



Developmental Disabilities Planning Council

Governor Andrew M. Cuomo

Sheila M. Carey, Executive Director

NYS Developmental Disabilities Planning Council 2016 Project Summaries



Helping Individuals with Developmental
Disabilities to Live Independently and
Participate Fully in the Community

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MESSAGE FROM THE DIRECTOR



Over the past five years, our Council has made significant contributions to the fulfillment of the goals of our State Plan, and in support of our ongoing mission to promote independence and community inclusion for individuals with developmental disabilities and their families.

I am proud of the excellent work that our Council has already completed and look forward to the work that is to come in fulfilling the goals of our State Plan, and in supporting our ongoing mission to promote independence and community inclusion for individuals with developmental disabilities and their families.

The NYS Developmental Disabilities Planning Council continues its commitment to exploring creative new ideas and emerging technologies to help meet the challenges of an ever-evolving service delivery system.

I wish to express my very deep gratitude to our Council Membership for their hard work and dedication. I am indeed fortunate to be associated with such an impressive body of talent, knowledge and experience. I would like to extend special thanks to our leadership: Chairperson James Traylor, our Vice-Chairperson Thomas Burke, and Consumer Caucus Chair Wendy Orzel for their willingness to accept the additional responsibilities of the Council's leadership roles.

As we reflect upon the Council's past, we must recommit ourselves to its future as we aggressively seek new and better ways to ensure that individuals with developmental disabilities from culturally diverse backgrounds are afforded every opportunity to determine the direction of their lives and to participate fully in the community as they wish to do.

Sheila M. Carey
Executive Director
NYS Developmental Disabilities Planning Council

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ACTIVE GRANTS

Children Youth & Families Committee

Robin Hickey, Program Planner

Partners in Health Education for People with Developmental Disabilities (PHEPD)

Grantees:

Daemen College (Physician Assistant Students)

Funding Amount: \$50,250 in Year 1, \$40,250 in Years 2&3

Grant period: 9/1/12-11/30/15

Daemen College (Nurse Practitioner Students)

Funding Amount: \$50,250 in Year 1, \$40,250 in Years 2&3

Grant period: 9/1/12-11/30/15

SUNY Binghamton (Nurse Practitioner Students)

Funding Amount: \$50,250 in Year 1, \$40,250 in Years 2&3

Grant period: 9/1/12-11/30/15

Wagner College (Physician Assistant Students)

Funding Amount: \$50,250 in Year 1, \$40,250 in Years 2&3

Grant period: 9/1/12-11/30/15

Hofstra University (PA Students)

Funding Amount: \$50,250 in Year 1, \$40,250 in Years 2&3

Grant period: 9/1/13-11/30/16

NYSDAAN (Technical Assistance)

Funding Amount: \$50,250 in Year 1, \$40,250 in Years 2&3, \$10,100 in Year 4

Grant period: 9/1/12-11/30/16

Project Description

Nurse practitioners (NPs) and Physicians Assistants (PAs) play an increasingly vital role in providing health care to people with various needs and yet they report receiving limited professional education and/or training about the health care of people with developmental disabilities. The intent of this training and professional development initiative is to enhance the knowledge and skill of nurse practitioners (NPs) and physician assistants (PAs) to provide quality health services to children and adults with intellectual and developmental disabilities. The PHEPD curriculum offers an interactive and interconnected set of lectures, clinical and non-medical experiences that can be integrated into the existing health care training and curriculum. The lectures and activities strengthen a student's awareness, knowledge, and increases their level of comfort and confidence and prepare students to successfully meet the diverse needs of patients they will encounter in their clinical practice.

Expected outcomes for this project include: implementation of the PHEPD curriculum with NP/PA students, introduction of the PHEPD curriculum as part of continuing education for practicing NPs and PAs via participation in statewide conferences and webinars, develop and implement sustainability plans for each of the college sites to ensure continuation of the PHEPD curriculum after the grant period has concluded, and explore ways to include or expand the use of the PHEPD curriculum in their other college health care instructional programs.

277 Nurse Practitioners and 344 Physician Assistants participated in the pilot projects from 2012-2015. The pre and post curriculum assessment shows a 43 percent increase in skills and competencies of NPs and PAs to screen for developmental disabilities, over a 25 percent increase in skills to communicate more effectively with parents and caregivers of children and adults with disabilities, and over a 40 percent increase in skills to make appropriate referrals to community agencies and services.

The PHEPD curriculum has been successfully aligned and integrated into the existing PA and NP curriculums offering a model for expanded use of the PHEPD curriculum to instructional programs for other health care professionals in the future (e.g. Master's Degree RNs, Health Care specialists). The PHEPD curriculum has also had a positive impact on the students enrolled in all sites in knowledge, understanding of developmental disabilities, effective communication, accommodations, and strategies to successfully engage people with disabilities and their families. Students have been most impacted by the experiential components of the curriculum, including home visits and clinical practice experiences.

Field-Initiated Ideas for Children who are Medically Fragile

Grantees:

ARISE

Funding Amount: \$40,000 per year

Grant period: 6/1/13-8/31/16

Starbridge (formerly The Advocacy Center)

Funding Amount: \$40,000 per year

Grant period: 6/1/13-5/31/16

Daemen College

Funding Amount: \$39,979 per year

Grant period: 6/1/13-8/31/16

Cardinal McCloskey Community Services

Funding Amount: \$40,000 per year

Grant period: 6/1/13-8/31/16

Project Description

A child or adult who is “Medically Fragile” is an individual with developmental disabilities who has substantial health care needs, has one or more chronic clinical conditions, significant functional limitations and more than average use of medical services.

This initiative focuses on individuals with developmental disabilities who often need supports and services from numerous systems. Funded projects have enhanced care coordination, decreased barriers, and promoted inclusion in the community for individuals who are medically fragile and their caregivers through training, educational courses, and intensive support and referral models.

Expected outcomes for this group of projects includes: promoting innovative approaches and demonstration models which are designed to improve services, supports, systems linkages, and systems navigation for individuals with developmental disabilities who are medically fragile; their families, and caregivers; promote involvement of people with disabilities and caregivers in the design and implementation of all aspects of the initiative, and promote the replication of successful practices, approaches, and information to other families and service providers at a regional level and statewide.

ARISE has implemented the “Connecting-the-Dots, Providing Holistic Family Support” program which focuses on reaching the parents of infants and young children with developmental disabilities who are medically fragile increase access to the resources and supports needed to improve outcomes for the entire family. To achieve this, ARISE has established working partnerships with Regional Perinatal Centers to identify families and provide them with information, resources, and assist them to link with appropriate community supports. Over 60 families have been served over the project period.

Starbridge has developed and implemented the “Meeting Children’s Medical Needs in your Home, School, and Community” in-person training and webinar series which is designed to enhance the ability of caregivers and providers to access and share information and resources to ensure individuals who are medically fragile with developmental disabilities are well served in the medical, educational and disabilities systems. Over 70 families, caregivers, and providers have been trained over the grant period.

Daemen College has developed a sequence of educational courses for registered nurses (RNs) and nursing students to learn more about caring and advocating for individuals who are medically fragile with developmental disabilities. Enrolled students participate in lectures and training focused on assessment of individuals with developmental disabilities who are medically fragile, patient-family communication, community care for individuals with developmental disabilities who are medically fragile, advocacy and access to community resources. Students also gain experience through service learning and direct engagement with community-based programs that provide care to individuals with disabilities who are medically fragile. Students spend an average of 50 hours engaging in service with individuals. Daemen College also implements a one-day community outreach program within area nursing programs called the “Ambassadors in Care program.” The educational sessions cover topics including: Communication and Advocacy and Accessing Community Resources. As a result of the educational courses and the “Ambassadors in Care Program”, over 185 nurses and nursing students have been trained over the grant period.

Cardinal McCloskey Community Services

Cardinal McCloskey Community Services (CMCS) established the infrastructure to provide home-based coaching and related supports for families who have children with developmental disabilities who are medically fragile. These families have been referred to CMCS due to a risk of abuse or neglect. The Project offers services including Home visits, parent training, and education and community referrals. 17 families were served through home visits and parent education activities to date. The family support specialist team implemented home visits with informal sessions designed to teach and model skills to support parents to provide daily care for their children.

A new feature in addition to the completed home visits and parent training included the creation of a series of family workshops run by clinicians and legal professionals. The workshops were held at CMCS and brought families together, in some cases with their children, for skill-building activities related to communication, enhancing parenting skills, and advocacy.

Navigating Multiple Systems (NMS)

Grantee:

The Council on Children and Families (CCF)

Funding Amount: \$100,000 per year

Grant period: 4/1/13-1/31/16

Project Description

The primary goal of the NMS initiative is to provide easily accessible resources, service information and tools to assist parents, family members/caregivers, youth, peer supports and front-line staff currently struggling to effectively and efficiently navigate multiple human service systems – eventually creating a web-based, ‘one-stop-shop’ for user-friendly, accurate and up-to-date information and tools. CCF is in the final stages of completing a web-based application and informational tools to address a range of information needs by expected users.

Expected outcomes for this project include: completion of the NYS Multiple Systems Navigator website. The MSNavigator website has been built with the following components and capabilities:

- Comprehensive Resource Database – Including websites, videos, hotlines, publications
- Comprehensive Program/Services Database – Including contact information, hours of operations, counties served, eligibility requirements, etc.
- Guidance Section –General guidance for Navigating Multiple Systems (i.e., how to get organized, how to work with others, etc.); and
- Family Support and Peer Advocacy Section – Providing contact information for cross-systems disability support.

Supported Decision-Making

Grantees:

Hunter College

Funding Amount: \$300,000 per year

Grant period: 4/1/16-3/31/21

The Council on Quality and Leadership (CQL)

Funding Amount: \$75,000 per year

Grant period: 4/1/16-3/31/21

Project Description

Supported decision-making (SDM) is a model that provides people with intellectual and/or developmental disabilities (I/DD) with the individualized supports and services necessary to make informed decisions. SDM emphasizes that the majority of individuals with disabilities, even those with significant disabilities, have the ability and the right to make important decisions impacting their lives.

SDM is an alternative to the court process of appointing a guardian. Individuals using SDM maintain the legal right and ability to make decisions impacting his or her life.

Through this initiative, the DDPC intends to demonstrate that SDM is a functioning alternative to surrogate decision-making and should be exhausted prior to anyone seeking or being granted guardianship over a person with I/DD. The goal will be to expand the models statewide for all individuals at risk of guardianship.

Through this 5-year initiative, Hunter College and the Council on Quality and Leadership will work directly with Disability Rights New York, the designated Protection and Advocacy for Individuals with Intellectual and Developmental Disabilities (PADD) Program, to develop educational materials and an educational campaign about SDM, pilot and evaluate supported-decision models with individuals with Intellectual and Developmental Disabilities.

Expected outcomes for this project include: evaluating the SDM educational campaign identifying culturally and geographically diverse participants interested in engaging in the SDM project, developing a specialized model for SDM mediation, formalizing decision-making plans or agreements between individual and support systems, collecting relevant data on individual outcomes and process to inform potential changes to Article 17.4 SDM Law and other relevant

laws, and identifying funding methodologies to ensure long-term sustainability of the SDM initiative.

START Phase 2 (Systemic, Therapeutic, Assessment, Respite, and Treatment)

Grantee: Office for People with Developmental Disabilities (OPWDD)

Funding Amount: \$325,000 per year

Grant period: 1/1/16-12/31/18

Project Description

START is an evidence-informed model of cross-system linkages that promotes the coordination of community services, natural supports and mental health treatment for people with intellectual and developmental disabilities and mental health issues. The intent of this project is to enhance the existing system of care, provide technical assistance and support, and fill service gaps to improve the quality of life for individuals with intellectual and developmental disabilities who have co-occurring mental health needs by creating a well-trained network at the community level that can better support individuals in their home and reduce the need for referrals to higher levels of care and/or more restrictive settings.

During Phase 1 of the project, START was successfully implemented in OPWDD Regions 1 (Western NY and Finger Lakes) and 3 (Capital District, Taconic and Hudson Valley). Phase 2 will support the START Project expansion in Region 4 (Metro, Brooklyn, Staten Island and Bernard Fineson), Region 5 (Long Island) and Region 2 (Central NY, Broome and Sunmount).

Expected outcomes for this project include: expanding START Services into OPWDD's regions 2, 4 and 5, continuing implementation and refinement within the two pilot regions 1 and 3, providing technical assistance, and trainings for START coordinators, START clinical teams, and community participants, and cataloguing strategies and promising practices from the implementation of culturally and linguistically accessible START services in Region 4.

Upcoming Initiatives

Children Youth & Families Committee

Robin Hickey, Program Planner

Youth Self-Advocacy

The need for advocacy, self-advocacy, training and leadership development for youth with developmental and other disabilities has been clearly documented. Research shows that development of advocacy and leadership skills are crucial to the successful transition of students with disabilities into adult life and should be provided while youth are still in school. Typically, youth with developmental disabilities have limited opportunities to develop leadership skills through traditional methods such as participating in school activities or mentoring experiences.

DDPC aims to develop a New York State Youth Advocacy and Leadership Network to develop independent living outcomes for youth with disabilities by providing training and opportunities to practice advocacy and leadership skills and facilitating long-term

linkages to leadership and systems advocacy opportunities for youth with disabilities.

Caregiver Supports

Research estimates that 65.7 million people in the United States are family caregivers to either an adult or child with a disability, which constituted 29 percent of the population. Research indicates that an estimated 16.8 million family caregivers are providing care for children with disabilities under the age of 18.

Several studies over the past decade have begun to document the needs of caregivers. In particular, literature shows that caregivers have limited access to socialization opportunities, limited information on how to cope with stress, and how to care for themselves while caring for others. DDPC aims to implement two evidenced-based training models, to assist caregivers to reduce stress and learn to cope more effectively with both short- and long-term stressful situations.

Active Grants

Systems Coordination & Community Education Committee

James Huben, Program Planner

2-1-1 New York

Grantee: United Way

Funding Amount: \$200,000 per year

Grant period: 9/1/14-3/31/16

Project Description

2-1-1 is an easy to remember telephone number that connects callers, at no cost, to information about health, disability, and human services available in their community.

The 2-1-1 service in the western part of the State created a specialty database of services for people with intellectual and developmental disabilities. Individuals can seek information by categories (i.e. employment), key words, program and agency. It's easy-to-use and provides DD-related information quickly and efficiently.

The DDPC funded a project to replicate this specialty database in the 9 other regions of the State (excluding New York City). Each of the 2-1-1 regions now operates a specialty database and are in the process of developing strategies to their websites through a public awareness campaign. Regions are currently developing and testing end-user surveys and providing periodic updates on web traffic and other data that may result from this project.

Inclusive Recreation Resource Center (IRRC)

Grantee: SUNY Cortland

Funding Amount: \$230,000 per year

Grant period: 12/1/14-11/30/15

Project Description

The Inclusive Recreation Resource Center at SUNY Cortland (IRRC) has created a database including almost 1,000 recreation and leisure sites assessed for usability, a state-of-the-art website, online and face-to-face training of certified assessors and an app for handheld devices. The resource was originally designed to provide more in-depth information to individuals with

developmental disabilities and their family members concerning the usability of recreation and leisure facilities.

Over the past 2 years, the IRRC has been conducting accessibility assessments at recreation sites operated by the NYS Department of Environmental Conservation (DEC) and the NYS Office of Parks, Recreation and Historic Preservation (OPRHP).

Specifically, the IRRC was provided funding to assess 400 DEC and OPRHP facilities, develop an app for handheld devices and to compile a document outlining ongoing barriers faced. The IRRC assessed 408 recreation sites in 2014-2015.

The data from all the assessments has been entered into the online recreation database on the IRRC website so that people with disabilities and their families can make better plans to participate and enjoy the outdoor recreation assets in New York State. Just as importantly, for each assessment completed, agencies were provided with reports on how to improve usability for people with disabilities. The reports have been used by parks and outdoor recreation sites to make capital improvement budget requests for physical changes.

Inclusion U Online, the training that prepares volunteers to be Certified Inclusivity Assessors is now live and three colleges have had their students complete the training and assist with completing assessments just this fall.

Partners-in-Policymaking (PIP)

Grantee: Cornell University

Funding Amount: \$250,000 per year

Grant period: 1/1/15-12/31/19

Project Description

Cornell University administers the Partners-in-Policymaking training which provides leadership and advocacy training and skill-building opportunities to individuals with intellectual and developmental disabilities and family members. The course, developed from Minnesota's trademarked program, was incorporated into an online, blended-learning format by Cornell University. The new format allows individuals who were unable to participate in the PIP training due to barriers such as mobility constraints, time demands, and transportation challenges, to successfully participate in the program.

The course instruction is given through an eight-module format using multimedia content, interactive assignments, discussion forums and interactive live webinars. Weekly office hours are available on a set schedule for individuals who require extra help.

Archived versions of each module are kept for individuals who are unable to attend the sessions. Two PIP classes are run annually during the spring and fall. The average class size is around 40, in an effort to ensure 70 graduates annually.

Cornell University and Starbridge, a project partner, are developing a feasibility report on the possibility of offering the Partners-in-Policymaking Program using a blended, interactive web-based delivery system to other entities on a fee-for-service basis.

Person-Centered-Planning in Foster Care (PCP)

Grantee: University of Rochester

Funding Amount: \$150,000 per year

Grant period: 1/1/14-12/31/16

Project Description

Many youth with developmental disabilities face tremendous challenges when navigating the service delivery system and transitioning into the adult service delivery system. By infusing person centered planning principles into the transition process for individuals with intellectual and developmental disabilities, the University of Rochester has established an enhanced model of service delivery coordination. The project engages individuals, biological and foster care families, State and local government agencies, and nonprofit providers in creating a strategic plan which removes the barriers to a more person-centered approach.

The project is completing work in the pilot areas of Westchester and Cattaraugus counties as well as New York City. Project work is beginning to develop a long-term, sustainable strategy for using person-centered planning in the foster care system and a system for scaling up the process to cover all areas of the State.

A plan for the implementation of a training program (including best practices and available tools and resources) is being developed and implemented in collaboration with the NYS Office of Children and Family Services (OCFS) with assistance by the NYS Office for People with Developmental Disabilities (OPWDD).

Upcoming Initiatives

Systems Coordination & Community Education Committee

James Huben, Program Planner

Sibling Supports

Over the last decade, increased attention has been given to siblings of individuals with intellectual and developmental disabilities (I/DD). Besides the importance of maintaining familial relations, the increased life expectancy of individuals with I/DD creates opportunities for siblings to fill support and advocacy needs once filled by parents.

In 2011, the DDPC worked collaboratively with Cornell University to identify needs and issues experienced by siblings of individuals with I/DD in New York State. Cornell University completed a Sibling Needs Assessment and issued a final report with their findings and recommendations to address the identified needs.

DDPC will initiate activities to develop an effective and responsive network for siblings of individuals with I/DD. Work will include the creation of a website portal, completing ongoing outreach to siblings, creating information, resources, and tools for siblings of individuals with I/DD based upon the needs and issues identified within the Siblings Needs Assessment and other information gathering activities.

Active Grants

Adult Issues Committee

James Huben and Robin Hickey, Program Planners

Workforce Transformation

Grantee: NYS Office for People with Developmental Disabilities (OPWDD)

Funding Amount: \$250,000 per year

Grant period: 9/1/13-8/31/16

Project Description

DDPC supported the creation of six Regional Centers for Workforce Transformation (RWTCs). These formal collaboratives of service providers were formed to ensure statewide system uniformity in competency-based training for DSPs. Competencies continue to be reviewed, evaluated and revised to reflect current and evolving service models and systems changes.

The RWTCs provide training and technical assistance for direct support professionals (DSPs), administrators, front line-supervisors, and families using instructional videos and face-to-face trainings. DDPC grant funds created a website (<http://www.workforcetransformation.org>) that includes training videos, manuals, webinars, various provider-shared resources, and evaluation tools. Over 2,800 people have received training since 2013.

This initiative has also supported the development and roll-out of instructional videos on the topics of self-determination, DSP professionalism and community participation.

Front Door: NYS Office for People with Developmental Disabilities, University Centers for Excellence on Developmental Disabilities (UCEDD) Collaboration

Grantee: NYS Office for People with Developmental Disabilities (OPWDD)

Funding Amount: \$225,000 per year

Grant period: 1/1/15-12/31/17

Project Description

The NYS Office of People with Developmental Disabilities (OPWDD) is working collaboratively with the three University Centers for Excellence on Developmental Disabilities (UCEDDs)* to develop training, on-line learning opportunities, and educational resources for individuals with intellectual and developmental disabilities, (I/DD) caregivers, families, service coordinators and other disability service providers on various topics.

Rose F. Kennedy Center UCEDD and OPWDD have created two educational webinars, the webinars address the topic of oral health, barriers to dental care access, and techniques for dental treatment.

OPWDD is working with Westchester Institute for Human Development (WIHD) to create training via online learning modules on the following topics: “Key Elements of Self-Direction” and “The Benefits of Self-Direction.”

OPWDD is also working with Strong Center for Developmental Disabilities, University of Rochester to assess the Pathways to Employment (P2E) program. P2E employment service examples include job readiness training, job coaching, career exploration, benefits management, and travel training to help people with I/DD develop pre-employment skills, engage in inclusive, integrated, community vocational experiences, and assist in the development of a vocational or career plan. Initial evaluation of P2E shows P2E services have been provided to over 360 participants.

** Rose F. Kennedy University Center for Excellence in Developmental Disabilities, Westchester Institute for Human Development UCEDD in affiliation with New York Medical College, and Strong Center for Developmental Disabilities, University of Rochester are 3 programs out of 68 across the United States and its territories. The core functions of the UCEDDs are to provide pre-service preparation and continuing education, services (including technical assistance, community education, and direct services), research, and information dissemination.

Inclusive Fitness Initiative

Grantees:

Daemen College

Funding Amount: \$50,000 per year

Grant period: 9/1/14-8/31/17

Research Foundation-SUNY Upstate Medical Center

Funding Amount: \$50,000 per year

Grant period: 9/1/14-8/31/17

Cornell University (Technical Assistance)

Funding Amount: \$50,000 per year

Grant period: 9/1/14-8/31/17

Project Description

The substantial health benefits of regular physical activity and exercise are well documented; however, people with developmental and other disabilities often lack inclusive access to physical activity and exercise. The intent of this grant initiative is to support fitness, wellness, and healthy lifestyle programs in New York State to become more inclusive by both promoting exercise and fitness opportunities and providing better access to fitness facilities for adults with developmental and other disabilities.

Daemen College and The Research-Foundation, SUNY Upstate Medical Center, are implementing programs models that are designed to improve inclusive fitness for adults with developmental and other disabilities. The two programs are implementing fitness, wellness, and healthy lifestyle activities that concurrently serve both individuals with and without developmental and other disabilities in both individual and group fitness and wellness options.

Expected outcomes include: implement a variety of fitness, wellness, and healthy lifestyle activities that will simultaneously serve adults with developmental and other disabilities with their peers without disabilities and increase professional development and training opportunities for fitness professionals including both front line and supervisory staff to support making fitness opportunities more accessible to people with developmental and other disabilities.

The project being implemented at Daemen College consists of two components: A “Train the Trainer” program intended for fitness professionals (e.g. Trainers) to understand how to better work with individuals with disabilities. Over 50 professionals have received training to date.

Daemen College is also implementing a biweekly, 8-week exercise program called, “Get Movin.” The program addresses: stretching, strengthening, cardio-fitness (endurance) and balance. Over 40 people have participated in fitness activities to date.

The project implemented at The Research Foundation, SUNY Upstate Medical Center, (SUNY Upstate), includes monthly clinics to introduce adapted sports and inclusive recreation to adults with developmental and other disabilities, their families, and providers. SUNY Upstate is also working with Syracuse City Department of Parks and Recreation at two Community Centers to implement inclusive fitness and group sport activities. The monthly sessions offer participation in individual and group sports and offer educational sessions about fitness and healthy living to participants. Over 70 people have participated in the fitness and group sport activities to date.

SUNY Upstate is also offering professional development to local parks and recreation staff as well as students in Physical Therapy, Adapted Sports and Recreation programs of study. Over 90 professionals have participated in the professional development and training opportunities to date.

To support the DDPC in its efforts to pilot inclusive fitness, wellness, and/or healthy lifestyle programs for individuals with developmental disabilities, Cornell University is providing comprehensive technical assistance and evaluation support to Daemen College and Research Foundation- SUNY Upstate Medical Center. Cornell University is assisting DDPC, Daemen College and SUNY Upstate to identify, compile, and disseminate best practices that result from the programs. Cornell University’s work has included the development of evaluation instruments, educating staff on the concept of inclusion, and providing guidance and support about marketing the programs, and strategies to support sustainability of the programs.

Grants Closed Within Last 5 Years

Children, Youth & Families Committee

Robin Hickey, Program Planner

START (Systemic, Therapeutic, Assessment, Respite, and Treatment)

Grantee: New York State Office for People with Developmental Disabilities (OPWDD)

Funding Amount: \$225,000 per year

Grant period: 2/1/13-1/31/15

Project Description

In 2015, DDPC concluded a grant with OPWDD to implement the University of New Hampshire's START model across NYS. START is an evidence-informed model of cross system linkages that promotes a system of community services, natural supports and mental health treatment for people with intellectual and developmental disabilities and mental health issues.

The intent of this project was to enhance the existing system of care, provide technical assistance and support, and fill service gaps to improve the quality of life for individuals with intellectual and developmental disabilities by creating a well-trained network at the community level that can better support individuals in their home and reduce the need for referrals to higher levels of care and or more restrictive settings.

Expected outcomes for this project included: conducting strategic planning forums and Advisory Council meetings with multiple cross-systems stakeholders and implementing START activities in OPWDD Regions 1 and 3.

The START model has been fully implemented in OPWDD Regions 1 (Western New York) & 3 (Capital Region). Region 1 has had 142 referrals and completed 104 intakes into START services. Region 3 has had 156 referrals and completed 129 intakes for START services. Both regions offer 24/7 home supports and respite services, and the NY START page has been developed and is available on OPWDD's webpage.

Bullying Prevention

Grantee: University of Buffalo, Alberti Center for Bullying Abuse Prevention

Funding Amount: \$50,000

Grant period: 12/1/13-11/30/14

Project Description

The University at Buffalo's Alberti Center for Bullying Abuse Prevention undertook a broad-based needs assessment to assist DDPC to develop a long-term strategic plan on bullying prevention for individuals with developmental and other disabilities.

A needs assessment of key stakeholders was conducted throughout New York State which included focus groups, interviews, and dissemination of surveys. Participants included individuals with developmental disabilities, families and caregivers, general and special educators, provider agency staff, employers, community members, and others.

A survey was conducted that received 350 responses. Focus Groups were held across the state with 68 key stakeholders. Expected outcomes from this project included: Engaging key stakeholders to identify needs and resources at local and state levels, implementing additional research, data collection, and analysis and providing a preliminary strategic plan to DDPC.

A final report titled "Bullying and Individuals with Disabilities: Needs Assessment and Strategic Planning" was produced. Specific goals were developed, along with suggestions for specific activities. Suggested goals included the following: increasing the ability of people with developmental disabilities to prevent and respond to bullying, increasing supports for people with developmental disabilities and their families to deal with bullying, and increasing general awareness about the problem of bullying for individuals with developmental disabilities through education. DDPC will use the findings from the report to inform and guide future work.

New York State Disabilities Advocacy Association & Network (NYS DAAN)

Grantee: New York State Disabilities Advocacy Association & Network

Funding Amount: \$100,000 per year

Grant period: 10/1/05-12/31/10

Project Description

In 2010, the DDPC concluded an initiative with NYS DAAN that provided cross-system linkages and resources for community-based disability advocacy and service organizations that are providing advocacy services to individuals with disabilities and their caregivers.

The goals of the Association were to create an “advocacy network” and strengthen advocacy and service systems for people with any disability and their families by connecting and coordinating advocacy resources throughout the state.

Expected outcomes for this project included: developing a membership and membership services including marketing of member trainings and products, and highlighting member best practices and services, creating a statewide and regional disability advocacy training and support calendar, and sponsoring (and expanding) an annual statewide conference on disability advocacy.

NYS DAAN built a statewide advocacy network, increased its visibility statewide, developed advocacy standards and principles of practice, launched advocacy standards training, and developed a website www.nysdaan.org which serves as a connection for individuals with disabilities and their families, and as a source of information for a wide range of topical areas including (Health, Housing, Education, and etc.). NYS DAAN also provided technical assistance, consulting, outreach, and marketing services to enrolled members.

First Responders Disability Awareness Training (FR-DAT)

Grantee: Niagara University

Funding Amount: \$100,000 per year

Grant period: 11/1/10-10/31/15

Project Description

DDPC launched a training initiative for First Responders because research identified that previous training for First Responders was limited in focus, typically including only one category of a First Responder (e.g. only police) or one type of disability, typically hearing impairments, visual impairments, Autism or Alzheimer's disease.

Previous training also provided limited information about how to interact with people with disabilities or what to do in a first encounter when needs present. To address this clear information and capacity gap, Niagara University developed a comprehensive curriculum-First Responders Disability Awareness Training (FR-DAT).

Training content includes, but is not limited to, myths and misconceptions of developmental disabilities and other disabilities most prevalent to response, disability etiquette including alternate forms of communication and interaction skills, and service provision and support.

This initiative focused on training and capacity building for first responders by implementing a train-the-trainer program and by providing training in various formats including in-person and web-based training for fire, police, law enforcement, and 9-1-1 operators.

Niagara University developed supporting resources including a resource manual, a Project website, apps, and videos, to complement the initial training. As a result of the train-the-trainer format, a total of 455 trainers were trained. Evaluative findings suggest that over 30,000 First Responders will be trained as a result of FR-DAT.

Pregnant Pause Mini Grants

Grantees:

Buffalo Prenatal-Perinatal Network, Inc.

Funding Amount: \$1,000

Grant period: 1/1/11-7/31/11

Maternal – Infant Services Network

Funding Amount: \$1,000

Grant period: 1/1/11-7/31/11

Mohawk Valley Perinatal Network

Funding Amount: \$1,000

Grant period: 1/1/11-7/31/11

Mothers & Babies Perinatal Network

Funding Amount: \$1,000

Grant period: 1/1/11-7/31/11

North Country Prenatal/Perinatal Council

Funding Amount: \$1,000

Grant period: 10/1/10-9/30/11

Northern Manhattan Perinatal Partnership, Inc.

Funding Amount: \$1,000

Grant period: 3/1/11-8/31/11

Perinatal Network of Monroe County

Funding Amount: \$1,000

Grant period: 1/1/11-7/31/11

Project Description

In 2011, DDPC awarded mini grants to seven Prenatal and Perinatal Networks in New York State to sponsor regional “Pregnant Pause” community outreach and education events. The “Pregnant Pause” events were designed to provide information about prenatal care, childhood safety, Fetal Alcohol Spectrum Disorders (FASD) and available community resources. The expected outcome for this mini-grant initiative was to increase community awareness about disability prevention and the importance of alcohol-free and substance free pregnancies.

Prevention of Fetal Alcohol Spectrum Disorders (FASD)

Grantees:

Learning Disabilities Association of New York State (LDANYS)

Funding Amount: \$50,000 per year

Grant period:11/1/09-10/31/11

The American Congress of Obstetricians and Gynecologists, District II/NY (ACOG)

Funding Amount: \$52,500 per year

Grant period:1/1/09-12/31/11

Project Description

In 2012, the DDPC concluded a Fetal Alcohol Spectrum Disorder (FASD) Prevention Initiative. Research has demonstrated that alcohol consumed during pregnancy increases the risk of alcohol-related birth defects and that no amount of alcohol consumption can be considered safe during pregnancy. Fetal Alcohol Spectrum Disorders (FASD) describes a range of birth defects resulting from prenatal alcohol exposure. Research and qualitative findings indicate that professionals generally lack knowledge about FASD and FASD prevention. To address this knowledge gap, DDPC launched a training initiative on FASD and an educational campaign promoting FASD Prevention.

Goals of the initiative included developing and adapting educational materials to develop a Fetal Alcohol Spectrum Disorder (FASD) curriculum and training. Training was rolled out regionally and covered the entire State over the grant period.

Learning Disabilities Association of New York State implemented activities to educate professionals about Fetal Alcohol Spectrum Disorder (FASD). Training included an overview of FASD, Diagnosis and Barriers to Diagnosis, Common Signs of FASD, prevention of FASD, and strategies for working with individuals with FASD. Through this initiative, the Learning Disabilities Association trained over 1,000 professionals from allied healthcare agencies, school districts, childcare centers, Head Start programs, and probation agencies.

As part of the FASD Prevention Initiative, DDPC and the American College of Obstetricians and Gynecologists, District II implemented an FASD prevention public awareness campaign. The

campaign consisted of the “Pregnant? Think! Don’t Drink!” handbook, an FASD patient education video, media outreach, and attendance at public health events.

ACOG developed and distributed the FASD prevention handbook entitled **Pregnant? Think, Don’t Drink!** The handbook provides guidance on alcohol use and its dangers and provides various national, state and local resources. Over 110,000 handbooks were distributed in print over the grant period. ACOG District II also ran a three-month radio and internet public service announcement across the State. Messaging reached over 753,400 women.

In addition, an FASD patient education video was developed and aired on the Newborn Channel, which plays in more than 1,000 hospitals throughout the U.S; including nearly 80 hospitals in New York State. During the project period, over 1,087,425 people viewed the piece on the Newborn Channel.

ACOG District II also worked with the New York State Office of Alcohol and Substance Abuse Services, New York State Office of People with Developmental Disabilities, New York State Academy of Family Physicians, New York State Association of Licensed Midwives, New York State Nurses Association, March of Dimes, American College Health Association, Planned Parenthood, and others to spread preventative messaging on FASD.

Children Who are Medically Fragile

Grantees:

The Children's Hospital at Montefiore (CHAM)

Funding Amount: \$35,000 in Year 1&2, \$45,000 in Year 3

Grant period: 4/1/08-3/31/11

St. Mary's Hospital for Children

Funding Amount: \$35,000 in Year 1&2, \$45,000 in Year 3

Grant period: 4/1/08-10/31/11

United Cerebral Palsy of New York City (UCP/NYC)

Funding Amount: \$35,000 in Year 1&2, \$45,000 in Year 3

Grant period: 4/1/08-3/31/11

Project Description

In 2011, the DDPC concluded an initiative to address unmet needs for individuals with developmental disabilities who are medically fragile and their caregivers. Projects included a family-centered collaborative home care planning model, a grassroots leadership and advocacy training model for caregivers and families, and a curriculum and training program designed to increase the pool of nurses who have the skills to provide care to children with developmental disabilities who are medically fragile.

The Children's Hospital at Montefiore (CHAM) developed a specialized, interdisciplinary, hospital-based team that provided family-centered, collaborative, home care planning for families of children who are medically fragile. The model sought to increase community-based linkages to primary care and home care services through transition planning and family empowerment. A total of 36 families received intensive support over the grant period, over 40 families and 140 service providers were trained in family-centered care, care planning, and transition planning for individuals with developmental disabilities who are medically fragile.

St. Mary's Hospital for Children (St. Mary's)

St. Mary's developed a curriculum, a series of leadership and advocacy trainings, and a transition tool kit for caregivers. The curriculum and training covered topics including planning for "aging out", future care planning, and various advocacy strategies. Over 150 families received training and support over the grant period.

United Cerebral Palsy of New York City (UCP/NYC) implemented a project designed to increase the pool of nurses who have the skills to provide care to children and adults with developmental disabilities who are medically fragile. UCP/NYC designed training for nurses and nursing students to respond more sensitively and knowledgeably to individuals with developmental disabilities who also have medically fragile conditions.

UCP/NYC partnered with Phillips Beth Israel School of Nursing and Kingsborough Community College Nursing Program to implement the "HealthLink for Nurses" training. Training covers topics including the principles of respect, person-first philosophy, patient and family-centered care, and offers a variety of communication and interaction strategies. The HealthLink for Nurses curriculum is delivered in 1 to 3 hour modules and incorporates lectures, videos, case vignettes, interviews, and group exercises. Over 350 nurses and nursing students were trained over the grant period.

Parent Partners in Health Education (PPHE)

Grantees:

St. Barnabas Hospital

Funding Amount: \$52,500 in Year 1, \$35,000 in Year 2&3

Grant period: 1/1/05-6/30/08

St. Elizabeth Family Medicine Residency Program

Funding Amount: \$52,500 in Year 1, \$35,000 in Year 2&3

Grant period: 1/1/05-6/30/08

Stony Brook University Hospital (Technical Assistance)

Funding Amount: \$52,500 in Year 1, \$35,000 in Year 2&3

Grant period: 1/1/05-6/30/08

Winthrop University Hospital

Funding Amount: \$52,500 in Year 1, \$35,000 in Year 2&3

Grant period: 1/1/05-6/30/08

Project Description

In 2010, the DDPC concluded a multi-year training initiative called “Parent Partners in Health Education” (PPHE). From 2005-2010, DDPC in collaboration with the New York State Council on Graduate Medical Education (COGME) implemented Parent Partners in Health Education (PPHE).

PPHE is a training program designed to educate medical residents to work more effectively with families and children with developmental disabilities. The PPHE Curriculum components include:

- Parent Interviews that help Residents gain an understanding of the experiences of raising a child with a disability from the perspective of the family.
- Required Lectures including an organizational session, Assessment of Developmental Disabilities in Primary Care, Legal Aspects and Accessing Services for Children and Adults with Disabilities, and Doctor-Patient-Family Communication.

- Community Agency Interviews that allow the Medical Residents to learn directly about available community resources and include at least one interview with an agency providing services to the paired family.
- Clinical Experiences that provide direct patient care experience with children and adults with developmental disabilities and give the Medical Resident opportunities to develop essential skills and highlight the integration of clinical, family, and community aspects of care.
- Community Medicine Case Presentations that allow medical Residents to share their knowledge of medical, social, and educational details about their assigned family and child with other medical Residents and faculty.
- Small Group Discussions that create a forum where Medical Residents can share in informal peer-to-peer exchanges.

Collectively, a total of 750 Medical Residents received training in PPHE. The 750 includes:

- 532 Pediatric Residents
- 200 Family practice Residents
- 11 Psychiatry Residents and 7 Faculty

Qualitative and Quantitative evaluation results from the grant show that the PPHE curriculum increases knowledge about working with families and individuals with developmental disabilities and that Medical Resident's opinions and attitudes were favorably changed by their PPHE experiences including findings that: Medical Residents felt that they were more aware of difficulties that families with children with developmental disabilities face, they felt more familiar with community and support services that are available to families, and the evaluations showed an increase in Medical Resident knowledge about developmental disabilities and a notable increase in their comfort level and ability to provide care.

Institute on Health Care Transition

Grantee: SUNY Upstate Medical Center

Funding Amount: \$150,000 per year

Grant period: 8/1/06-9/30/10

Project Description

In 2010, the DDPC concluded a grant with SUNY Upstate Medical Center (SUNY Upstate) to develop centralized expertise in the transition of youth with developmental and other disabilities from Pediatric to Adult Healthcare. SUNY Upstate Medical Center developed a web-based portal and infrastructure to support young adults (ages 14-25 years) as they transition from pediatric to adult health care. SUNY Upstate developed a web-based curriculum and toolkit for youth, caregivers, Medicaid service coordinators, and health care providers.

Feedback from focus groups and other information gathering identified the need for the Healthy Transitions curriculum and tools which cover key skills in areas such as scheduling an appointment, getting health insurance, advocacy (speaking up at the Doctor's office), understanding disability and health, setting health goals, managing medications, and locating community resources. Based on feedback, materials for each of these skills were developed.

A total of 77 Health Transition workshops / trainings were held across the State. Initially the workshops were designed to simply introduce people to the Healthy Transitions project. Train-the-Trainer workshops were later implemented to support dissemination of the curriculum across the State. Dissemination of the Healthy Transitions curriculum and toolkit occurred via workshops and presentations.

Over the project period more than 10,593 individuals, families, and providers accessed various components of the Healthy Transitions curriculum and toolkit.

Middle School Socialization Project- Rural Expansion

Grantee: Best Buddies New York

Funding Amount: \$90,000 per year

Grant period: 9/1/09-8/31/11

Project Description

Best Buddies New York developed a statewide technical assistance model that launched local/regional chapters to promote and foster friendship opportunities for middle school aged youth with and without disabilities. DDPC sought to expand socialization opportunities for middle school aged youth with and without disabilities in designated rural areas of New York State including schools located in Columbia, Warren and Washington counties. The Best Buddies model is a peer-match model where students with disabilities are paired with students without disabilities to promote and foster friendship opportunities.

Expected outcomes for this project included: establishing a minimum of 12 new Best Buddies chapters in NYS over the grant period by working with identified school districts to launch BBNY programs and create regional events.

Each Best Buddies chapter ensured that a minimum of 10 students with disabilities were paired with 10 students without disabilities. Twice per month, students visited with each other in-person and also participated in at least five inclusive group activities to develop social skills within larger group settings.

BBNY also provided training to teachers and students on the Best Buddies social inclusion model and provided general disability awareness training. BBNY also provided ongoing technical assistance including monthly leadership trainings.

As a result of DDPC efforts and funding, BBNY established 13 rural chapters statewide and provided mentoring and socialization opportunities to over 293 youth, and trained over 338 youth and faculty.

Closed Grants

Systems Coordination & Community Education Committee

James Huben, Program Planner

Congregational Inclusion

Grantee: New York State Office for People with Developmental Disabilities (OPWDD)

Funding Amount: \$65,000

Grant period: 7/1/14-12/31/15

Project Description

The goal of this project was to increase the congregational inclusion of people with intellectual and developmental disabilities (I/DD) in the Hispanic community. Throughout this project, OPWDD staff worked with congregations, and voluntaries to improve the inclusivity of individuals with intellectual and developmental disabilities and enhance their congregational life.

Project outcomes included documenting strategies and best practices that led to congregational inclusion for project participants. The project developed online resources, which are available in Spanish. Spiritual Awareness training was provided with ongoing technical assistance to agencies serving Hispanic individuals with intellectual and developmental disabilities.

Over 150 individuals with developmental disabilities, agency providers, and OPWDD Developmental Disabilities Regional Offices (DDROs) staff were trained in how to support congregational inclusion. In addition to identified activities, DDPC and OPWDD staff conducted a series of focus groups with project participants, specifically Hispanic participants. The focus groups highlighted the importance of the Church in the Hispanic community and that churches can be a networking method and connection to this often under-served community.

Partners-In-Policymaking (PIP)

Grantee: Cornell University

Funding Amount: \$200,000 per year

Grant period: 1/1/10-12/31/14

Project Description

Partners-in-Policymaking is an innovative advocacy and leadership training program that teaches individuals with intellectual and developmental disabilities (I/DD) the power of advocacy, and how it can change the way people with disabilities are supported, viewed, taught, live, and work.

Cornell successfully retooled the PIP program into an innovative distance learning training model. There are over 1,000 Partners graduates statewide.

PIP provides participants with the knowledge and skills they need to influence the issues, agencies, and people affecting their lives and encourages active participation in public, system, and policy discussions that impact their lives and their role in the community.

The project actively recruits individuals with intellectual and developmental disabilities and their family members. The project has focused outreach efforts on populations including siblings, fathers, youth (age 18-21), and representatives of the Hispanic community as program applicants.

Cornell continues to expand the use of online learning technologies and will be compiling a final report for DDPC which includes identification of specific strategies that assist Partners-in-Policymaking to expand and sustain.

Multicultural Participation in Partners-in-Policymaking (PIP)

Grantee: New York Association of Emerging and Multicultural Providers, Inc.

Funding Amount: \$12,000

Grant period: 7/1/15-12/31/15

Project Description

The Multicultural Partners in Policymaking (PIP) program was a pilot aimed at increasing the participation of un- and underserved groups, particularly racial and ethnic minorities living in poverty areas of New York State in PIP. The DDPC aimed to increase the advocacy skills of individuals with intellectual and developmental disabilities and family members from culturally diverse populations.

The grant identified mentors within multicultural agencies to provide technical assistance to diverse PIP participants throughout the course. This approach allowed the core tenets of the Partners training to be given in a supported and culturally-sensitive environment to populations that were previously difficult to reach, and thereby increase the leadership capacity of individuals from a variety of cultural communities.

Expected outcomes for this project included: increasing participation of people with intellectual and developmental disabilities and their families from racial and ethnic communities in the PIP program, improving the leadership and advocacy skills of participants thereby improving the diversity of leadership in disability advocacy coalitions across NYS, improving graduation and success rates of participants, and gaining a better understanding of the role agencies can play in supporting PIP participants.

This grant has provided support to staff at three multicultural agencies (Sinergia, Thrive Network, and Unique People Services) to provide one-on-one support and personalized mentorship to help individual participants in successfully graduating from the course. The three multicultural agencies each helped 2 individuals (6 total) from the Latino (2), Asian American (2) and African American (2) communities to successfully complete the Partners in Policymaking Program.

Inclusive Recreation Resource Center (IRRC)

Grantee: SUNY Cortland

Funding Amount: \$175,000 Year 1-3, \$99,000 Year 4&5

Grant period: 1/1/07-12/31/11

Project Description

The Inclusive Recreation Resource Center at SUNY Cortland was established to foster a sustainable statewide resource that promotes inclusive recreation, sports and leisure activities. The project developed an online Inclusivity Guide, and implemented an inclusivity training entitled “Inclusion U” and “Recreation Inclusion Tips and Tools” for use by Medicaid Service Coordinators (and others) involved in the design and/or implementation of the daily activities of individuals with intellectual and developmental disabilities. The IRRC provided statewide technical assistance to recreation sites and recreation providers, and provided education and technical assistance for individuals trained as trainers.

In phase 2 of the project, SUNY Cortland worked with OPWDD to incorporate the Inclusion U assessment training into the continuing education catalog for Medicaid Service Coordinators (MSC's) and other direct care workers. A new three hour training, entitled “Recreation Tips and Tools” was developed to support the ongoing work and training requirements of MSC's.

Closed Grants

Adult Issues Committee

Escape-Now and ESCAPE DD

Grantee: Teacher's College at Columbia University

Funding Amount: \$41,500 per year

Grant period: 9/1/13-5/31/15

Project Description

The overall purpose of the ESCAPE Project was to update and revise the ESCAPE-DD Curriculum (Khemka & Hickson, 2008). Specifically, the Project produced a sustainable, web-based version of an updated curriculum, entitled ESCAPE-NOW: Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment for Individuals with Developmental Disabilities – NOW (Khemka & Hickson, 2015).

ESCAPE-NOW is designed to meet the need for an up-to-date, effective, evidence-based abuse prevention program to teach women and men with intellectual and developmental disabilities to make effective, self-protective decisions in a broad range of abuse situations.

The final version of the updated Escape-Now curriculum was completed in May of 2015. All components of ESCAPE-NOW are accessible on a Wiki Scholars internet site: (escapenow.wikischolars.columbia.edu).

Aging in Community

Grantee: New York State Office for People with Developmental Disabilities (OPWDD)

Funding Amount: \$59,972 over a two-year period

Grant period: 10/1/09-3/31/12

Project Description

In 2012, the DDPC concluded a grant with OPWDD and the New York State Office for the Aging. The Aging in Community initiative began with a booklet, which provides themes to consider for nursing home diversion and discharge. The booklet provides stories with lessons that illustrate specific themes. Examples of themes include: (1) implementing innovative strategies that address special needs as people age, (2) when services in a nursing home are not appropriate for the person, consider alternative options, and (3) consider cross-system supports and enhancements to a home, e.g. with staff, training, or living environment modifications to support people in their home of choice.

DDPC funding resulted in the production of a Public Television program that focused specifically on concerns related to aging for people with developmental disabilities and their caregivers. An "Aging in Community" training package was also produced. The "Aging in Community" training DVD showcases successful ways that community involvement can help families and individuals stay in the home of their choice.

Addiction Treatment

Grantee: New York City Department of Health & Mental Hygiene

Funding Amount: \$40,000 per year

Grant period: 7/1/09-6/30/12

Project Description

In 2012, the DDPC concluded a grant with the New York City Department of Health and Mental Hygiene. This New York City-based Pilot Project was designed to increase admission of people with developmental disabilities who are dealing with addictions into Addiction Treatment Centers (ATCs) and other OASAS supported programs.

The New York City Department of Health & Mental Hygiene sought to increase program completion rates and provide referrals and admittance to at least 12 individuals with developmental disabilities (annually) who were identified as requiring in-patient chemical dependency rehabilitation into an OASAS administrated/certified Addiction Treatment Center (ATC).

DDPC grant funding supported the creation of a position to better serve individuals across the Developmental Disability and Substance Abuse/Chemical Dependency services systems. The Sobriety Community Linkages Coordinator (SCLC) assisted individuals to access and engage in care and treatment including inpatient rehabilitation and aftercare services.

The SCLC position was designed to provide a flexible range of client services. Services included screening for program enrollment, motivation counseling, helping individuals with developmental disabilities to acclimate to inpatient rehabilitation treatment settings, and providing linkages to aftercare in outpatient programs.

As the project rolled out, additional services were added, including facilitation of residential placements and linkage to vocational programs. Over 30 individuals with developmental disabilities received services.

In addition to providing direct support to individuals, the project included a training component for chemical dependency treatment providers. Over 200 providers were trained over the life of the project. Training topics included characteristics of developmental disabilities, the prevalence of substance use for individuals with intellectual and developmental disabilities, the disease model of addiction, how to identify possible substance abuse in people with disabilities, and how to make a referral for a screening or treatment.

Direct Support Professionals Alliance

Grantee: Direct Support Professionals Alliance of NYS (DSPANYS)

Funding Amount: \$22,000 per year

Grant period: 1/1/10-3/31/13

Project Description

In 2013, the DDPC concluded an initiative with with DSPANYS. This project was a continuation and expansion of a two year effort to establish a New York State chapter of the National Alliance of Direct Support Professionals for the purpose of promoting the DSP profession and advancing the career paths of Direct Support Professionals (DSPs).

The intent of the Project was to:

- Support information dissemination and capacity building related to the development of standardized training, performance, and competency requirements for DSPs, and
- Conduct learning seminars on core competency training, based on research and evaluation.

DSPANYS co-sponsored six regional forums. The forums focused on the new OPWDD Code of Ethics for DSPs, competency standards for direct support professionals, and tools and techniques for evaluating DSP performance.

The forums also included information and resources on how provider agency leadership can meet training requirements. 300 agency executives and senior staff attended the forums.

Literacy Zones

Grantees:

ARISE

Funding Amount: \$45,597 in Year 1, \$ \$94,402.25 in Year 2

Grant period: 7/1/10-12/31/12

Allegany ARC

Funding Amount: \$70,000 per year

Grant period: 7/1/10-9/30/12

Project Description

In 2012, the DDPC concluded projects with Allegany ARC and ARISE to demonstrate how Literacy Zones can positively support people and parents with developmental disabilities. Literacy Zones provide a continuum of literacy services from early childhood through adulthood, including assistance and support for at-risk youth to enable them to complete high school and succeed in postsecondary education or advanced training.

Expected outcomes for this project included: conducting extensive outreach about Literacy Zone services, providing pre-employment and employment training, and assisting with linkages to social services and other community supports.

Both the ARISE Project and the Allegany ARC Project improved intake, collaboration, services navigation, and access for individuals with disabilities. Programs provided training to individuals with disabilities that included job readiness, financial and health literacy, benefits advisement, and disability awareness.

The ARISE Project was geared toward making connections with agencies that work with large numbers of refugee and new American populations. ARISE successfully partnered with 71 agencies as a result of this grant initiative. Over 1080 individuals and staff were trained over the life of the grant. By working with Literacy Zone staff, ARISE assisted in redesigning their intake forms to better identify people with disabilities in need of supports, services, or referrals.

The Allegany ARC Project included establishing formal linkages with 48+ community partners to develop strategies to identify individuals with developmental disabilities and/or families who wished to receive Literacy Zone services. Allegany ARC identified over 200 individuals with developmental disabilities and/or their families for opportunities leading to expanded access to services.

Shared Living

Grantee: NYS Association of Community & Residential Agencies (NYSACRA)

Funding Amount: \$55,000 over a two year period

Grant period: 4/1/11-3/31/13

Project Description

In 2013, the DDPC concluded a grant with NYSACRA to develop a Statewide Community of Practice on Shared Living. Shared living is an arrangement by which an individual, a couple, or a family in the community and a person with a disability choose to live together. Other terms that encompass the shared living approach include mentor and/or host family, supported living, and life sharing. The ultimate goal of this initiative was to make Shared Living one of many viable residential options for individuals with developmental disabilities in NYS by establishing a statewide learning community and demonstrating effective approaches to Shared Living.

Expected outcomes of the Shared Living Project included:

Establishing a formal Statewide Learning Community for Shared Living; identifying “promising practices” in the implementation of Shared Living in New York and other states, and establishing mentoring relationships where experienced agencies act as mentors to eight provider agencies that want to learn how to implement effective shared living practices.

NYSACRA established a Learning Community of more than 90 providers, self-advocates, family members, policymakers and experts interested in examining and advancing shared living opportunities in New York State for people with developmental disabilities.

Four policy workgroups were convened to explore key issue areas and identify recommendations for legislative, policy or training reforms needed to expand shared living opportunities.

The project developed a curriculum and resource compendium on various aspects of shared living. NYSACRA also designed a mentoring program for agencies interested in developing shared living opportunities.

Healthy Families New York

Grantees:

Institute for Family Health

Funding Amount: \$40,000 per year

Grant period: 6/1/11-5/31/13

Sinergia, Inc.

Funding Amount: \$40,000 per year

Grant period: 6/1/11-5/31/13

Family Nurturing Center

Funding Amount: \$39,600 per year

Grant period: 6/1/11-5/31/13

Project Description

The NYS Office of Children and Family Services (OCFS) has over 30 Healthy Families New York (HFNY) Programs statewide, serving approximately 6,000 families per year. Of these families, approximately 275 families have a person with a disability as the head of household.

The goal of the 3 pilot programs was to demonstrate effective and sustainable collaboration with the State Healthy Families New York program. This initiative was intended to improve outcomes with at-risk families, and decrease their involvement with Child Protective Services. To improve support for parents with intellectual and developmental disabilities, programs improved family connections with community resources, delivered parent education to improve parenting skills, and implemented procedural, assessment, or curriculum modifications for parents. Home visits and frequent contact were key components of implemented activities and supports.

The Institute for Family Health's Ulster County Healthy Families program collaborated with multiple agencies to improve home visiting and other support services to families headed by individuals with disabilities. Through a partnership with the Ulster/Green ARC, Ulster County Healthy Families provided comprehensive assessments, home visits, direct services, and instructional parent training to assist families headed by persons with developmental disabilities. The Institute for Family Health provided 280 home visits to enrolled families and collaborated with Ulster-Greene ARC to conduct workshops for Healthy Start Program staff about developmental disabilities; modified and/or developed several materials targeting parents including activity posters.

Sinergia Inc. in New York City collaborated with the Healthy Families University Settlement Society to conduct outreach, home visits, and service coordination that linked families to the OPWDD system. Sinergia provided support groups and skill development to help families connect to and use natural community supports to better sustain their families.

The Family Nurturing Center, an affiliate of Kids Oneida hired a full-time Developmental Disabilities Advocate who became trained as a Healthy Families Support Worker and a Nurturing Parenting Program® Facilitator. The Advocate served as the primary contact with community-based disability service agencies; court, and social services systems; completed over 30 home visits with parents with developmental disabilities; and provided family and professional development to better serve parents with developmental disabilities.

Over the grant period, 154 families were directly served by the three project sites. A total of 697 people were trained as a result of grant activities including 102 individuals with disabilities who are heads of household, 74 family members, and 402 providers.

Project SEARCH

Grantees:

Rockland BOCES

Funding Amount: \$80,000 in Year 1&2, \$70,924 in Year 3

Grant period: 9/1/11-8/31/14

Westchester Institute for Human Development (WIHD)

Funding Amount: \$80,000 in Year 1&2, \$78,861 in Year 3

Grant period: 9/1/11-8/31/14

Project Description

DDPC created two regionally-based Project SEARCH located within Rockland and Westchester counties. Rockland BOCES and Westchester Institute for Human Development (WIHD) implemented the Project SEARCH High School transition program

The Project Search High School Transition Program is a business led, one-year school-to-work program that takes place entirely within the workplace. Total workplace immersion facilitates a seamless combination of classroom instruction, career exploration, and hands-on training through at least three worksite rotations.

Expected outcomes for both programs included increasing the number of transition-age students (18-21) with developmental disabilities who entered into competitive employment opportunities

and sites had to successfully implement Project SEARCH mandated components. Mandated Project SEARCH components include but are not limited to the following:

Employment takes place in inclusive and integrated work settings. Employees (students with developmental disabilities) are directly hired by the partner “Host” business and earn the prevailing wage for a given job. Employees work 20 hours each week or more.

Project SEARCH is a partnership with support and resources from a Business site, Education (Schools), Vocational Rehabilitation, (Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR) and a Community Rehabilitation Provider. The “Host” Business must provide an on-site classroom and include an employability skills curriculum that is taught each day and customized to the business.

Students are on site at the business each school day for a minimum of six hours for an entire academic year. Work rotations are not volunteer work. Students participate in the internships 20 – 25 hours a week.

Both programs successfully implemented Project SEARCH components for over 40 students with developmental disabilities. Cumulatively between the two programs, 22 students secured jobs of their choice as a result of Project SEARCH activities.

Telemedicine

Grantee: Center for Disability Services (CFDS)

Funding Amount: \$100,000 over 2.5 year period

Grant period: 11/1/08-5/31/11

Project Description

In 2011, The Center for Disability Services (CFDS) concluded a pilot project to test tele-monitoring of individual health status for people with developmental disabilities who are aging.

Tele-monitoring is defined as an automated process for transmitting data on an individual’s health status (e.g. Blood Pressure, Pulse, Oxygen Saturation, weight and glucose readings) from home to the respective health care setting.

Direct Support Professionals worked with 25 adults with developmental disabilities in urban and rural areas of Albany and Rensselaer counties to implement tele-monitoring activities.

Routine health readings were taken daily by trained staff or individuals who had been trained to monitor their own health / condition status. Results were reported electronically to a Primary Care Nurse for evaluation.

The goal of the project was to prevent or reduce the number of emergency room and office visits for enrolled participants. Additionally, the project sought to identify the practical challenges of implementing a tele-monitoring approach to assess the individual health status of people with developmental disabilities who are aging.

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* Represents DDPC Council Membership as of February 18, 2016

Want More Information?

If you have questions or would like more information about the New York Developmental Disabilities Planning Council, please call or email us, 9:00am to 5:00pm, Monday through Friday.

You may also find more information by visiting our website at: www.ddpc.ny.gov.

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