



# Highlights: Annual Report

Maryland  
Developmental  
Disabilities  
Council

*A Message from*  
THE MARYLAND DEVELOPMENTAL DISABILITIES COUNCIL

Dear Friends and Colleagues,

This is the Council's annual report for our federal fiscal year 2009, which covers the period October 2008 through September 2009. This report is appropriately called Highlights because we are not able to report on everything the Council is engaged in or accomplished through our work and the projects we funded. Rather, we have attempted here to provide a snapshot of projects and initiatives the Council funded and activities and advocacy directly undertaken by Council members and staff, including outcomes. Our work includes issues that cover the lifespan.

As this report illustrates, our mission is to bring about lasting systemic change and build sustainable capacity in the community to support people with developmental disabilities and their families in all facets of life. We do this through education and advocacy, supporting people with developmental disabilities and their families to speak for themselves both individually and collectively, and by investing in promising and innovative ideas and initiatives.

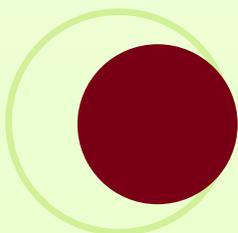
We want to acknowledge the many individuals with disabilities, family members, advocates, policymakers, and organizations that we partnered with to bring about needed change this past year. We look forward to building on those relationships.

Many challenges remain that demand our attention. We will continue to work with our partners on these and other critical priorities with a continued sense of urgency.

Sincerely,

*Liz Weintraub*  
Chairperson

*Brian Cox*  
Executive Director



*Many challenges remain that demand our attention.*

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## OUR VISION

The Council believes that all people with developmental disabilities should receive the support they need to maximize independence, be productive, and lead the lives they choose in the community. Practices that segregate and isolate people with disabilities must end.

## OUR MISSION

The Maryland Developmental Disabilities Council is a public policy organization that advocates for the inclusion of people with developmental disabilities in all facets of community life.

## TO ACCOMPLISH OUR MISSION THE COUNCIL:

- Educates and informs policymakers about issues of importance to people with developmental disabilities and their families.
- Advocates for services, policies and practices that support people with developmental disabilities to exercise self-determination and lead productive, fulfilling lives.
- Designs and funds innovative projects that promote community inclusion and improve services and supports.
- Focuses on bringing about lasting improvements in the areas of: education and early intervention, child care, employment, transportation, community supports, recreation, housing, health, and quality assurance.

The majority of Council Members are people with developmental disabilities or family members of people with a developmental disability. One member is a person or a family member of a person once or now institutionalized. The Council includes representatives from state agencies, the Protection & Advocacy System (Maryland Disability Law Center) and the University Center on Excellence in Developmental Disabilities (Maryland Center for Developmental Disabilities). Other Council members include representatives from local agencies and non-profit organizations that provide services and supports to people with developmental disabilities.

*WORKING FOR COMMUNITIES THAT INCLUDE AND SUPPORT EVERYONE.*

## FROM INSTITUTIONS TO COMMUNITY

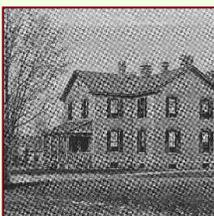
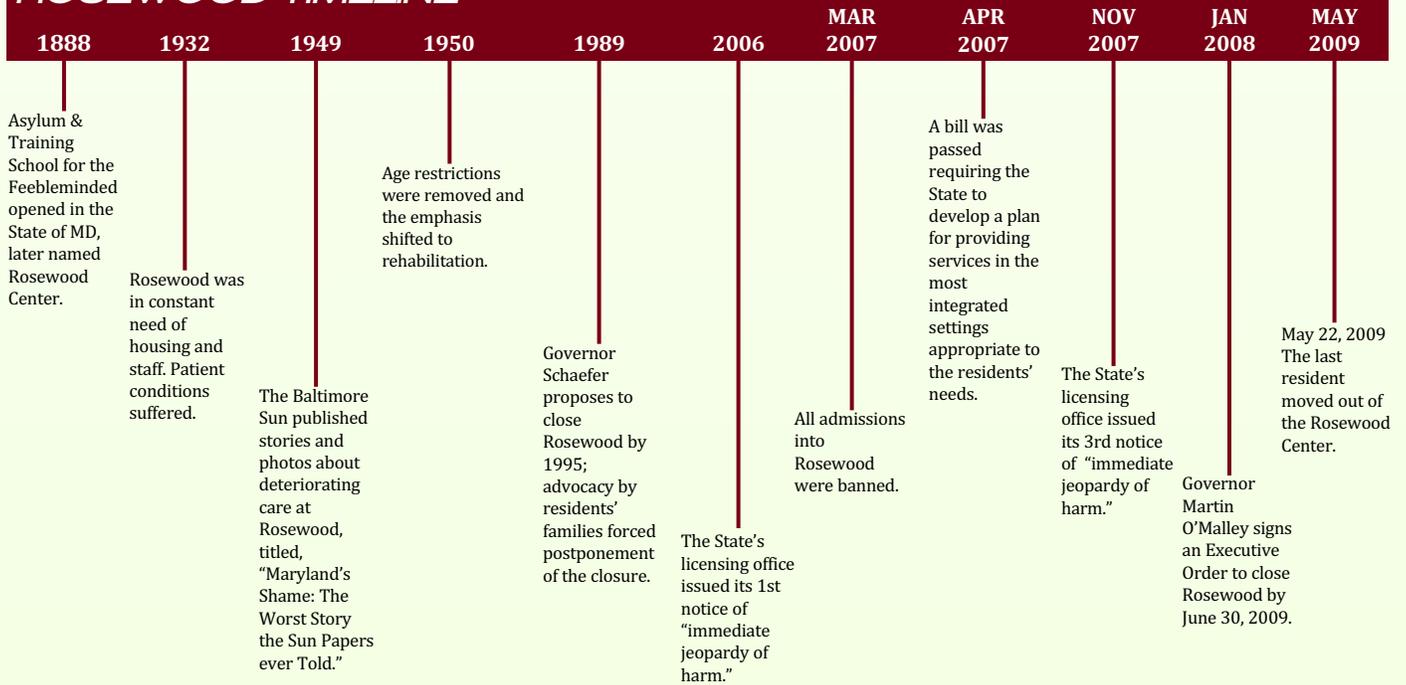
### *Rosewood Center Closed!*

After two decades of advocacy by the Council and many other organizations and individuals, Maryland's largest institution for people with intellectual disabilities, Rosewood Center, closed on May 22, 2009. Eleven people moved to a new forensics facility, 2 to a nursing facility and 148 into the community. This long sought outcome was roundly celebrated by disability rights activists.

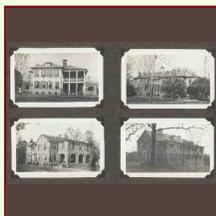
Related activities and outcomes in 2009 included successfully advocating for limitations on who would go to the forensics facility and advocating for community options to diminish the need for facility-based services. The Council also collaborated with the Developmental Disabilities Administration on a project to inform, support and mentor families of residents in other DDA facilities to encourage them to consider community options.

Realizing that there is much to learn from the closure of Rosewood as many people remain institutionalized in Maryland and throughout the nation, the Council began the development of a documentary and a publication. These will be used to educate the community, legislators, families, the press and others. The Council provided seed funding for the documentary about the closure of Rosewood and secured additional funding needed to complete the production. The Council is also funding and coordinating the production of a publication that will feature compelling stories and pictures of a diverse group of people who left the Rosewood Center to live their lives in the community. The publication and documentary will be complete in 2010.

### ROSEWOOD TIMELINE



1888



1932



1950



2006



2007



2008

## BRIAN'S STORY

"Give me a kiss," his mom, Alyce, would say, and Brian would lean his head forward to receive her kiss - a gesture which evolved into a gentle tapping of heads to show affection.

Born in 1952 with an untreatable metabolic disorder and autism, Brian moved into Rosewood at age 13. He lived there for the next 43 years. Alyce made the long drive to visit him every month.

At Rosewood Brian retreated into himself. Blind, he also lost the use of his legs and hands, and was increasingly unresponsive. "Rosewood lacked the right kind of staff and attitude to rehabilitate him," His sister, Judy, notes. His weight shrank, necessitating a feeding tube.

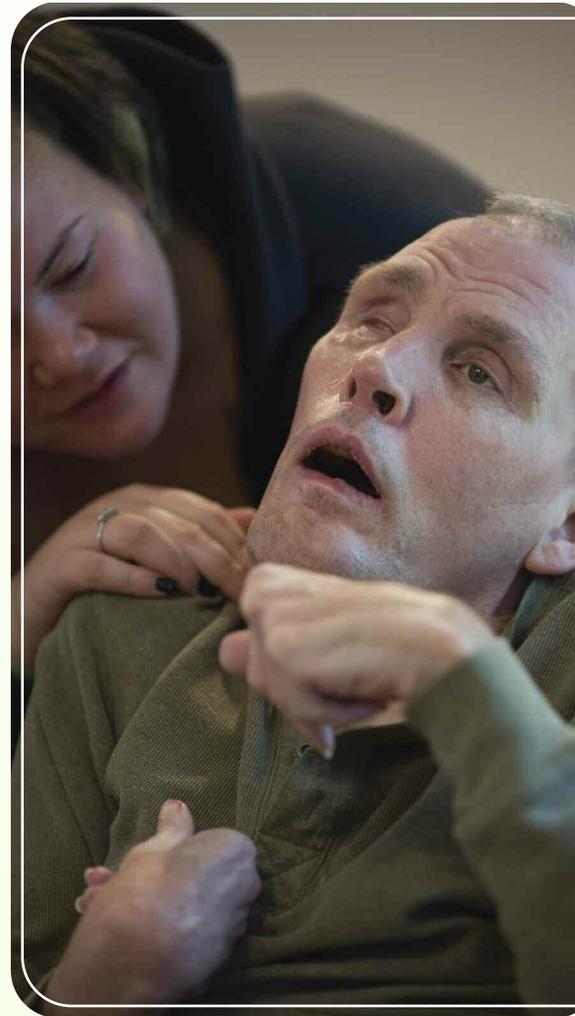
Alyce continued to visit her son until she died in 2006. She believed the institution was the safest place for Brian, and opposed its closing. Judy had agreed with her mother for many years, but gradually she saw new possibilities.

In the summer of 2008, Brian moved into a house with three housemates and support staff. There, Brian has come to know what Judy calls the "blessing of smallness." Judy praises a dedicated direct support staff and an overall philosophy for positive changes in Brian's life.

"The staff excels in their ability to study him," Judy explains. "They're learning to read him, to crack the code of Brian."

"Brian has choices now," Judy says. "And more of a life." He can eat the food he prefers, and he has put on some much needed weight. He can walk a little around the house. He recently took a road trip, went fishing, and took a dip in the ocean for the first time in his life.

"Brian is so much more responsive than when he arrived," says his support staff. "He has begun to smile and reach for my hand, and he does this funny, affectionate head tap with me."



Photography by Jennifer Bishop



## INCREASING ACCESS TO COMMUNITY SUPPORTS

### *Waiting List Education & Advocacy*

Increasing the availability of essential community services and supports for people with developmental disabilities and their families remains one of the Council's top priorities. In 2009 our work on this issue included educating policymakers about the need for significantly more funding to reduce the Developmental Disabilities Administration's waiting list and the impact of specific approaches like increasing Maryland's alcohol tax as a dedicated revenue source. The Council engaged the help of a media consultant and co-sponsored an independent public opinion survey that found that 75% of those surveyed would favor a five-cent per drink increase in the alcohol tax to fund services for people with developmental disabilities.

Education and advocacy strategies also included:

- The EndTheWaitNow.com website featuring fact sheets, waiting list stories and videos, FAQs and opportunities to get involved.
- Serving on DDA's Waiting List Advisory Committee and advocating for fair and effective policies and practices that impact how people's needs are accounted for and addressed.
- Increasing Council support of the End the Wait Now! Campaign to develop cohesive strategies and implement more grassroots activities and outcomes.



### *End The Wait Now! Campaign*

The Arc of Maryland is managing this advocacy campaign in collaboration with the Council and other developmental disabilities coalition member organizations. The ETWN Campaign, a viable force for change, empowers people with developmental disabilities, their families, and other advocates to tell their stories, demand attention, offer solutions and seek support for Waiting List funding.

In 2009, the ETWN Campaign increased membership to 1600 and:

- Delivered 18 waiting list stories to all legislators;
- Testified at bill hearings in support of funding for the Waiting List;
- Held four local meetings with legislators and a Town Hall meeting attended by 85 people;
- Participated in a press conference and a rally that were covered by TV stations and newspapers; and
- Worked with Loyola College where students wrote Waiting List stories, contacted legislators and the Governor, and produced YouTube videos. [www.endthewaitnow.com](http://www.endthewaitnow.com)

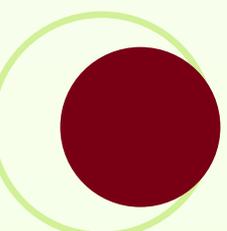
## EXPANDING FAMILY RESOURCES AND SERVICES

### *Advocating for Quality Child Care Standards*

The quality of a child care program is tied to the ability of the program to provide appropriate services and supports to all children, including those with disabilities. In support of this, the Council worked with MSDE's Department of Early Childhood Development and Office of Child Care to begin to develop a comprehensive Quality Rating and Improvement System (QRIS). The Council is working to ensure that the QRIS includes specific requirements that child care programs be both physically and developmentally accessible to children with developmental disabilities and delays and can accommodate their needs. For parents of children with disabilities, an evaluation of the program's ability to provide appropriate services and supports to their child is as important as an evaluation and rating of any other component of the child care program. Our expectation is that this will ultimately lead to more inclusive child care settings where children with disabilities learn and play with their non-disabled peers.

### *Project Include ME*

Project Include Me (PIM) supports the inclusion of children with developmental disabilities and delays in typical child care settings by providing training and equipment, and conducting on-site consultation to licensed child care providers in Wicomico County. Throughout the two year Council grant period, PIM helped maintain 66 children in childcare and trained 16 child care providers about the support and service needs of children with autism, epilepsy and a variety of behavior needs. In June 2009, the Maryland State Department of Education started funding PIM to sustain services in Wicomico County and to expand into Somerset and Worcester Counties. Approximately 100 people from numerous child care providers attended a kick-off event which included training on the ADA and child care settings.



*"Community Works helps our students understand family needs, which will ultimately make them better practitioners. It also enhances family productivity..."*

*Faculty of the Towson University, Occupational Therapy Department*

### *Community Works*

Community Works, a project of the Maggie's Light Foundation, increased the capacity of respite services by utilizing untapped community resources and creating a web-based bulletin for families to connect with college students for respite care. A partnership between Maggie's Light Foundation, Towson University's Occupational Therapy Program and The Arc of Baltimore, the project identified students studying in fields such as Special Education, Speech Therapy and Nursing who were interested in providing respite services for families caring for children and young adults with developmental disabilities. In just one year Community Works expanded its program to Carroll County Community College and is currently working to establish itself at two additional universities. In June of 2009, Community Works received an anonymous contribution of \$50,000 ensuring that the project will continue to educate students and provide families with the care they need after Council funding has ended. [www.maggieslight.org](http://www.maggieslight.org)

### *Family NET Works*

Family NET Works, an in-house initiative of the Council, hosts a resource enriched website for families of children with developmental disabilities. In 2009 the website averaged over 8,000 visitors per month and an interactive list-serve has over 260 members. Parents, advocates and professionals continue to use Family NET Works to share ideas, access resources and provide much needed support. [www.family-networks.org](http://www.family-networks.org)

## ADVOCATING FOR INCLUSIVE EDUCATION PRACTICES

### *Maryland Coalition for Inclusive Education: Accelerating Systems Change*

In 2009, the Maryland Coalition for Inclusive Education (MCIE) empowered parents to make lasting changes to local school systems' policies and practices so more students with disabilities are educated in their neighborhood schools alongside their non-disabled peers. MCIE trained more than 250 parents across the state and worked with parents and the community in Anne Arundel, Montgomery, and Prince George's Counties to increase inclusive practices for their students. Parents in Montgomery and Prince George's Counties were supported to give testimony to their local boards of education on inclusive practices. The advocacy about inclusive education with the Board of Education in Prince George's County led to the establishment of an additional inclusive classroom. [www.mcie.org](http://www.mcie.org)

### *Project Discovery*

Project Discovery continued to utilize an innovative approach, established through this Council grant, to facilitate the transition process for middle and high school students with disabilities in the Howard County Public School System. Project Discovery was a vehicle to partner with families, community agencies and employers to ensure meaningful, individualized transition planning for students with disabilities. Students were supported to develop representation portfolios with a focus on customized employment, self-employment, and/or participation in career training or higher

education. The second year of Project Discovery realized many successes. It expanded access to Howard County Community College classes, programs and services for graduating students and established access to vocational training opportunities for students with more significant disabilities who had been previously denied access. Although Council funding ended, strategies established through this project have been incorporated into policies and practices so more students with disabilities will continue to benefit.

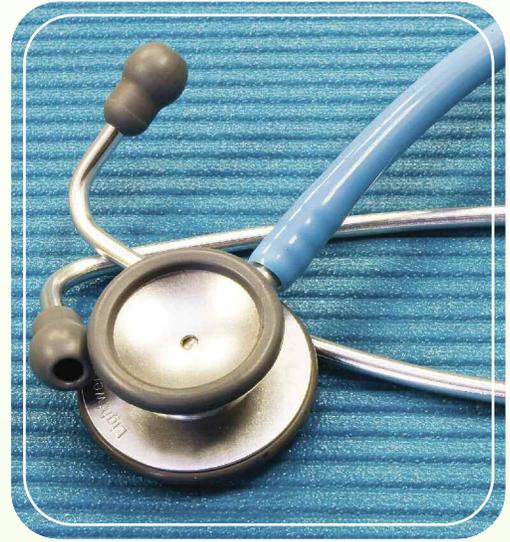


## PROMOTING PROGRESSIVE HEALTH CARE PRACTICES

The Council continues to support three health related projects that address the issues of access to health care, quality of services, training for people with developmental disabilities and health care professionals, and outreach.

### *HOMES Project - Helping Obtain Medicaid Essential Services*

In its second year of the project, the Maryland Disability Law Center (MDLC) continued to make a significant impact by improving access to Medicaid and DDA's community waiver services for people with developmental disabilities. Through its work to remove systemic barriers, MDLC successfully reversed denials of nutritional supplements and the Medicaid Program's failure to permit providers to file appeals on behalf of people when they were denied healthcare services. MDLC is also working to improve coverage for augmentative communication devices and assessments under Medicaid. In its outreach efforts, the HOMES Project disseminated two publications – one for advocates and one for people with developmental disabilities – that provide information on how to access services through Maryland Medicaid. Additionally, MDLC trained 70 self-advocates, 640 professionals, providers, service coordinators and family members, and provided training to 18 attorneys who have agreed to accept pro bono referrals. [www.mdlclaw.org](http://www.mdlclaw.org)



### *Families as Faculty*

Families as Faculty, a project of The Parents' Place of Maryland, provides educational opportunities for medical students, residents, and allied health professionals to learn about the daily lives of children with developmental disabilities and their families. The Parents' Place has partnerships with a public health policy class at Johns Hopkins and two different programs at the University of Maryland—one is for residents going through their Behavioral Pediatrics rotation and the other is with third year medical students in their pediatrics clinical rotation. In the course of this past year, the project arranged home visits with families for 66 students. Students and residents at the University of Maryland rate this experience the highest of their clinical rotations. [www.ppm.org](http://www.ppm.org)

*"The Families as Faculty visit helped me to think about how my decisions have long-reaching consequences for my patients and their families. It taught me to be open and listen..."*

*Tiffany K., resident of the University of Maryland Behavioral and Developmental Pediatrics rotation.*

### *Impact of Consent*

The Impact of Consent Project, an initiative of Resource Connections of Prince George's County, focuses on increasing meaningful participation of people with developmental disabilities in healthcare decision-making. The project offers training for self-advocates about informed consent for healthcare and provides guidance in appointing a Health Care Agent. Healthcare empowerment information is available to families, healthcare providers and support staff to help them understand that intellectual disability does not preclude all decision-making power. In 2010, look for the Impact of Consent website designed for a variety of audiences. [www.rcpgc.org](http://www.rcpgc.org)

## SUPPORTING LEADERSHIP AND ADVOCACY

### *Cross Disability Rights Coalition*

The Cross Disability Rights Coalition (CDRC) is a Council supported self-advocacy group led by people with disabilities. CDRC forged ahead with their commitment to deinstitutionalization by joining the Council and others in strongly advocating for the closure of the Rosewood Center, which finally became a reality in 2009. In addition to other activities, CDRC members developed educational materials regarding the crucial role assistive technology plays in communicating with service providers about a person's wants and needs. The information was presented at three statewide conferences reaching over 150 people. [www.thecdrc.org](http://www.thecdrc.org)

### *Legislative Internship*

The Council has funded the Legislative Internship through People On the Go of Maryland and The Arc of Maryland for five consecutive years. The internship supports a person with a significant developmental disability to work with a Senator during the legislative session. In 2009 People On the Go of Maryland, a statewide self-advocacy group, selected Brent



Debnam to work in the office of Senator Delores Kelley. Brent wrote and presented testimony on 8 bills, prepared and delivered a presentation at Developmental Disabilities Day at the Legislature on removing the term "mental retardation" from Maryland law and participated in a press conference about legislation to raise funds for community services.

### *Small Grants*

The Council's Small Grants are utilized in many different ways to educate and train people with developmental disabilities and their families, support capacity building and systems change, and increase advocacy efforts that promote true community inclusion.

Below is a diverse list of activities for 2009:

- *Autism Society Seminar:* trained 50 people to learn strategies for supporting people with autism in their transitions to adult life.
- *Youth Leadership Forum:* educated 17 high school students about independence, career goal setting and the legislative process, which included visiting with elected officials in Annapolis.
- *Sinai Hospital's Hope conference:* brought together experts in the field of epilepsy, families and caregivers to collaborate on new research, treatment options and patients' rights.
- *PACT: Together Time project:* supported a parenting skills and development program for a diverse group of parents with intellectual disabilities who have young children.
- *The Arc of Carroll County:* provided a free screening of the movie Autism the Musical to 150 people to raise public awareness and promote understanding.
- *MD Respite Care Coalition Annual Conference:* attended by 225 participants who benefited from 12 workshops on topics ranging from grassroots advocacy to challenges for the Hispanic community.
- *MCIE and The Arc of Baltimore:* trained Maryland educators, self-advocates and parents on how to maximize the participation of students with disabilities in their schools and communities.
- *Research Project:* conducted research to improve supported employment practices.
- *High School training program:* staff from a Catholic school visited a high school in South Carolina and gathered resources and materials to expand inclusive educational programs in Maryland.
- *Epilepsy Association of the Eastern Shore:* secured newspaper advertisements and radio announcements to promote positive images of people with epilepsy; an estimated 87,000 people were reached.

## WATCH FOR OUTCOMES FROM MAJOR NEW PROJECTS FUNDED BY THE COUNCIL IN 2010

Five employment projects will help agencies improve the employment outcomes of people with developmental disabilities through customized approaches.

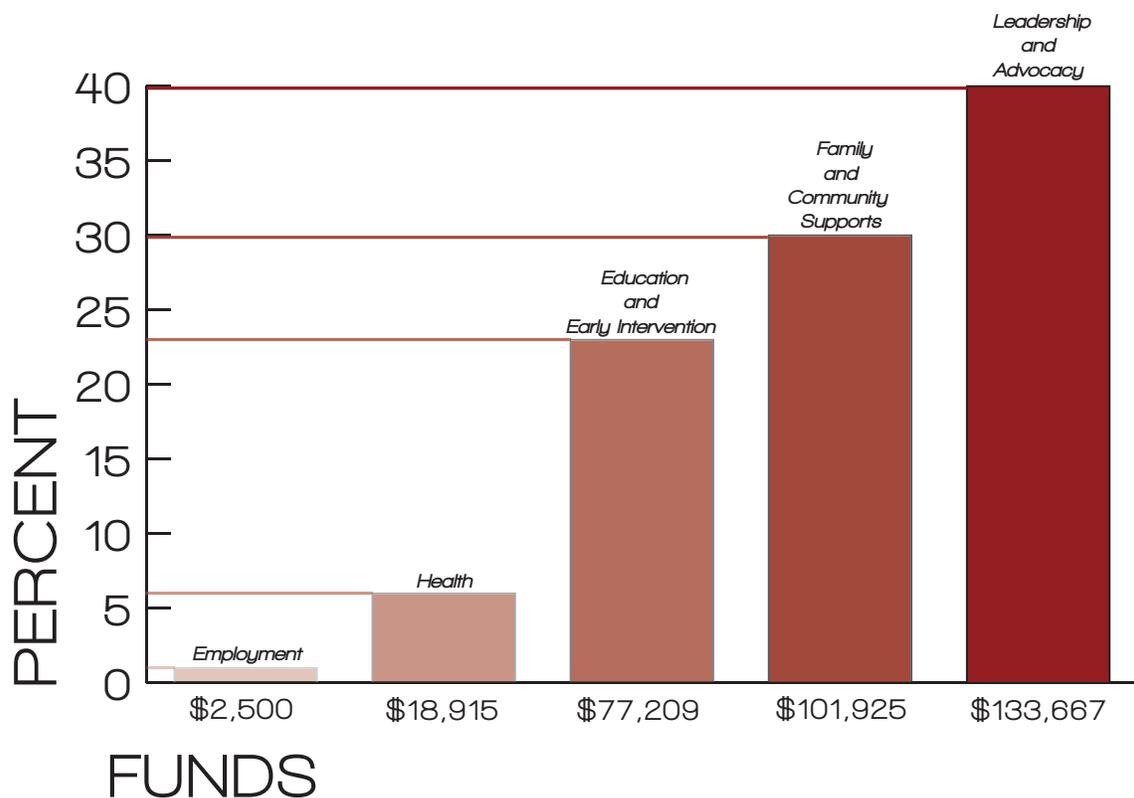
MCIE Maryland Leadership/Action Network will train and support parents to affect change in their communities and the State to support

the full inclusion of students with disabilities in their neighborhood schools.

HER Associates Equal Access to Information and Resources Research Project will result in specific recommendations to improve and/or expand access to information and resources for culturally diverse families living in Maryland. [www.md-council.org](http://www.md-council.org)

## 2009 PROJECT EXPENDITURES

The Maryland Developmental Disabilities Council is funded through a grant authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000. The Maryland Developmental Disabilities Council is 100% federally funded.



**TOTAL PROJECT EXPENDITURES IN 2009: \$334,217**

## Council Members

Liz Weintraub  
Chairperson  
Montgomery County

Tom Webb  
Vice-Chairperson  
Kent County

Carol Ann Baglin  
Represented by  
Karla Saval  
Maryland State  
Department of Education

JoEllen Barnhart  
Washington County

Patricia Bayliss  
Maryland Department  
of Aging

Damon Briggs  
Montgomery County

Eric Lee Cole  
Montgomery County

Eva Cowen  
Montgomery County

Sharon Dockery  
Montgomery County

William DuSold  
Anne Arundel County

George Flamer  
Talbot County

Gail Godwin  
Baltimore City

Angela Harp  
Baltimore County

Polly Huston  
Division of  
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Catriona Johnson/  
Michael Chapman\*  
Developmental  
Disabilities  
Administration

Department of Health  
and Mental Hygiene

Aaron Kaufman  
Montgomery County

Virginia Knowlton  
Maryland Disability  
Law Center

Dawn Koplos  
Anne Arundel County

Joan Lawrence/  
Chris Smith\*  
Maryland Center  
for Developmental  
Disabilities

Wendell McKay  
Howard County

Vicki Mills  
Frederick County

Aileen O'Hare  
Montgomery County

Lynne Pattison  
Frederick County

Grace Pushparany-  
Williams  
Prince George's County

Steve Pyles  
Prince George's County

Tim Quinn  
The Arc of Northern  
Chesapeake Region

Julie Randall  
St. Mary's County

Cathy Raggio  
Maryland Department  
of Disabilities

Jose Sanchez  
Baltimore County

David Schlegel  
Cecil County

Paula Suter  
Baltimore County

Jeri Wasco  
Montgomery County

Robert Watson  
Prince George's County

Jane Wessely  
Department of Health  
and Mental Hygiene

\*Served partial terms

## Council Staff

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Deputy Director

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Policy Specialist

Rachel London  
Director of Children  
& Family Policy

Linda Nelson  
Office Manager

Stephanie Watkins  
Family NET Works,  
Resource Specialist

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