

Westchester Institute for Human Development Annual Report 2013

# EDUCATE. INNOVATE. ADVOCATE.

# WIHD creates better futures

for people with disabilities, for vulnerable children, and for their families and caregivers.

## WIHD accomplishes

its mission through:

- professional education
- innovative services and supports
- community training and technical assistance
- research and information dissemination



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#### MESSAGE FROM THE CEO

#### **EXCELLENCE IN LEADERSHIP**

At WIHD, we believe that our society is strengthened when people with disabilities and vulnerable children and their families receive the support and opportunities they need to live healthy and productive lives as members of the community. And, we believe that as a University Center for Excellence in Developmental Disabilities (UCEDD), WIHD has an obligation to provide excellence in leadership to help ensure that.

Our theme for this year's annual report is "Building on Excellence." WIHD is a diverse community of leaders - faculty, staff, students, clinicians, and families - committed to strengthening research, policy, and practice in order to improve the lives of people with disabilities, vulnerable children, and their families. Our expert staff and faculty provide leadership at local, state and national levels, through rigorous research, innovations in technology, evidence-based practice, training, and dissemination of products and information. There is a culture of excellence at WIHD that embraces an open exchange of ideas and the pursuit of new opportunities that will make a difference.

Excellence develops through partnerships, including collaborations with self advocates, family members, community organizations, colleges and universities, state and federal agencies, foundations, and donors. These partnerships are key to achieving our vision.

We are excited to share this annual report of our work at the Westchester Institute for Human Development UCEDD and thank you for taking the time to learn more about us. We look forward to continued collaborations and welcome your input. It is through the process of receiving feedback and input that our work stays responsive to the needs in our community, our state, and our nation.

ansley Bacon, Ph.D.

Ansley Bacon President and CEO

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## INNOVATING FOR BETTER FUTURES: UCEDD



There are approximately
4.5 million individuals
with developmental
disabilities in the U.S.

The importance of a UCEDD or University Center for Excellence in Developmental Disabilities is crucial to the approximately 4.5 million individuals with developmental disabilities (DD) in the U.S. They do not have access to appropriate services, the workforce to support them is not well-trained, and they are at greater risk for abuse and neglect.

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) is the fundamental federal law supporting and enhancing the lives of people with developmental disabilities and their families. The DD Act funds "administration and operation" costs of 67 UCEDDs (including WIHD) at universities in every state and territory. The purpose of the UCEDD network is to promote opportunities for individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life; to provide leadership in the field of developmental disabilities; and to advise Federal, State, and community policymakers.

Each UCEDD, including WIHD, must carry out the following "core functions"

- training of students and continuing education for professionals
- · community training and technical assistance
- demonstration projects and clinical services
- research and evaluation
- dissemination of information

Each UCEDD chooses the areas of emphasis in which they work.

WIHD's areas of emphasis:

- HEALTH
- CHILD WELFARE
- ASSISTIVE TECHNOLOGY
- SELF-ADVOCACY AND FAMILY PARTNERSHIPS
- APPLIED BEHAVIOR ANALYSIS

## INNOVATING FOR BETTER FUTURES: LEND Interdisciplinary Leadership Training Program

Skilled and creative leadership is required to improve health and developmental outcomes for children with disabilities and their families. The LEND Program (Leadership Education in Neurodevelopmental and related Disabilities) prepares health and education professions graduate students, and family members of people with disabilities, for leadership roles working with and on behalf of children with disabilities and their families. LEND is an interdisciplinary leadership training program, funded by the Maternal and Child Health Bureau of the federal government at 43 universities around the country. WIHD's LEND Program provides 300 hours of innovative interdisciplinary leadership training each year to 20-25 trainees from ten disciplines. The training focuses on the skills and knowledge required for leadership in advocacy, policy, research, education and training, and clinical systems to assure best outcomes for children with disabilities and their families. In 2013, twenty-three WIHD LEND trainees completed the 300-hour LEND Program. In addition, LEND faculty and trainees from WIHD collaborate at the local, state and national level in research, training and advocacy activities. LEND faculty provide consultation and technical assistance to professionals and organizations in our local community, at the state level, and across the nation.

...skills and knowledge required for leadership in advocacy, policy, research, education and training, and clinical systems to assure best outcomes for children with disabilities and their families.



#### **Project LAUNCH**

Project LAUNCH is a public health approach to improving school readiness of all children and to assure incorporation of evidence-based mental health/ behavioral health screening and services into primary care practice. The project aims to facilitate the healthy development of children pre-birth through eight years old, supporting them to reach physical, social, emotional, behavioral and cognitive developmental milestones, thus establishing a solid foundation for success in school and beyond. In 2013, Project LAUNCH completed school readiness profiles for 333 children.

# INNOVATING FOR BETTER FUTURES: WIHD Training and Continuing Education Programs

In 2013 we provided **clinical training** for

33 first-year and9 second-yearMaster's Degree students.

The WIHD Training and Continuing Education Programs serve to expand an individual's academic or professional credentials.

- Graduate Program in Speech-Language Pathology: WIHD's Speech and Hearing Center serves as the primary clinical site for the Graduate Program in Speech-Language
   Pathology at the School of Health Sciences and Practice of New York Medical College.

   All first-year and selected second-year students receive clinical training at WIHD.
   In 2013, we provided clinical training for 33 first-year and nine second-year Master's
   Degree students.
- Graduate Courses: WIHD's staff and faculty are recognized for special expertise in
  working with children and adults with disabilities, vulnerable populations and families.
   By offering specialized education and training to graduate students at area colleges
  and universities they have an important role in disseminating best practices developed
  at WIHD.
- Continuing Education for Professionals: Professionals in the areas of health and
  education require frequent updates on their knowledge and skills in order to provide
  the best quality services to children and adults with disabilities, vulnerable populations
  and families. WIHD faculty develops and offers continuing eduation conferences,
  workshops, and on-line training based on the best evidence from the scientific
  literature and on their model services and programs at WIHD. In 2013, 369
  professionals participated in 16 WIHD continuing education offerings.



### **INNOVATING FOR BETTER FUTURES:**

#### **Self-Determination Project**

People who are self-determined make things happen in their own lives. They know what they want and how to get it. They choose and set goals and work to reach them. They advocate on their own behalf, and are involved in solving problems and making decisions about their own lives. The National Gateway to Self-Determination Project (2009 – 2013) was funded by the U.S. Administration on Intellectual and Developmental Disabilities. WIHD collaborated with four other UCEDDs (University of Missouri, University of Kansas, University of Illinois-Chicago, and University of Oregon) for this project. The overall goal was to develop resources, tools, and strategies to promote self-determination for people with intellectual and developmental disabilities (I/DD). WIHD led the development of two major products: Research to Practice Brief on Self-Determination and Health, that describes the relationship between self-determination and health, and explores how self-determination can reduce the significant health disparities experienced by people with I/DD; and the UCEDD Self-Determination Self-Assessment Checklist, a tool to determine the degree to which UCEDD policies, practices, and personnel are promoting self-determination for people with I/DD and their families.

**UpState Kids** 

The causes of developmental delay are not always easily determined. UpState Kids is a longitudinal statewide study of the risk and protective factors that contribute to developmental delays and outcomes. It will enroll approximately 6,000 families whose children were born in New York State in 2008 and 2009. WIHD was funded as a site for evaluation of child development. This year, 141 UpState Kids study subjects received full evaluations of development and behavior.

The overall goal of the project was to develop resources, tools, and strategies to help promote self-determination for people with intellectual and developmental disabilities.



#### VULNERABLE CHILDREN: Child Welfare Services



Child Welfare Services provides a range of clinical interventions, assessments, supports, consultation, technical assistance and training to children, families and professionals involved with the child welfare system in Westchester County. Our skilled staff work to strengthen birth, foster and adoptive families, promote child safety, well-being and permanence and enhance the capacity of Department of Social Services staff to work efficiently and effectively. In 2013, we served more than 350 children and families and their non-offending family members. The Children's Advocacy Center ensures that children and families get the critical support and appropriate trauma resources they need.

- Project IMPACT provides intensive, in-home parent training and support to parents
  with an intellectual/developmental disability whose children are at risk of foster
  care placement because of reported abuse or maltreatment. No child whose parent
  participated in the program in 2013 entered foster care and 100% of the families
  that completed the program in 2012 remained intact after one year. 100% of parents
  demonstrated an improvement in at least one parenting skills domain at completion
  of the program.
- WIHD provided pediatric medical care to 271 children in foster care over the past twelve months.
- Almost 125 children in foster care received specialized mental health treatment at WIHD in 2013.
- In 2013, 53 families received hands-on parent training at WIHD and half of those parents successfully completed the program.
- Over 125 children in family foster care received educational care and coordination to
  ensure timely enrollment in school upon placement into foster care and appropriate
  educational services as the children exit foster care to permanent placement.
- 79 families and 124 children participated in WRAP (Westchester Resource for Adoption Program). WRAP provides training and education for professionals to become adoption competent, training and education for adoptive parents to help them understand the needs of their children, monthly support groups, short term clinical assessment, crisis intervention, and a resource library.

#### 10

# **VULNERABLE CHILDREN:**Children's Advocacy Center (CAC)

The CAC offers a child-friendly, neutral environment in which to conduct multidisciplinary assessments of suspected child sexual and severe physical abuse. Here, professionals work as a team to manage suspected cases of abuse from the initial investigation through prosecution and offer medical, therapeutic and other support services to the child victim and their non-offending family members. The CAC ensures that children and families get the critical support and appropriate trauma resources they need.

- The CAC served almost 500 children in 2013. The CAC service delivery model saves court, child protection and investigative dollars averaging \$1,000 per child abuse case, compared to non-CAC communities.
- Step-Up-For-Kids Walk; 113 children and adults participated in WIHD's first annual Step-Up-for-Kids Walk to raise awareness about child abuse and critical funds for WIHD's Children's Advocacy Center. The walk raised over \$7,000.



The CAC ensures that children and families get the **Critical SUPPORT** and appropriate interventions they need.

## PEOPLE WITH DISABILITIES: WIHD Health Services

Individuals with intellectual and developmental disabilities have significant health disparities and often have multiple, co-existing, and chronic health problems. WIHD patients are often unable to communicate directly about their health and typically come for health appointments with several caregivers over time. Their care and ongoing support requires a health care program committed to getting to know patients well and committed to taking a long-term view of patient health care.

for general anesthesia. The WIHD Mobile Dental Van travels to community agencies and programs that serve patients who are medically frail and/or unable to travel. In 2013, there were 6,408 visits to our dental clinic that served 2,205 patients. There were 1,834 visits to our dental van, which served 1,107 patients.

- WIHD's Primary Care Program is staffed with internal medicine
  and family practice physicians, nurse practitioners, and nurses
  who provide routine medical care and strive to serve as a
  "medical home" for patients. In 2013, there were 4,761 visits to
  our primary care program that served 1,416 patients.
- WIHD's Specialized Health Care Program has created a comprehensive health care model that effectively responds to acute health care needs while also promoting optimal health over time. Staffed with physicians, nurses, and consulting specialists, our specialty medical services include: psychiatry, neurology, endocrinology, cardiology, ENT, ophthalmology, gynecology, urology, gastroenterology, podiatry and rehabilitation medicine. In 2013, there were 15,110 visits to our specialty care program that served 2,675 patients.
- Reports from the Special Olympics/Special Smiles program indicate that individuals with intellectual and developmental disabilities are almost twice as likely as the general public to have untreated cavities, root remnants, missing teeth, gingivitis, and/or severe periodontal disease. In the WIHD Dental Program, our team of specially-trained dentists, hygienists, and dental assistants provides services ranging from routine preventative dental care to oral surgery. When necessary, WIHD patients can be seen in the Westchester Medical Center (WMC) dental clinic for conscious sedation or the WMC Ambulatory Surgery Center



## SPEECH AND HEARING CENTER AND BEHAVIORAL PSYCHOLOGY PROGRAM

#### **Speech and Hearing Center**

The Speech and Hearing Center identifies, evaluates, and diagnoses speech, language, swallowing, and hearing disorders, and provides prompt, quality intervention.

- In-patient services: WIHD's speech-language pathologists (SLP)
  and audiologists provide a full range of services to inpatients at
  the Westchester Medical Center, a tertiary care teaching
  hospital. In 2013, there were more than 8,725 visits with our
  SLPs and 1,611 visits with our audiologists. Our audiologists
  also screened 950 babies and provided auditory brain stem
  response testing for 40 children with hearing issues.
- Out-patient services: WIHD's Speech and Hearing out-patient program provides a full range of services to individuals ranging in age from newborns to senior citizens. We serve not only individuals with disabilities, but also the general public. In 2013, there were 2,217 visits to our program, which served 290 patients. There were 3,780 visits to our audiology department, which served 2,124 patients.
- Cochlear Implant Services: More than 700,000 people in the
  U.S. have severe to profound hearing loss. WIHD's Cochlear
  Implant Program is offered in collaboration with the Department
  of Otolaryngology at the Westchester Medical Center and is
  the only implant center in the lower Hudson Valley. Twenty-five
  children and adults received cochlear implants.



#### **Behavioral Psychology Program**

Individuals with developmental disabilities are estimated to be 3-4 times more likely than those in the general population to experience an emotional, behavioral, or psychiatric disorder.

The application of behavioral principles to the assessment and treatment of individuals is a well-documented, effective approach for addressing challenging behaviors in individuals with disabilities.

In the Behavioral Psychology Program at WIHD, our team of highly trained psychologists and staff provide behavioral assessment and treatment services related to challenging behavior. We provide training and consultation to caregivers and schools, and generalize these gains to the home and community.

- WIHD serves as the Lower Hudson Valley Regional Center for Autism Spectrum Disorder (RCASD). In 2013, RCASD provided workshops for 177 people, 100 school personnel, 54 community professionals, and 23 parents.
- There were 880 behavioral psychology clinic visits for 50 patients.

# Individuals with developmental disabilities are estimated to be

3-4 times more likely than those in the general population to experience an emotional, behavioral, or psychiatric disorder.

#### ASSISTIVE TECHNOLOGY PROGRAM

Assistive Technology (AT) is any device that helps a person with a disability complete everyday tasks. It includes everything from remote controls and talking software, to hearing aids and typing phones, to wheelchairs and adjustable standers. Our AT program provides a loan program, information and referral services, device demonstrations and training, and school consultations.

- In 2013, our AT staff provided 454 evaluations and/or device trainings for 58 individuals.
- Our Loan Program gives children and adults, free of charge, immediate access to
  equipment through extended equipment loans. It also provides hands-on device
  demonstrations and evaluations for children and adults to determine what type of
  AT best matches their needs. In 2013, we provided 399 device demonstrations to 337
  individuals and loaned 214 pieces of AT to 150 individuals.
- WIHD's AT Program serves as one of twelve regional TRAID (Technology Related
  Assistance for Individuals with Disabilities) Centers for New York serving Westchester,
  Rockland, and Putnam Counties. In 2013, our TRAID Center loaned 364 AT devices to
  294 individuals, and demonstrated 1,131 pieces of AT equipment to 1,604 individuals.
- Our expert staff provides training to health and educational professionals (e.g.,
  graduate students, special education teachers, occupational therapists, speech
  therapists, physical therapists) to ensure better selection, use, and integration of
  assistive technology in home and school environments. Every year, we offer graduatelevel AT courses for Manhattanville College, Concordia College, and Pace University.
   We also lecture at Mercy College, Touro College, and Columbia University.

# our TRAID Center loaned **364 AT devices** to 294 individuals



#### EARLY CHILDHOOD SERVICES

Our Early Childhood Services assist families of children with developmental delays. Our staff helps with the coordination of and access to early intervention and evaluation services.

- WIHD's Early Childhood Direction Center (ECDC) helps families of infants and preschool
  children with special needs find interventions for their children, negotiate school
  systems, and identify federal resources and entitlements. ECDC also provides ongoing
  support and training to Early Childhood professionals in education and social services.
   In 2013, the ECDC provided direct assistance to 581 parents and provided training for
  188 parents, 1,065 special educators, and 207 general educators.
- There are several thousand children aged birth-three in the Early Intervention Program in Westchester County, who have developmental delays and receive services such as speech, physical, and occupational therapy. Each of these children is entitled to service coordination by regulation. WIHD's Family Connection provides families with highly trained service coordination professionals who are valuable sources of information regarding community resources such as housing, childcare, entitlement programs, and mental health services. Our coordinators act as a source of encouragement, help to empower families to work within systems, and advocate for their children. They also help families prepare for the time when service coordination is no longer available to them. In 2013, Family Connection provided coordination for 2,089 children.

In 2013,
Family Connection
provided coordination for 2,089 children.



#### COMMUNITY SUPPORT NETWORK

The Community Support Network (CSN) provides information, practical help, support in system navigation, and a place where people with intellectual and developmental disabilities (I/DD) and their families can get answers to their questions. It is staffed by individuals with disabilities and family members of individuals with disabilities.

- The Special Education process can be intimidating to some families; this may lead to misunderstanding and result in poor outcomes. WIHD's Special Education Parent Center (SEPC) is a resource for parents of children with disabilities in the seven counties of the Lower Hudson Valley (Westchester, Rockland, Orange, Putnam, Ulster, Dutchess, and Sullivan) providing educational materials, training, workshops, and individual consultation regarding the special education programs. In 2013, our SEPC provided 1,550 consultations to parents, 645 consultations to professionals and hosted conferences for 1,765 individuals and educators.
- Our Parent-to-Parent Program provided 102 families of children with I/DD with information about community resources and emotional support.
- WIHD is creating a more effective path for housing for people
  with I/DD. There is a pressing need for affordable, accessible
  housing for people with I/DD. The CSN is helping to meet that
  need by developing a Housing Resource Guide to provide
  information and resources concerning entitlements, eligibilities,
  housing alternatives, and individualized living options.
- Emergency Preparedness: My Safety, My Responsibility, My Plan is
  a multi-session program to train adults with I/DD to understand
  and be prepared for emergencies. A Personal Emergency Plan
  is developed for each person. A Family Edition of this program
  is also available. In 2013, we provided direct emergency training
  for 100 adults with I/DD and 45 families.

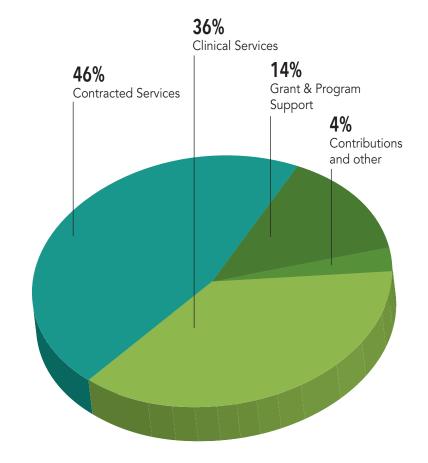
- Project SEARCH serves people with disabilities through an
  innovative workforce and career development model that
  benefits the individual, workplace, and community. The High
  School Transition Program is a one-year internship for students
  with disabilities in their last year of high school, whose goal is
  competitive employment. In 2013, 15 students participated in
  Project SEARCH and 10 prior year students found employment.
- Through Medicaid Service Coordination and Consolidated Supports and Services, WIHD provides Medicaid Service Coordination using a person-centered model to optimize selfdirection, and offers both start-up support and brokerage for New York State's Consolidated Supports and Services Program.
   In 2013, we provided direct service coordination to 140 families and technical assistance to 250 professionals and families.



## 2013 FINANCIAL REPORT

#### **TOTAL REVENUE - \$17,437,559**

- CONTRACTED SERVICES | 46%
- CLINICAL SERVICES | 36%
- GRANT AND PROGRAM SUPPORT I 14%
- CONTRIBUTIONS AND OTHER 1 4%







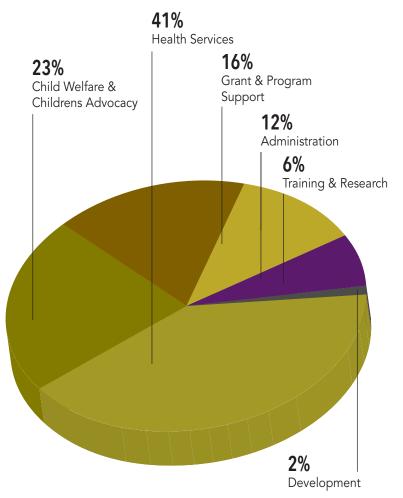
CHILD WELFARE AND CHILDREN'S ADVOCACY I 23%

GRANT AND PROGRAM SUPPORT I 16%

ADMINISTRATION I 12%

TRAINING AND RESEARCH | 6%

DEVELOPMENT I 2%



#### Our Margin of Excellence: The Role of Philanthropy at WIHD

AT WIHD, PHILANTHROPY IS WHAT MAKES THE DIFFERENCE BETWEEN A GOOD AND A GREAT CENTER Funding from grants, contracts, and clinical fees provide only basic support for clinical services, professional training and education, community training and consultation, and research and dissemination. Private support is required to truly achieve excellence and provide leadership in promoting healthy and inclusive lives for people with disabilities and vulnerable children. Private funding allows WIHD to attract and retain the best and brightest faculty, staff, and trainees; to offer the highest quality, evidence-based services in state-of-the-art facilities right in our community; to conduct innovative, cutting-edge research; and to expand our reach throughout the county, state, and country.

#### **Child Welfare Initiative**

RENOVATING THERAPEUTIC SPACE FOR FOSTER CARE CHILDREN AND THEIR FAMILIES

By the time children are removed from their home and placed in foster care, they have already experienced significant trauma that has impacted their ability to function in the world. WIHD helps more than 300 children per year to make sense of the experiences that led them to be placed in foster care, and supports their families as they begin the healing process. Presently, WIHD's staff experts use eight outdated rooms to provide therapeutic intervention to foster children and their parents. Children in foster care deserve a space that is created especially to meet their needs and that sends a powerful message that we recognize the potential within each of them to have a better future.

#### **Assistive Technology Initiative**

BUILDING CAPACITY TO MEET THE NEED Assistive technology can be the key to healthy development, learning, and independent living. In the lower Hudson Valley options for assistive technology resources are limited. WIHD's Assistive Technology Program provides technology solutions to over 1,600 children and adults each year, and trains professionals in over 35 school districts to provide optimal access to learning experiences for children with disabilities. It has ensured that 55 individuals who are blind or visually impaired became competitively employed. But these programs and services only scratch the surface. Our goal over the next three years is to at least double both the number of people reached with assistive technology solutions and the number of professionals and family members trained in using assistive technology.

#### **Health Care Initiative**

BETTER HEALTHCARE FOR ADULTS
WITH COMPLEX DISABILITIES
Adults with developmental disabilities
often have chronic health conditions
and less-favorable health outcomes than
people who do not have disabilities. WIHD
wants to change that. That's why we're
expanding our primary care health services
to create a medical home for the more than
5,000 patients we see each year. We're
renovating our facilities to create a patientcentered, family friendly environment.
We're expanding access to our clinicians
by providing more evening hours and a
24/7 on-call service.

Private **Support** is required to **truly** achieve **excellence**...

## LEVEL OF GIVING-ANNUAL REPORT LISTING

The support that we get from our generous donors makes all the programs at WIHD possible. This list acknowledges all the contributions made in the fiscal year 2012-2013. We at WIHD would like to thank you for your support ensuring that we can continue our work servicing the community.

OVER \$25,000 IN GIVING

Anonymous

\$10,000 AND OVER

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The WIHD Community Advisory Committee is appointed by the Board of Directors for their knowledge and dedication, and includes individuals with disabilities, family members, representatives of State protection and advocacy systems, developmental disabilities councils, state service agency directors, local agencies, private nonprofit groups concerned with providing services for persons with developmental disabilities, and other individuals with expressed interest in the field. Appointment terms are three years. Every other year, the Committee elects a Chair and Vice-Chair for a two-year term. The full Committee meets regularly at least four times per year, and the Executive Committee meets more frequently as needed.

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