MARYLAND DEVELOPMENTAL DISABILITIES COUNCIL

highlights 2014

ANNUAL REPORT

empowerment

opportunity

inclusion

Working so that people with developmental disabilities are included in all facets of community living

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Dear Friends and Colleagues,

Eric Cole

With a host of critical issues demanding attention in 2014, the Council forged new partnerships, invested in promising new initiatives and implemented new strategies advancing progress on a range of priorities in support of our vision and mission. We are pleased to share with you the year's progress and successes. Here are just a few elaborated on in this issue of Highlights:

- Promoted systems change by helping service providers move from facility based to community based supports
- Helped build capacity by advocating for a new mandate that all 14,500+ childcare providers in Maryland will receive training in the ADA and inclusion
- Generated momentum supporting a growing self-advocacy movement

Not all of our work culminates in a completed outcome within one year's time. Much of our work marks the milestones of a long run that began in the 1970's with the passing of the federal Developmental Disabilities Assistance and Bill of Rights Act. This long run is intended to ensure that Marylanders with developmental disabilities of all ages are fully engaged in the community with the same opportunities most people without disabilities enjoy: finding purpose in work, school, leisure…. life… while finding opportunity to form true bonds of friendship and of intimacy.

We invite you to learn more about these milestones in this issue, including our public policy work and the accomplishments other organizations have made through support of the Council's grant funding.

The Council would not be effective without the support of partnerships with organizations and individuals. Really, Highlights is a celebration of what we have accomplished, together.

"We are excited by the opportunity to build on growing collaborative partnerships, bringing new ideas and strategies to solve challenging problems by asking: 'What is possible?'"

— Brian Cox

Sincerely,

Eric Cole, Chair person

Brian Cox, Executive Director

MARYLAND DEVELOPMENTAL DISABILITIES COUNCIL

OUR VISION:

The Maryland Developmental Disabilities Council envisions a state where all people with developmental disabilities exercise control over their lives, reach their full potential, and lead healthy, fulfilling lives with enriching relationships.

OUR MISSION:

The Maryland Developmental Disabilities Council's mission is to advance the inclusion of people with developmental disabilities in all facets of community life by eliminating barriers, creating opportunities, empowering people, and promoting innovation.

TO ACCOMPLISH OUR MISSION THE COUNCIL:

- Educates and informs policymakers about issues of importance to people with developmental disabilities and their families. Advocates for policies, practices, laws and services that support people with developmental disabilities to exercise control over their lives, reach their full potential, and lead productive, meaningful lives.
- Designs & funds initiatives that increase community inclusion, improve services and supports, and increase opportunities for people with developmental disabilities to pursue their hopes, dreams and aspirations.
- Promotes innovative approaches to supporting people to live, learn, work and enjoy community life.
- Advocates for the elimination of barriers that create separation and segregation and limit opportunities for full inclusion and community participation.
- Raises public awareness about people's contributions and capabilities so differences are respected, attitudes change, and inclusion and equality become an expectation.
- Supports people with developmental disabilities and their family members to develop advocacy and leadership skills to affect change in their own lives and the lives of others.

The Council works in partnership with people with developmental disabilities and their families, as well as other individuals and organizations, to bring about lasting change. We develop a five year State Plan that establishes our priorities and serves as a roadmap for accomplishing our goals.

WHO WE ARE:

A small staff working on behalf of the Council to carry-out our mission and address the priorities and goals established in the Council's Five-Year State Plan. The Maryland Developmental Disabilities Council is part of a national network of DD Councils.

Just shy of 600 people attended DD Day at the Legislature with one participant commenting, "I would only wish it could get bigger and stronger and even more vocal."

ADVOCACY

DD DAY AT THE LEGISLATURE

Developmental Disabilities Day at the Legislature 2014 was a rousing success. This premier annual legislative event, co-sponsored by the Council in collaboration with the DD Coalition, drew record attendance limited only by the size of the venue. More than half of attendees were people with developmental disabilities and family members. The theme was "**Respect**," and the day began with recognition of students from two elementary schools that won a "**Together We're Better**" contest highlighting school inclusion. This brought new energy and broader attention to DD Day. Lt. Governor Anthony Brown addressed the gathering and spoke about accomplishments and unfinished business. Following a legislative briefing, participants responded to a "call to action" by meeting with their legislators to share personal stories and advocate for needed funding and passage of priority legislation.

Aaron Kaufman, a member of the DD Council and Public Policy Specialist for The Arc of Maryland, addresses the crowd.

LEGISLATIVE SESSION

During the **2014 legislative session** the Council followed 60 priority bills and monitored another 114 bills for their impact on people with disabilities and their families. Council members and staff testified at key budget and bill hearings and provided written testimony on a variety of other bills dealing with issues like services for children, healthcare and housing. Using a range of educational and advocacy strategies, we helped legislators make informed decisions that will have a positive impact on people with developmental disabilities.

"When I testify it's important to help legislators feel what we're feeling. I try to put them in our shoes and remind them that they'll need someone to take care of them one day. We just want our piece of the American dream just like everyone else, before it's too late." — Damon Briggs

Senators Mac Middleton and Guy Guzzone with Chief of Staff Susan Lawrence pose with Damon after receiving the award

The Council supports people with developmental disabilities and family members to testify. Committees should hear directly from the people most impacted by their decisions. Damon Briggs, a Council member with cerebral palsy, illustrated this when he testified on a bill that would lead to increased wages for direct support professionals. Damon testified before a packed hearing room, with media present, about the importance of the bill and the impact of direct support staff on peoples' lives. Damon's compelling testimony was met by applause, many compliments about his effectiveness, and an Achievement Award from the Maryland Association of Community Services.

"If you don't advocate—someone will advocate on your behalf, and it may not be to your liking."

— Mat Rice,
Policy Specialist with POG

Mat Rice

PEOPLE ON THE GO—ENGAGEMENT & OUTREACH

With Council support, **People on the Go** of Maryland (POG) continued to expand Maryland's advocacy community through formal trainings, educational presentations, participation on boards and commissions of significance, and increased communications. Notably, Ken Capone, POG's Public Policy Coordinator, was appointed to serve on the President's Committee for People with Intellectual and Developmental Disabilities. In total, POG had a voice on 18 statewide commissions, coalitions, and groups.

Ken Capone prepares remarks at DD Day.

Other notable POG accomplishments included:

- Reaching over 700 recipients with a quarterly newsletter
- Engaging 121 people at the 2rd annual self-advocacy conference, "The Future is Looking Brighter"
- Developing a legislative agenda providing technical assistance and policy platforms for 5 self-advocacy groups across the state
- Presenting the history of cerebral palsy, school inclusion, self-advocacy and self-determination to youth from two school systems; and educated first responders
- Addressing youth at the Kennedy Krieger Institute High School Adolescence Lecture Series on self-advocacy and self-determination
- Providing training and support on affordable & accessible transportation services to self-advocacy groups in Southern Maryland leading to an increase in membership with the St. Mary's chapter

Keynote presentation at the POG Conference

Looking ahead, in partnership with the Maryland Center for Developmental Disabilities, POG is developing plans to build an energized and sustainable advocacy membership on the Eastern Shore.

PROJECT ACT IN ACTION!

Project ACT (Advocacy, Communication, and Transition) continued to contribute positively to the lives of Somerset and Worcester County transitioning youth, families, and school systems. Teachers from Somerset County describe use of the Positive Personal Profile (PPP) and "Whose Life is it Anyway?" planning tool as "transformative." Additionally, through Council support, youth attended the Maryland Transitioning Youth Conference, benefiting from leadership, self-advocacy and self-determination trainings. To better evaluate progress of the students, Project ACT staff developed a videotape assessment tool, a modification of The Arc US' paper/pencil self-determination scale.

Project leaders are coordinating the first annual Eastern Shore Transition Conference in 2015 with plans for school administrative staff to take over this responsibility independently in future years. Another self-sustaining initiative provided technical assistance to the Tri-County Council (Somerset, Worcester, and Wicomico), helping families successfully navigate the transition to post-secondary education.

"By the end of the first session, he was speaking louder and clearer and making eye contact with his listeners. By the fourth session, when asked along with the rest of the participants to give a "presidential speech," convincing the audience to vote for them, he spoke with such poise and confidence that I couldn't believe it was the same young man who three months prior didn't want to leave his mother's side. He, along with many of the youth participants, had learned to stand up and advocate for himself — a true feat by any measure!"

— Project ACT staff

In Maryland, only 56% of children with disabilities are fully ready for kindergarten as compared to 85% of their non-disabled peers.

The 2013-2014 School Readiness Report, MSDE

CHILD CARE

BUILDING CAPACITY IN THE COMMUNITY FOR CHILDREN

The Council was active throughout 2014 to build the capacity of childcare providers by increasing training opportunities, highlighting best practices and supporting the expansion of programs. The Council is focusing on a variety of activities that will increase access to high quality, inclusive childcare programs where children with and without disabilities can learn and play together.

The Council's strong advocacy and ongoing effort to make sure childcare providers have the skills and knowledge to care for and educate children with and without disabilities, resulted in the development of a state mandated training about the Americans with Disabilities Act (ADA) and inclusive practices for all childcare providers.

The Council was actively involved on the ADA Training Workgroup which began to develop training required for all childcare providers – over 14,000 people - by 2016.

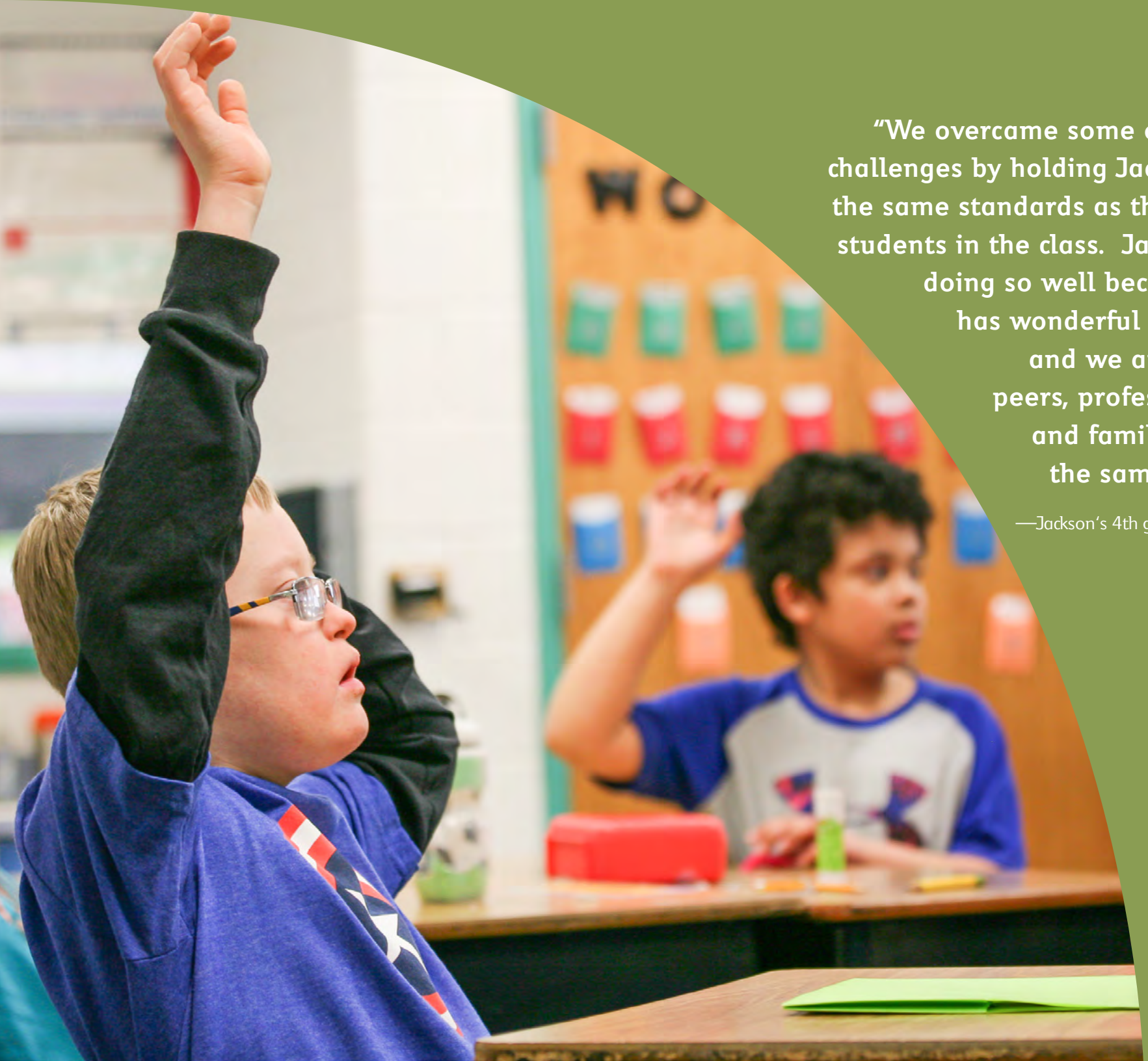
"It is critically important that Maryland families have access to high quality child care where their children, with and without disabilities, can thrive. I am thrilled to see the tremendous progress the Maryland Developmental Disabilities Council has made towards that goal."

— Senator Bill Ferguson

Focusing on building capacity through increased training opportunities, the Council continued to implement the recommendations in our 2012 report, ***Barriers to Quality Child Care and Out of School Time Activities in Maryland*** by:

- Funding Eddyline Media to film "real-life" scenarios showing the positive impact of inclusion when children with disabilities are meaningfully engaged in child care. The videos will also serve as public service announcements used to educate the general public about the benefits of including all children together.
- Collaborating with Maryland Family Network to complete the English and Spanish versions of an e-learning training module "Working with Children with Developmental Disabilities." Fifty childcare professionals completed the training in the first month it was released.
- Partnering with the Office of Genetics and People with Special Health Care Needs to develop and fund a new initiative increasing the skill and knowledge of childcare providers through training and technical assistance in underserved, outlying areas. The project will be implemented fully in 2015.
- Training almost 100 childcare providers at the annual Maryland State Child Care Association's state conference about the Americans with Disabilities Act and the inclusion of children with disabilities.

Increasing capacity, skill and knowledge of childcare providers is a high priority.



"We overcame some of these challenges by holding Jackson to the same standards as the other students in the class. Jackson is doing so well because he has wonderful support and we are all — peers, professionals, and family — on the same page."

—Jackson's 4th grade teacher

EDUCATION

ALL MEANS ALL!

All children and families should have access to high quality, inclusive education. Students with disabilities and their families are demanding greater access to inclusive education beginning early and continuing through higher education. In response, the Council partnered with a variety of stakeholders to expand options and promote opportunity by:

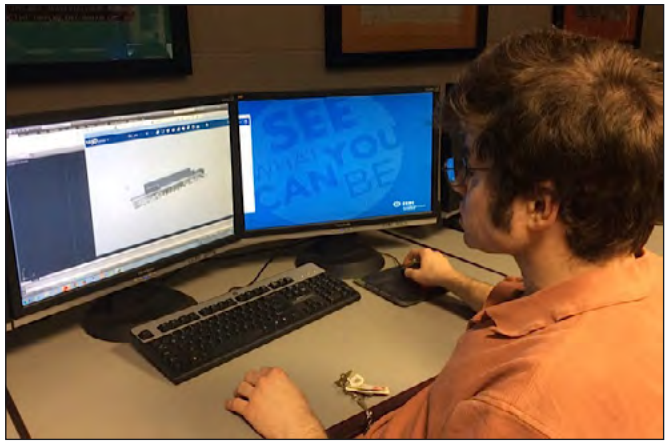
- Supporting the expansion of prekindergarten funding to ensure opportunities are increased for all children, including children with disabilities. ***All means all!***
- Supporting legislation switching the burden of proof to local school systems in all due process hearings. Currently school systems have access to more resources, information and expertise creating an unfair advantage over families.

"Many of the DD Council priorities and recommendations are directly noted and addressed in the Division's strategic plan. With two aligned plans, I anticipate measurable progress for Maryland's students with disabilities and their families."

— Marcella E. Franczkowski,
Assistant State Superintendent
Division of Special Education /
Early Intervention Services
Maryland State Department of Education

- Providing comments to the Maryland State Department of Education on proposed regulations to ensure graduates of public high schools have options that are community-based, inclusive and consistent with Centers for Medicare & Medicaid's (CMS) Home and Community Based Services (HCBS) guidance.
- Facilitating input from Think College (the national clearinghouse for information about post-secondary options for students with intellectual and developmental disabilities) to the Task Force for Expanding Credit and Noncredit Courses for Students to ensure the task force's report included best practices.
- Collaborating with MSDE to find potential opportunities to work together to promote inclusive dual-enrollment programs for students, ages 18-21, to enroll in college courses while still finishing high school.

Aileen O'Hare, DD Council member, graduates with a bachelor's degree in communications from University of Maryland University College.



After graduating with a Certificate of Completion, with support Andrew is taking courses on Computer Aided Design and hopes to obtain his GED.

tHiNK COLLEGE!

FAMILIES

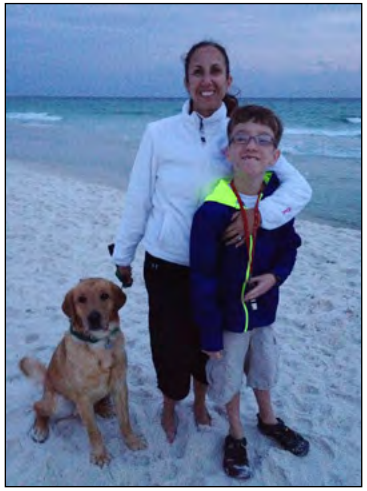
SUPPORTS TO FAMILIES REMAINED A PRIORITY FOR THE COUNCIL AND IN 2014 OUR FOCUS WAS IN TWO AREAS:

In collaboration with DDA and stakeholders, the Council continued to lead efforts to improve DDA's Low Intensity Support Services (LISS) program. After making 25 recommendations in 2013, most of which were agreed to by DDA, the Council reconvened the LISS Stakeholder Workgroup and developed nine additional recommendations in 2014. The Council also provided input to DDA regarding statutory and regulatory changes to support these improved policies.

The Developmental Disabilities Administration invited the Council to co-lead establishment of a ***Community of Practice for Supporting Families*** (CoP) that will focus on supporting families and individuals with intellectual and developmental disabilities to be fully engaged in their communities throughout the lifespan. This work is modeled after a national initiative involving six states. A community of practice (CoP) is premised on the belief that the sum of the community knowledge is greater than the sum of individual knowledge. A core leadership team was formed and initial planning began.

Only 6% of total DDA spending in Maryland went toward family support.

[The State of the States in Developmental Disabilities University of Colorado, accessed 4/8/15, http://www.stateofthestates.org/]



Next steps in 2015 include: mapping Maryland resources available to families and expanding the CoP to include individuals, families, professionals and others across systems to engage in priority setting that leads to improvements in formal and informal supports.

SIBLINGS

In 2014, the Council responded to a growing awareness that siblings (both children and adults) of individuals with developmental disabilities need information, support and resources. A survey of school-age siblings, adults, and other family members identified **unmet needs** as well as **promising solutions.** As a result the Council:

- Conducted a highly successful sibling photo contest titled, "A Picture is Worth a 1,000 Words." The contest illustrated the positive, important relationships between siblings with and without disabilities. Sixty dynamic photographs submitted by parents and siblings helped us reach well beyond the disability community. The contest reached 9700 Facebook users with 4900 viewing the photos and over 850 people casting votes for "Fan Favorite."
- Co-hosted a forum for adult siblings that drew 50 people. This was the first step in establishing and supporting an adult sibling network in Maryland. A panel of siblings shared personal experiences, followed by an open dialogue. Attendees shared that this was the first time they had heard from people with similar responsibilities, hopes and concerns, and appreciated the opportunity to network.
- Engaged in early planning for a statewide sibling conference with sibling leaders and other organizations. The first of its kind in Maryland, siblings of all ages will be included with the aim of helping participants connect, feel understood and supported, and gain information useful in their sibling role. This event will take place in the fall of 2015.

As this work evolved, it became evident that numerous, diverse activities are needed in Maryland to build and sustain support to siblings of all ages. In response, The Council dedicated funding to hire a Special Projects Coordinator focusing on sibling issues beginning in 2015.

Voted "fan favorite" in the Council's photo contest. Over 850 Facebook users cast votes.

SIBLING SURVEY

59% responded:
"I never get to talk about this and I'm just looking to connect with people who 'get it.'"

64% responded:
"I need to learn how the Maryland service delivery system works and I would like to develop advocacy skills and strategies"

17% of adults receiving DDA services are engaged in competitive, community based employment. Fifty percent of adults receiving DDA services are engaged in facility based actitivies that are not paid.

According to 2014 data from the MD State Employment Leadership Network

EMPLOYMENT

REAL PAY, REAL WORK, REAL COMMUNITY!

Recent changes in federal policy have brought increased focus on employment and day services across the country. Now more than ever, implementation of strategies are needed that increase integrated competitive jobs and access to participation in community activities for people with developmental disabilities. The Council continues to be engaged in initiatives leading to improved employment opportunities and meaningful community alternatives for Marylanders with developmental disabilities. Accomplishments include:

- Advising the **DDA Employment Outcome Data** group to implement a data collection system measuring progress in supported employment and community based services over time. Initial results indicate that over 5,500 adults in Maryland still attend facility-based non-work centers highlighting the work yet to be done.
- Providing support and guidance to Maryland's participation in a federal initiative called the ***Employment Learning Community (ELC): Improving Employment Systems & Services for Individuals with ID***. The initiative coordinates eleven state agencies and stakeholder partners focusing on employer engagement as a cross-system goal.
- Completion of **3-year grants** awarded to Penn-Mar Human Services, Goodwill of Monocacy Valley, Ardmore Enterprises, and The Arc of Howard County, resulting in the employment of 23 adults and 75 staff trained in person-centered planning, discovery & employment customization, self-employment, systematic instruction, and job development. This work will lead to further employment of additional individuals in the coming years.

Kevin boards the bus independently to go to work.

DDA EMPLOYMENT OUTCOME DATA

Initial results indicate that over 5,500 adults in Maryland still attend facility-based non-work centers highlighting the work yet to be done.

- Supporting **Project SEARCH** (PS) activities in Maryland through a grant to national PS headquarters for training and support to Maryland based PS programs implemented by SEEC, The Arc Baltimore, The Arc of Central Chesapeake, and The Arc of Howard County. So far over 30 people (teachers, job coaches, job developers and vocational staff) have been trained on best practices leading to better employment outcomes for transitioning youth, with additional activities planned through 2015.
- Expanding best practices with the **Employment Supports for Transitioning Students** (ESTS) initiative. Three providers received assistance building integrated employment services and shifting to community based services. As a result, 11 people obtained employment and 33 people benefited from employment discovery services or work based experiences.

Providing leadership and advocacy throughout the state, the Council's participation on the DDA Employment First Advisory Group, Supported Employment Leadership Network, and the DDA Employment Regulations Work Group influences formation of employment policies, practices and regulations promoting alignment with civil rights principles of inclusion and full community integration.

Maryland's developmental disabilities community service system is at a critical juncture. With clear direction from the federal government to implement a transition plan for full compliance with the Home and Community Based Setting Rules (HCBS), the Council is positioned to provide guidance, leadership, and resources as people with disabilities, family members, advocates, providers, and state officials work collaboratively toward truly being an Employment First state offering services fully integrated into community settings.

United Cerebral Palsy's (UCP) *Case for Inclusion 2014 Report* ranks Maryland 27th in the nation for meeting standards measuring the following indicators for overall quality of life for people with developmental disabilities: health & safety, the degree of independence, productivity, and family supports.

OTHER INITIATIVES

THE UNCONFERENCE

How common is it to attend an event and actually accomplish something? Determined to engage a group of like-minded people in a way that supported both thinking and action, the Council experimented with a new approach: a two-day gathering called the "UnConference." An intentionally small group of twenty-three people attended, representing a mix of people with developmental disabilities, advocates, family members, and professionals. Embracing the flexible, participatory structure, one group coalesced around the future of self-directed, individualized services in Maryland and drafted an agenda to meet with the new DDA director. Another group conceived of a way to recognize businesses that do a good job employing or serving people with developmental disabilities. After identifying criteria to review businesses, they created the name PurchaseMaryland, designed a logo, and set up a Facebook page: **PurchaseMD**.

Driven solely by the participants, the environment and structure of the UnConference resulted in renewed energy, new connections, and new ideas. Here is some feedback from two participants:

"I am taking home so many things that I can use"

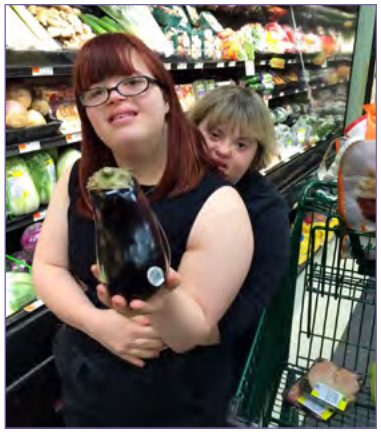
"I'm so excited about the next steps that I can't even put it into words!"

PurchaseMD is a positive forum in which to share businesses that support full equality of people with and without physical and developmental challenges. As a community, we should financially support businesses that support us. Looking for a business to support or do you have a business to recommend?

Look for PurchaseMD in your Facebook search bar.

HOME AND COMMUNITY BASED SERVICES (HCBS)

If you lived here you would be home by now…



In early 2014, the Centers for Medicare & Medicaid Services (CMS) issued a final rule defining what kinds of services can be covered through Medicaid-funded home and community-based services (HCBS) programs. Impacting all people receiving Medicaid funding administered through the Developmental Disabilities Administration (DDA), the new rule intends to ensure that individuals have full access to the benefits of community living. Soon after the rule was issued, with support from the MD Disability Law Center and MD Center for Developmental Disabilities, the Council hosted a public forum to inform a diverse audience of about 150 people of the impact of the rule as well as opportunities to be involved as Maryland develops a transition plan to ensure full compliance. Leaders from CMS, the Administration on Intellectual and Developmental Disabilities, the Association of University Centers on Disabilities and Bazelon Center participated.

As state planning progressed through 2014, the Council provided routine updates, engaged in public forums, and provided input into the transition plan. We will remain active in 2015 and beyond as the State moves to further refine and implement the transition plan.

Clare and Katie enjoy living independently in the community with CSLA (Community Supported Living Arrangement) supports.

MD INCOME TAX CHECK-OFF

Marylander's have the option on their state tax returns to contribute to three different funds by simply checking a box. One of these "check-offs" directly benefits individuals with developmental disabilities by helping to fund community services for people on DDA's waiting list. This is the newest check-off and it is not widely known so the Council invested funds in 2014 to expand public awareness. We purchased 35 radio ads, 50 online ads, and a banner ad on a radio station's website at reduced cost. Thirty-six ads also ran on CityBizLIst, an online resource to businesses in Baltimore and DC, at no cost. In total, the Council's $2000 investment leveraged $16,000 worth of advertisement.

SMALL GRANTS

… support great ideas!

The Council approved ten **small grants** this past year! Here is a sampling of the results:

- The Arc of Howard County, partnering with the Columbia Festival of the Arts, brought Sprout Films to town for a community wide arts festival in which "…a sold out audience included a number of movie buffs, people with developmental disabilities and their advocates, and the general public, making this a true inclusionary event."
- Several young, budding advocates and family members attended Be the Future, an advocacy conference in D.C. put on by TASH, an international leader in disability advocacy. Says one attendee, "I used it to help me understand better how to advocate for myself and people like me in my community." – Oliver S.
- The Montgomery County Transition Work Group received funding to help expand capacity for participants and exhibitors for their annual Transition Conference. One parent emailed, "What an amazing array of exhibitors to give assistance to our families as they navigate the transition years."
- Wicomico County Public Schools started a program called Peer Buddies bringing children with and without disabilities together to form friendships through a matching process and participation in planned, routine social activities.

A sampling from Columbia Festival of the Arts, 2014: 46/47, a short film about "being different" (whether 46 or 47 chromosomes) playing with habitual stereotypes by asking an implied question, "What is normal?"

Does your organization have a great idea?

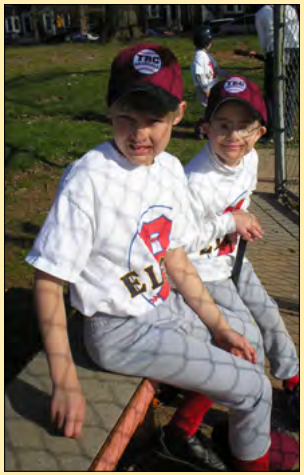
Find more information about our small grants at **http://www.md-council.org/funding**

Peer Buddies head outdoors to play

WHAT TO WATCH FOR IN 2015:

- Peer Buddies will have been up and running for a complete year—we can't wait to share stories of friendship and community with you that will result from this terrific project.
- Results from 3 Community Empowerment Grants funding:
  - Prince George's County Adults with DD Citizen Advisory Committee to hire a consultant leading in the development of a strategic plan to promote full inclusion of people with developmental disabilities into community life.
  - Southern Maryland Center for Independent Living to provide information to local businesses on ADA requirements for reasonable accommodations and resources to meet the requirements.
  - Howard County Autism Society to hire a consultant with the goal to identify creative housing options as well as identifying opportunities and barriers so people with IDD can live independently in a home of choice with appropriate supports.

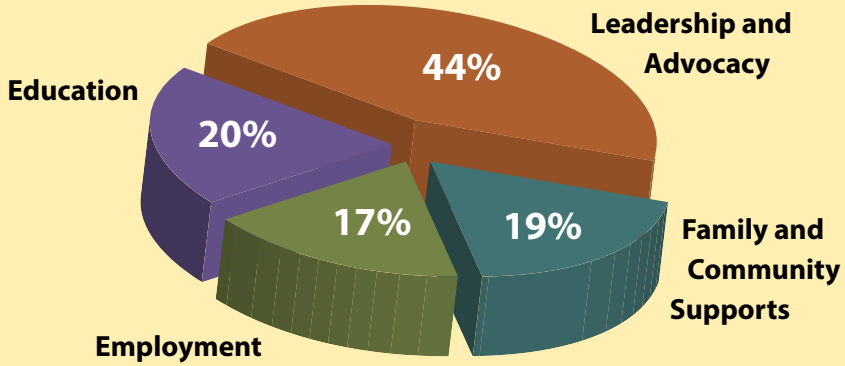
Children with and without disabilities socialize at school as a part of an intentional strategy to facilitate friendships through the Peer Buddies program.



INVESTMENTS IN MARYLAND

We consider our grant funding to be an investment to build a better community, an inclusive community, a stronger Maryland.

TOTAL PROJECT INVESTMENTS IN 2014: $414,299



Family and Community Supports	**$ 80,268**	**19%**
Employment	**$ 68,950**	**17%**
Education and Early Intervention	**$ 83,206**	**20%**
Leadership and Advocacy	**$ 181,875**	**44%**

Funding for this publication is authorized by Subtitle B of the Developmental Disabilities Assistance and Bill of Rights Act of 2000, from the U.S. Department of Health and Human Services, Administration on Community Living, Administration on Intellectual and Developmental Disabilities, Washington, D.C.

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BE EMPOWERED

There are many reasons to connect with the Maryland DD Council:

- Access to grant funding supporting your organization's systems change efforts and advocacy ideas.
- Receive timely updates about legislation and activities impacting quality of services and supports for children and adults with IDD.
- Be informed about upcoming statewide conferences, events and workshops.
- Be a part of the conversation driving change in Maryland.

To receive information, stories and updates impacting services and supports for children & adults with developmental disabilities:

- Sign up for our monthly newsletter, ***Council Connections***, and News You Can Use (NYCU) by
- visiting our website **www.md-council.org** or by calling us at 410-767-6249

Find us (and like us!) on Facebook Find us on Facebook

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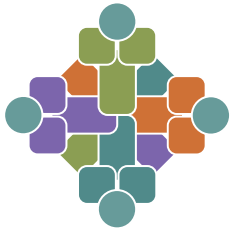

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