIC AIDS

Title: Developmental Disabilities & HIV:
Training for Services & Policies

Grantee: Children's Hospital
Developmental Evaluation Clinic - UAP
300 Longwood Avenue
Boston, Massachusetts 02115

Grant Number: 90DD0152

Description:

The focus of this project is on service delivery to infants with congenital HIV infection, older children with acquired infection, youth and young adults at risk, infected adults with mental retardation, and primary care providers. Resource and training materials will be provided on family support issues, external areas affecting service delivery, income and liability, and models of service delivery.

Project Period: December 1, 1988 to November 30, 1990

Project Officer: Raymond Sanchez
(202)245-1962

Grantee Contact: Allen Crocker, M.D.
(617)735-6509

Title: An HIV/AIDS Curriculum for Individuals with Mental Retardation/Developmental Disabilities

Grantee: Oregon Health Sciences University
Crippled Children's Division
Child Development and Rehabilitation Center
P.O. Box 574
Portland, Oregon 97207

Grant Number: 90DD0151

Description:

This project will develop, field test, and disseminate nationally an authoritative and comprehensive curriculum package for training in the nature of HIV infection and AIDS risk reduction in a format suitable for persons with MR/DD or other learning limitations. Working committees of professionals from a consortium of public and private groups will steer the project and develop the concepts for the curriculum. Use of these materials will increase knowledge about HIV/AIDS, reduce risk behavior, and mitigate anxiety about the AIDS virus in the target populations. The ultimate goal of the project will be to reduce the incidence of AIDS in these populations, and its transmission to others. Major products will be: 1) a 60-page curriculum of detailed lessons and activities; 2) an instructor's guide with recommended policies for use and adaptation to various audiences; 3) twenty-minute videotape segments for use in four learning sessions; and 4) tools to assess learner needs and outcomes.

Project Period: December 1, 1988 to November 30, 1990

Project Officer: Kay Smith
(202) 245-2984

Grantee Contact: James Lindemann, Ph.D.
(503) 279-8320

VII. MENTAL RETARDATION/MENTAL ILLNESS (MR/MI)

Title: A Model for Developing Mental Retardation/Mental Illness (MR/MI) Intervention Services in Existing Community Mental Health Centers

Grantee: Cincinnati Center for Developmental Disorders (UACCDD)
Bland & Bethesda Avenues
Cincinnati, Ohio 45229

Grant Number: 90DD0155

Description:

UACCDD, in conjunction with 5 Community Mental Health Centers (CMHCs), will establish a service/training model to increase mental health services to persons with MR/MI and their families. The project will also function as an MR/MI collaborative effort; serve 75 persons annually with MR/MI through case consultation taught to a core group of 12; provide 100 hours of training annually to 1500 professionals; evaluate the model's effectiveness; identify and evaluate alternative funding; and disseminate project findings through a replication manual, a newsletter, and presentations. National leaders in the field of MR/MI will consult with the project to provide training and to review the content and format of the replication manual. An advisory committee will ensure consumer participation, evaluation of the model, and its applicability to planners/policy makers, service providers, and consumers. The project intent is to disseminate knowledge, develop skills, and create service incentives for persons with MR/MI to receive mental health services in existing CMHCs.

Project Period: January 1, 1989 to December 31, 1991

Project Officer: Kay Smith
(202) 245-2984

Grantee Contact: Esther Lee Pederson, M.Ed.
(513) 559-4639

VIII. INTERNATIONAL/TECHNOLOGY TRANSFER

Title: Shepherd Spinal Center/Alyn Hospital International Spina Bifida Program

Grantee: Shepherd Center for the Treatment of Spinal Injuries, Inc.
2020 Peachtree Road, NW
Atlanta, Georgia 30309

Grant Number: 90DJ0107

Description:

The objectives of this program are: 1) to provide direct medical services/programs to spina bifida individuals; 2) to provide support programs for spina bifida individuals/families for attainment of healthy psychosocial functioning; 3) to provide education in local communities regarding spina bifida individuals, their needs, and ways to meet them; and 4) to gather statistics regarding the spina bifida population. These objectives will be achieved via three specific programs: psychosocial support, outreach, and transitional living.

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Project Period: January 1, 1988 to December 31, 1990

Project Officer: Evelyn Shepard
(202) 245-2982

Grantee Contact: Judy K. Reinoehl
(404) 352-2020

Title: Opening Technology to the Developmentally Disabled:
An International Research Project Between the United States
and Israel

Grantee: University of California
Graduate School of Education
Special Education Program
Santa Barbara, California 93106

Grant Number: 90DJ0108

Description:

This project is a three-year international study to experimentally explore computer technology opportunities for persons with developmental disabilities. Two approaches will be used to conduct the study: the first being a review of employment possibilities for persons with developmental disabilities; and the second being a series of studies on the ability to match individual skills with job demands in different microcomputer job contexts. Reports will be prepared on a series of experimental studies analyzing demands in controlled, simulated, and naturalistic settings. Other products include discussion papers on the employment opportunities available for persons with developmental disabilities using computer technology in the United States and in Israel, task analyses of basic data entry procedures, and modules for assessing and remediating performance deficits in cognitive, motor, and social domains.

Project Period: February 1, 1988 to January 31, 1991

Project Officer: Kay Smith
(202) 245-2984

Grantee Contact: Melvyn I. Semmel, Ed.D.
(805) 961-4562

Title: Project INDEX (New England Information on Disabilities Exchange)

Grantee: Eunice Kennedy Shriver Center
University Affiliated Program
200 Trapelo Road
Waltham, Massachusetts 02254-6368

Grant Number: 90DD0143

Description:

The purpose of this project is to determine the feasibility and desirability of establishing a regional information and referral system which will address the needs of persons with developmental disabilities in New England. The study will be carried out with the collaboration of DD Councils, Protection and Advocacy Agencies, and UAPs in New England. A project Advisory Committee composed of representatives of all 3 organizations with some representation from each State and of consumers and case managers will monitor the progress of the study and advise staff. Computerized databases are included in the study, in six areas. They are: demonstration programs, regional programs, consultant registry, person-to-person networks, national assistance organizations, and information and referral systems.

Project Period: September 1, 1988 to May 30, 1990

Project Officer: Judy F. Moore
(202) 245-2911

Grantee Contact: Robert Bass, Ph.D.
(617) 642-0246

Title: Project to Determine the Feasibility and Desirability of Developing a National Information and Referral System for Persons with Developmental Disabilities

Grantee: University of South Carolina
Center for Developmental Disabilities
University Affiliated Program
Benson Building, Pickens Street
Columbia, South Carolina 29208

Grant Number: 90DD0142

Description:

The purpose of this project is to determine the feasibility and desirability of developing a nationwide information and referral (I&R) system for persons with developmental disabilities. The study will assess the informational needs of persons with developmental disabilities and the current methods of providing information and referral throughout the country. It will also determine the feasibility of alternative approaches to a nationwide information and referral system through actual development and testing of specific integration models. The study will be conducted in three phases: 1) determine the perceptions of the developmentally disabled community toward a nationwide I&R system; 2) study and analyze state-of-the-practice in the field of I&R; and 3) develop and demonstrate an organizational prototype of alternative models of a national I&R system or network of systems.

Project Period: September 1, 1988 to June 30, 1990

Project Officer: Judy F. Moore
(202) 245-2911

Grantee Contact: Girish Yajnik, M.B.A.
(803) 777-4435

INFORMATION AND REFERRAL

Title: Improving the Advocacy Functions of The Protection and Advocacy System Through Training and Technical Assistance

Grantee: National Association of Protection and Advocacy Systems
300 "I" Street, N.E., Suite 212
Washington, DC 20002

Grant Number: 90DD0150

Description:

This project is an innovative technical assistance and training program designed to serve the Protection and Advocacy (P&A) systems across the country. Focusing on peer review, training of managers, nursing home reform, and legal training, specific project activities include the refinement of the P&A system peer review process, development and implementation of a national training program to improve management of P&A agencies, enhancement of a broker support system, development of model collaborative programs, technical assistance programs pertaining to OBRA, and continuation of a legal training track at the NAPAS Annual Conference.

Project Period: December 1, 1988 to November 30, 1989

Project Officer: Delorise B. Anderson
(202) 245-2975

Grantee Contact: Patti Green Roth
(202) 546-8202

Title: Technical Assistance to Developmental Disabilities (DD) Councils

Grantee: National Association of Developmental Disabilities Councils
Suite 103
1234 Massachusetts Avenue, N.W.
Washington, DC 20005

Grant Number: 90DD0141

Description:

This project will provide technical assistance to DD Councils in order to assist with the new planning and reporting requirements in the 1987 DD Act Amendments. The project will provide support for analysis of a national consumer outcome and satisfaction survey and technical assistance on Federal and state program and policy analysis. The project will conduct analyses of the data submitted by states resulting from conducting a consumer survey in order to show state-by-state comparisons and to develop a national aggregation of the data. By presenting this information in useable, understandable forms, this project will assist DD Councils in conducting additional analyses and in using the consumer survey data to affect public policy questions. The technical assistance will focus primarily on information brokering and sharing among Councils and other components of the developmental disabilities network in order to address issues of process and content that will arise during development of the 1990 reports. This effort will support a coordinated approach to the new requirements and will assist Councils in their long-term planning and advocacy responsibilities.

Project Period: August 1, 1988 to July 31, 1989

Project Officer: Lynne Lau
(202) 245-2823

Grantee Contact: Christina Metzler
(202) 347-1234

TECHNICAL ASSISTANCE

Title: Technical Assistance to Improve the Functions Performed by the UAP Network

Grantee: American Association of University Affiliated Programs
8630 Fenton Street, Suite 410
Silver Spring, Maryland 20910

Grant Number: 90DD0163

Description:

The goal of this project is to expand and improve the technical assistance functions performed by UAPs. The project goals are to: 1) identify the capacity of the UAPs and Satellite Centers for providing the technical assistance needed to address emergent issues of national significance in the field of developmental disabilities; 2) develop systematic procedures and protocols for establishing and maintaining a national and coordinated Technical Assistance network; and 3) initiate the Technical Assistance Network at the local, state, and national levels. The UAPs will provide inventories of technical assistance needs and available resources to meet those needs. Network representatives will analyze needs and resources and devise strategies to match them. UAP representatives with needed technical assistance resources (materials, person hours) will provide technical assistance to other programs (on-site or via telephone), to serve as colloquia facilitators (in centralized training/technical assistance sessions attached to other meetings), and to contribute information on resources that would be of assistance to others and accessible through the AAUAP.

Project Period: September 1, 1989 to August 31, 1990

Project Officer: Judy F. Moore
(202)245-2911

Grantee Contact: Ann Rudigier
(301) 588-8252

TECHNICAL ASSISTANCE

Title: Increasing Advocacy Capacity of State DD Councils by Replicating Partners in Policymaking

Grantee: World Institute on Disability
1720 Oregon Street, Suite 4
Berkeley, California 94703

Grant Number: 90DD0161

Description:

Partners in Policymaking is an innovative national model of leadership training for persons with developmental disabilities, young parents, and other family members. It is designed to provide state-of-the-art knowledge about developmental disabilities issues and to develop competencies of the participants to become effective advocates in influencing public policy at all levels of government. This project will directly assist up to 12 states by replicating the Partners in Policymaking program. The World Institute on Disability, in cooperation with the Minnesota Governor's Planning Council on Developmental Disabilities, will conduct the project and will sponsor an intensive training academy for the participating states, provide necessary follow-up technical assistance, and produce an information packet for all other states and territories. The Minnesota Governor's Planning Council on Developmental Disabilities designed and has operated Partners in Policymaking for the past three years and is funding a fourth year beginning on October 1, 1989. Over one hundred people have been trained in the Partners program and the results have dramatically increased consumer empowerment, participation in state and regional policy commissions, interaction with public officials, and an increased role in the development of public policy.

Project Period: September 1, 1989 to August 31, 1990

Project Officer: Evelyn Shepard
(202) 245-2982

Grantee Contact: Edward V. Roberts
(415) 486-8314

TECHNICAL ASSISTANCE

Title: Technical Assistance to Developmental Disabilities Councils

Grantee: National Association of Developmental Disabilities Councils
Suite 103
1234 Massachusetts Avenue, N.W.
Washington, D.C. 20005

Grant Number: 90DD0162

Description:

The Technical Assistance to Developmental Disabilities (DD) Councils 1989 Project will develop training materials and supporting documents on how DD Councils can use the media to promote the policy recommendations contained in the 1990 Reports mandated by the 1987 amendments to the Developmental Disabilities Assistance and Bill of Rights Act. The project will also develop a compilation of the state and territorial 1990 Reports, including a section on common themes and critical issues. Training will also be provided to DD Councils on how to use these materials to gain public, and particularly media, attention in support of implementing the 1990 Reports. Training and products will promote nationwide events in early 1990 to enhance visibility of the reports with all governors and state legislatures. The project will also design a strategy to develop consensus among DD Councils on a common policy agenda and coordinated implementation plan.

Project Period: August 1, 1989 to July 31, 1990

Project Officer: Lynne Lau
(202) 245-2823

Grantee Contact: Susan Ames-Zierman
(202) 347-1234

Title: To Enhance Advocacy Functions of State Protection and Advocacy Systems for Persons with Developmental Disabilities

Grantee: National Association of Protection and Advocacy Systems
300 "I" Street, N.E., Suite 212
Washington, D.C. 20002

Grant Number: 90DD0164

Description:

This project will conduct training and technical assistance activities for State Protection & Advocacy Systems (P&As) in three central areas: (1) internal program development and management procedures; (2) planning for service delivery through policy and regulatory analysis; and (3) training on legal strategies. The primary objective of this project is to improve the advocacy functions of P&As through these training and development activities. The project enhances the overall mandate of P&As to protect legal and human rights of persons with developmental disabilities, and to integrate these individuals into the community. The major product of this project is a comprehensive, organized method of training and technical assistance for P&A directors, mid-level managers, attorneys, and advocates. These training and technical assistance activities will be available to all P&A staff through conferences, material and procedures development, and one-to-one assistance on problems and issues.

Project Period: December 1, 1989 to November 30, 1990

Project Officer: Shirley Redmond
(202) 245-2899

Grantee Contact: Curtis L. Decker
(202) 546-8202

TECHNICAL ASSISTANCE

XI. ONGOING DATA COLLECTION SYSTEM

Title: National Recurring Data Set Project: Ongoing National and State-by-State Data Collection and Policy/Impact Analysis on Residential Services for Persons with Developmental Disabilities

Grantee: University of Minnesota
Department of Educational Psychology - UAP
6 Pattee Hall
150 Pillsbury Drive, SE
Minneapolis, Minnesota 55455

Grant Number: 90DD0145

Description:

This project will sustain the National Recurring Data Set Project through the collection of annual statistics on residential services on a state-by-state basis and the aggregation of those statistics to provide an ongoing, up-to-date picture of changing patterns in residential care nationally. The project will continue to provide timely policy surveys and research synthesis projects of importance to policymakers. It will also continue to expand its capacity to serve the data and policy analysis needs of State DD Planning Councils, Protection and Advocacy agencies, UAPs, ADD, as well as other Federal, state and provider agencies.

Project Period: September 30, 1988 to September 29, 1990

Project Officer: Judy F. Moore
(202)245-2911

Grantee Contact: Robert H. Bruininks, Ph.D.
(612) 648-4848

Title: Development of Data Collection Procedures for Those Adults with Developmental Disabilities in Vocational and Day Programs or in Need of Such Programs

Grantee: Children's Hospital
Developmental Evaluation Clinic - UAP
300 Longwood Avenue
Boston, Massachusetts 02115

Grant Number: 90DD0154

Description:

This project seeks to fill the current information void by collecting national data documenting on the full range of day and vocational service utilization for persons with DD, by establishing an estimate of duplication across State agency programs, by estimating the number of persons waiting for services, by augmenting existing state data collection efforts to expand the amount and depth of available information, and by analyzing selected policy issues related to day and/or vocational services. The project includes a national survey of key state agencies to collect information regarding types of day or vocational programs, number and characteristics of persons with developmental or other related disabilities served or waiting for services, and selected employment measures (such as wages and hours). Project results will be disseminated using a number of methods, including a technical assistance manual, a report outlining the results, dissemination meetings with key state personnel, journal articles, and ongoing technical assistance.

Project Period: December 1, 1988 to November 30, 1990

Project Officer: Judy F. Moore
(202) 245-2911

Grantee Contact: William Kiernan, Ph.D.
(617) 735-6506

ONGOING DATA COLLECTION SYSTEMS

Title: National Mental Retardation/Developmental Disabilities
(MR/DD) Direct Care Staff Wage Data Base

Grantee: University of Illinois at Chicago
ISSDD/SHP
1640 West Roosevelt Road
Chicago, Illinois 60608

Grant Number: 90DD0153

Description:

This project will continue and expand the MR/DD Expenditure Data Base Project which has documented state-by-state MR/DD expenditures since FY 1977. A long-term direct care wage data base addendum to the Expenditure Data Base will represent an important policy tool for the nation's continuing reconfiguration of its service system. Specifically, the project will document the current wage status of direct-care staff in residential settings, with emphasis on identification of wage disparities across the institutional and community service sectors. The intent of the project is to provide empirical data on a state-by-state and national basis to all State DD Councils, to consumer and other advocacy groups, and to policymakers committed to facilitating the development of a quality community-based service system.

Project Period: December 1, 1988 to November 30, 1990

Project Officer: Judy F. Moore
(202) 245-2911

Grantee Contact: David Braddock, Ph.D.
(312) 414-1647

INTERAGENCY\DEPARTMENTAL COLLABORATION

Title: New England UAP/RAP Collaboration

Grantee: Children's Hospital
Developmental Evaluation Clinic - UAP
300 Longwood Avenue
Boston, Massachusetts 02115

Grant Number: 90CJ0114

Description:

This project is a collaboration between the UAP at the Boston Children's Hospital, the New England Resource Access Project (RAP) at Education Development Center, Inc. (EDC), and the North Shore Community Action Program (NSCAP) Head Start program to provide demonstration clinical services to approximately 12 moderately and severely handicapped children. Allied health professionals will provide 5 staff training sessions and 17 classroom demonstrations at the NSCAP Head Start program and its classroom programs for abused and homeless children. Mental retardation, serious emotional disturbance, and multi-handicapping conditions are the categories of disability particularly targeted. Intensive parent involvement in all aspects of the project will be assured. Two handbooks documenting project activities and describing the strategies developed will be produced by EDC staff. The UAP and EDC will conduct extensive dissemination activities. This project is a jointly funded effort of the Administration for Children, Youth and Families, and the Administration on Developmental Disabilities.

Project Period: February 1, 1989 to January 31, 1991

ACYF Project Officer: Jane DeWeerd
(202) 245-0562

ADD Project Officer: Kay Smith
(202) 245-2984

Grantee Contact: Bruce Cushna, Ph.D.
(617) 735- 6505

INTERAGENCY/DEPARTMENTAL COLLABORATION

INTERAGENCY AGREEMENT

**Between the
Center for Fire Research
National Institute of Standards and Technology
U.S. Department of Commerce**

and the

Administration on Developmental Disabilities

Purpose:

The purpose of this joint effort between the National Institute for Standards and Technology (NIST) and the Administration on Developmental Disabilities (ADD) is to assure a high level of fire safety in Board and Care Homes and to decrease the cost of achieving this safety. In addition, the agencies identified below will be participants in this endeavor and will be committing funds independently to NIST:

- National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitative Services (OSERS), Department of Education
- Administration on Aging (AoA), Office of Human Development Services (OHDS), Department of Health and Human Services
- Health Standards and Quality Bureau, Health Care Financing Administration (HCFA), Department of Health and Human Services
- Social Security Administration (SSA), Department of Health and Human Services
- National Institute on Mental Health (**NIMH**), Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA), Public Health Service (PHS), Department of Health and Human Services

Funding Level:

NIDRR, AoA, and HCFA will contribute \$50,000 each for each year of the two year project. SSA will contribute \$25,000 each year for two years, NIMH will contribute \$25,000 for one year, and ADD will contribute \$37,500 for each year of the two year project.

Duration: FY 1989 through FY 1991

Project Officer:

Kay E. Smith
(202) 245-2984

INTERAGENCY AGREEMENT

Between the

Social Security Administration

and

Administration on Developmental Disabilities

Purpose:

The purpose of this interagency agreement is to conduct a survey on Education and Training of Disabled Americans.

The survey, conducted by Louis Harris and Associates, will focus on ways of improving education and training programs for individuals with disabilities. It is sponsored by the International Center for the Disabled (ICD) in collaboration with the University Affiliated Program (UAP) at Boston Children's Hospital. ADD will oversee the project activities with SSA providing technical assistance to ICD in preparing the survey questionnaire.

Funding Level:

SSA has made a lump sum payment of \$15,000 to ADD for funding the survey. ADD's contribution is \$9,300, bringing the total funding level to \$24,300.

Duration:

FY 1988

Project Officer:

Raymond Sanchez
(202) 245-1962

MEMORANDUM OF UNDERSTANDING

Between the

Administration on Aging

and the

Administration on Developmental Disabilities

Purpose:

The purpose of this memorandum of understanding is to promote a better understanding of programs serving the elderly and disabled persons between the national network on aging and the developmental disabilities network, to improve services to older persons with developmental disabilities, and to demonstrate a commitment at the national level between AoA and ADD regarding serving older persons with developmental disabilities.

Funding Level:

ADD is contributing \$150,000 to this effort.

Duration:

Indefinite

Project Officer:

Judy Moore
(202) 245-2911

INTERAGENCY AGREEMENT

Between the

**National Institute on Mental Health
Alcohol, Drug Abuse and Mental Health Administration
Public Health Service**

and the

Administration on Developmental Disabilities

Purpose:

The purpose of this interagency agreement is to provide specific technical assistance and training activities to Protection and Advocacy Agencies (P&As) funded by NIMH's Protection and Advocacy Program and ADD.

The focus of this agreement is on P&As that serve mentally ill individuals in residential facilities. The technical assistance and training activities will include internal program development and management procedures, coordination and facilitation of the annual meeting for P&A coordinators of the program for the mentally ill, and training on legal strategies.

Funding Level:

NIMH is contributing \$25,000 to ADD's recently funded technical assistance grant of the National Association for Protection and Advocacy Systems (NAPAS) in the amount \$99,000.

Duration:

December 1, 1988 to November 30, 1989

ADD Project Officer:

Raymond Sanchez
(202) 234-1962