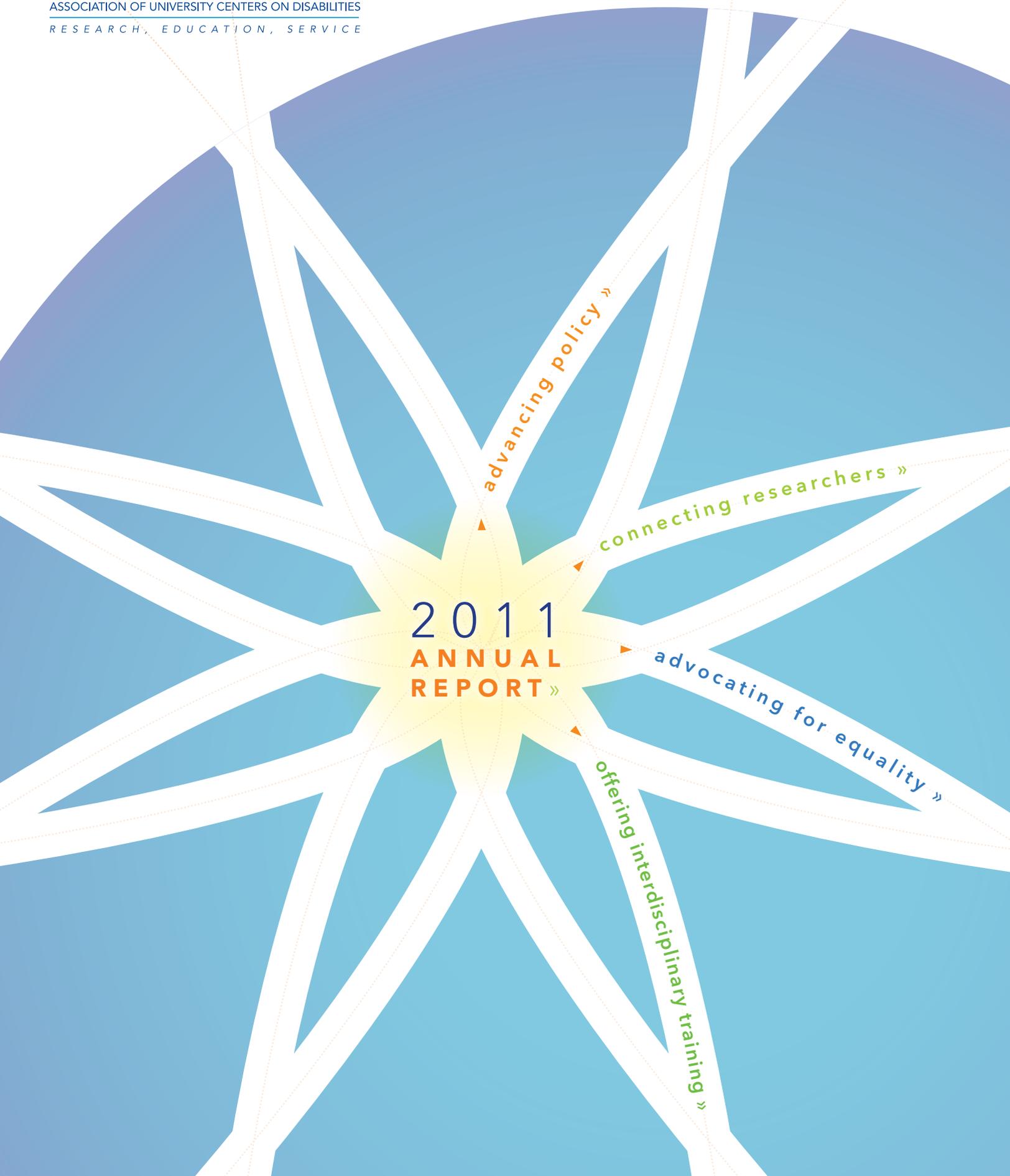




ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH, EDUCATION, SERVICE

Annual Report July 1, 2010 – June 30, 2011



2011
ANNUAL
REPORT »

advancing policy »

connecting researchers »

advocating for equality »

offering interdisciplinary training »

AUCD supports 67 UCEDDs (University Centers for Excellence in Developmental Disabilities), 43 LENDs (Leadership Education in Neurodevelopmental and related Disabilities Programs), and 15 IDDRCs (Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers).

It's happening all around the world: individuals with disabilities and their families are finding resources, speaking up, and gaining recognition. With each successive generation of advocates, parents, trainees, faculty, and researchers, the disability rights movement is moving forward—working to improve lives and make society more open and accessible to everyone.

As always, the Association of University Centers for Disabilities

stands with its national network of member centers to promote initiatives that train leaders, aggregate critical resources, and disseminate practices and information that support people with disabilities—all so that they can live self-determined lives. Through partnerships and the coordinated efforts of professionals, family members, and self-advocates, AUCD has made a marked difference in the lives of people with disabilities and their families in 2011.

moving

To learn more about AUCD, contact an AUCD member Center, or access resources on developmental disabilities, public health, policy, and more, visit www.aucd.org or contact aucdinfo@aucd.org.

AUCD's mission is to advance policy and practice for and with people with developmental and other disabilities, their families, and their communities by supporting our members in research, education, and service activities that achieve our vision.

Self-Advocates Speak

Melody Cooper is assertive. And that's exactly what you want in a self-advocate—someone who is confident and conscientious and, when necessary, won't take *no* for an answer.

But Cooper wasn't always so self-assured.

"It took me a long time to figure out [how to self-advocate], but now it's a piece of cake," she says.

This determination is evident in Cooper's dual roles as the Arc of Indiana's Self Advocate Employment Specialist and president of Self Advocacy Indiana (SAI).

"For years, I thought there was no life for me," Cooper says. "Now I have everything I want. If I can have that life, you can too."

But even someone as put-together as Cooper can use some additional support—especially when she's part of a burgeoning civil rights movement. That's why AUCD helped to pilot five, regional self-advocacy summits in 2011. These meetings allowed self-



lead," Commissioner Lewis says.

Self Advocates Becoming Empowered (SABE), AUCD, National Association of Councils on Developmental Disabilities (NACDD), and National Disabilities Rights Network (NDRN) received funding for these summits from ADD. AUCD played a coordinating role, working with state and national developmental disability and self-advocacy organizations.

With a head full of ideas and a heart full of passion, Cooper is ready to get started implementing the ideas that sprang from the summit—as well as searching for even more ways to inform and encourage. She's thrilled to be entering into her second year as president of SAI.

"I can't believe a whole year has gone by," she says. "I'm ready for another."

That's a good thing, because these summits? They were just the beginning.



forward ▶

advocates and professionals to share success stories and brainstorm ways to raise awareness, promote accessibility, and develop leadership and partnerships.

"To listen to some of the things we all had to say—that's what we wanted and needed," Cooper says.

She attended the two day summit in Ohio, but there were others in Georgia, California, Missouri, and Rhode Island. Attendees represented 30 states, each of which sent a team of 9 to 12 self-advocates and professionals.

The summits were designed to give primary voice to self-advocates, and each produced creative recommendations to promote and enhance self-advocacy. Attendees worked as cross-disability teams to review what their states were doing well and generate ideas to improve and expand self-advocacy.

Hosted by the Administration on Developmental Disabilities (ADD), Commissioner Sharon Lewis attended each summit to hear the feedback and to talk with self-advocates and disability partner organizations.

"We all know—whether we are talking about service providers, individuals who work for the government, family members, or individuals working for network entities—that we all benefit when self-advocates have an opportunity to design the policies, design the service systems, and most importantly,



The 2011 summits helped build an active network of self-advocates across the country. More summits are planned for 2012.



5 self-advocacy summits in 2011
30 states represented
351 participants

At the summits, participants agreed to take the following actions:

- **Strengthen self-advocate initiatives**
- **Promote inclusion**
- **Educate others about disability issues**
- **Address policy issues, including education, employment, transportation and community services**
- **Write self-advocacy initiatives into the Developmental Disabilities Act**



As a developmental pediatrics fellow, Stephanie Blenner, now a developmental pediatrician at Boston Medical Center, knew she wanted to be a strong advocate for those with developmental disabilities.

“LEND training has helped immensely in transitioning into faculty positions, first at the Center for Development and Disability at the University of New Mexico and now at Boston Medical Center/Boston University School of Medicine,” Blenner says. “I have been able to contribute to statewide advocacy groups in both states, largely due to the skills I learned through LEND.”

Employers are recognizing the importance and need for interdisciplinary training of the future workforce. Through AUCD’s advocacy efforts, LEND training programs have expanded over the past several years, growing in both the number of programs around the country and the number of trainees they attract. This expansion comes at a critical time, as the research, professional training, and clinical services provided by LEND and Developmental Behavioral Pediatrics (DBP) training programs are needed more than ever to address the rapid growth of children diagnosed with autism spectrum disorders and other developmental disabilities.

Growing Great Leaders

When Aaron Bishop’s advisor suggested that he consider Leadership in Neurodevelopmental and Related Disabilities (LEND) training, he thought, “Why not?” What the University of Wisconsin student didn’t know was that the program would change his life.

“Being a part of LEND was one of the best experiences of my life,” he says. “It all boils down to two words: civil rights.”

Bishop didn’t know very much about developmental disabilities at the time. But by the third week of training—where he learned about the challenges faced by people with disabilities and their families—he was hooked.

“I wanted to become a part of the movement,” he remembers. “It was an awakening. I wasn’t aware of the discrimination that people with disabilities face on a daily basis.”

In fact, Bishop has played an important role in the movement. After graduating with a master’s degree in social work, he went on to work as a staff member for the US Senate’s Committee on Health, Education, Labor, and Pension. Today, he’s the Executive Director of the National Council on Disability.

By preparing professionals in a wide variety of disciplines, LENDs help promote good practices and a solid understanding of those who have or are at risk of developing developmental disabilities. A focus on interdisciplinary education, family-centered, and culturally competent care, and community partnerships fosters best practices and exceptional leadership.



Like Bishop, Blenner’s training benefits her community. And she’s actively paying it forward, as a faculty member in a DBP training program.

“Medical training teaches you how to come to thoughtful conclusions as a professional in concert with a patient in an individual circumstance,” she says. “LEND teaches you that the big issues in our field can only be addressed by working together with others and then provides the tools and framework to begin contributing on a systemic level.”

In 2011, AUCD member LEND and UCEDD training programs continued to produce leaders in the field, who put their newfound knowledge to work in ways that make a difference in their communities. In addition, AUCD supported research, publications, and clinical and demonstration services.

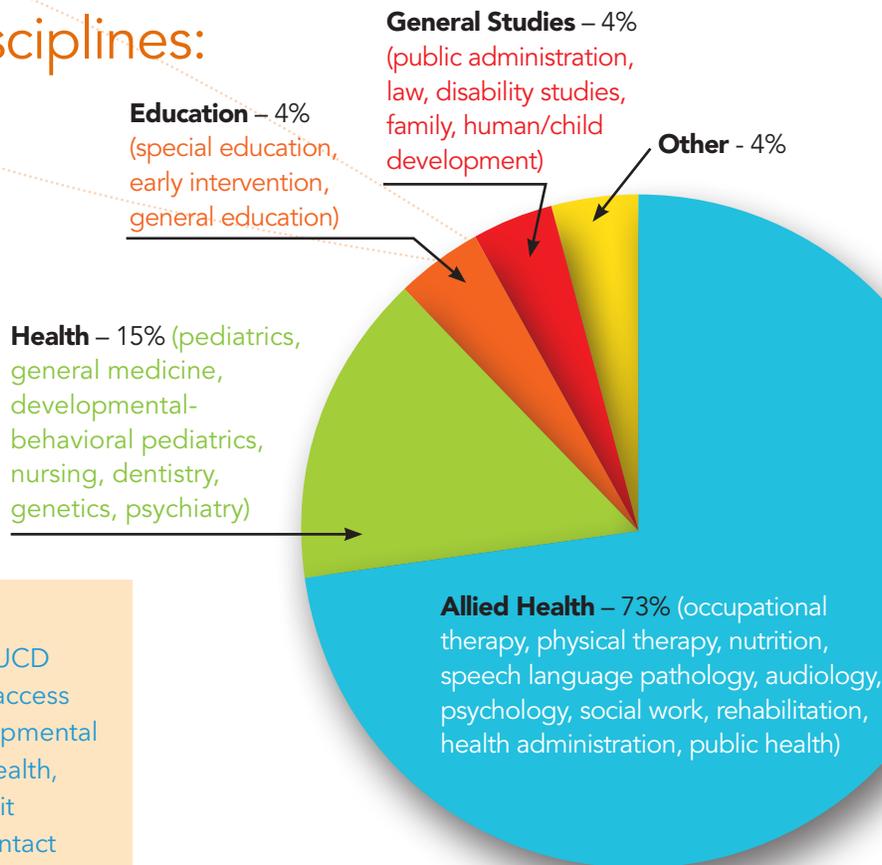
Together, AUCD's 43 LENDs and 67 UCEDDs produced:



- 287** courses
- 1,203** projects with a research component
- 2,096** articles in peer-reviewed journals
- 6,054** trained professionals
- 44,102** infants and children received interdisciplinary diagnostic services through LEND programs to confirm or rule out ASD or DD.
- 60,273** infants and children were screened through LEND programs for autism spectrum disorders (ASD) or other developmental disabilities (DD).
- 480,164** clinical and demonstration services

- 82%** of trainees who graduated 5 to 10 years ago are now in leadership positions
- 56%** in academic leadership
- 48%** in clinical leadership
- 25%** in public health leadership
- 28%** in public policy and advocacy leadership

Trainee Disciplines:



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Partnering for Public Health

“Public health is all about partnerships.”

That’s how Ismaila Ramon sees his work as an AUCD Surveillance and Epidemiology Fellow with the Centers for Disease Control. In fact, developing alliances is the underpinning of AUCD’s cooperative agreement with the CDC National Center on Birth Defects and Developmental Disabilities (NCBDDD). As a fellow, Ramon is able to work within a triangle of federal, state, and non-governmental organization services and policy makers.

“The AUCD network anchors these partnerships,” Ramon explains. “It’s such a rich network, which means I have access to a whole lot of resources.”

The fellowship allows graduate, post-doctoral, and mid-career professionals who are enrolled or employed at AUCD member programs to further their professional development through direct training at NCBDDD. In a marriage between the center’s and the fellows’ interests, all parties benefit, providing support for three initiatives: “Learn the Signs. Act Early.”, surveillance and epidemiology, and developmental disabilities.

But the partnerships don’t stop there. Fauzia Malik, a physician assistant working as the education and outreach program manager for Envision New Mexico’s Developmental Screening Initiative, is also an Act Early Ambassador with AUCD.

“Being an Ambassador mirrors my objectives in my job,” she says. “But it allows me to do more than I could.”

Having access to “Learn the Signs. Act Early.” materials is critical at a time when states are cutting funding. “With these materials, I can show families how to get the resources they need,” Malik says.

AUCD also provides public health and disability research opportunities and helps translate research findings into action. Sixteen Research Topics of Interest and three Collaborative Researcher Awards were facilitated over the last year.

In addition, AUCD provides technical assistance to the 16 State Disability and Health Grantees awarded by NCBDDD for preventing secondary conditions and promoting the health of people with disabilities. With this technical support and its national meeting of more than 120 disability and health experts, the association aggregates input from grantors and key partners.

The result? More partnerships and an even greater commitment to serving those with disabilities and their families.

“My experience as an Act Early Ambassador has definitely influenced where I am today,” Malik says.

And the feeling is mutual.



In partnership with NCBDDD, AUCD has been a leader in integrating disability issues in public health:

- Coordinated **21** Research Topics of Interest on topics ranging from early identification to Fragile X to reaching underserved families
- Supported **3** AUCD fellows at the CDC’s National Center on Birth Defects and Developmental Disabilities (NCBDDD)
- Supported **3** Collaborative Research Awards to emerging scientists to conduct public health and disability research for NCBDDD
- Provided technical assistance to **16** State Disability and Health Programs
- Supported **10** Act Early Ambassadors working in their states to promote early identification of autism and developmental disabilities



AUCD contributed to a variety of initiatives throughout the country.

- *Through an MCHB contract, AUCD worked with and supported 11 audiology programs, focusing on training new pediatric audiologists to meet the growing need to screen and treat infants with hearing loss.*
- *Through funding from ADD and a sub-award from the Institute for Community Inclusion, AUCD promoted the involvement of UCEDDs in developing postsecondary education opportunities for students with developmental disabilities.*
- *AUCD joined with the Gateway to Self-Determination at the University of Missouri and other UCEDD partners to develop and disseminate materials on self-determination.*
- *AUCD partnered with the National Service Inclusion Program funded by the Corporation for National Service to facilitate the full integration and participation of individuals with disabilities in community service opportunities.*



FINANCES

The economy has been troubled, but AUCD's finances are solid. Despite tough economic news in 2011, AUCD pushed forward in its commitment to members. Instead of cutting back on programs, AUCD launched several new projects and initiatives while expanding others.

In 2011, AUCD's numbers remained strong:

*Total revenue and support: just under **\$7.7 million**
From grants and contracts: about **\$6.9 million**
From membership fees: about **\$600,000***

*Total expenses: Just over **\$7.4 million**
Contracts and consultants: about **\$4 million**
Salaries and benefits: about **\$2 million**
Travel and Conferences: about **\$500,000***

*Net assets grew 22% or about **\$275,000** over last year.*

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AUCD teamed with coalitions and partner organizations to promote the inclusion of disability concerns in these policy areas:

- Affordable Health Care Act
- Family support
- Combating Autism Act reauthorization
- Workforce Investment Act
- CLASS Act
- Postsecondary Education Act
- Lifespan respite
- Medicaid and Medicare funding
- Long-term services and supports
- Disability program budget appropriations
- Convention of the Rights of Persons with Disabilities
- Health disparities
- Preventing harmful restraints and seclusion



Ongoing Research

It's a big acronym with big responsibilities. The Eunice Kennedy Shriver IDDRCs (Intellectual and Developmental Disabilities Research Centers) were established by Congress in 1963 to promote biomedical and behavioral research. AUCD has fifteen member IDDRCs who receive P30 core grant funding. Each IDDRC supports 40 to 100 research projects, in fields like chromosomal conditions, biochemical processes, and metabolic issues. Eight of these are co-located in universities with UCEDDs or LENDs, allowing them to quickly and efficiently share research results nationwide.



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