



Maryland Developmental Disabilities Council

EMPOWERMENT • OPPORTUNITY • INCLUSION

**FIVE YEAR STATE PLAN
FY 2017-2021**



Maryland Developmental Disabilities Council

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STATEMENT OF VALUES

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.

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.



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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.

Legal Authorization

The Maryland DD Council is an independent self-governing organization established in 1971 and funded through the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). The Council receives an annual federal funding allocation administered through the Administration on Intellectual and Developmental Disabilities (AIDD). Disability Rights Maryland (formerly Maryland Disability Law Center) and Maryland Center for Developmental Disabilities (MCDD) are also funded through the DD Act and the three organizations work collaboratively on shared priorities.

SECTION I: COUNCIL IDENTIFICATION

PART A. State Plan Period: October 1, 2016 through September 30, 2021

PART B. Contact Person: Krista Mason
Phone Number: 410-767-2914
E-mail: kristam@md-council.org

PART C. Council Establishment:
(i) Date of Establishment: 11/12/1971
(ii) Authorization: State Statute Executive Order N/A
(iii) Authorization Citation: 01.01.1987.08 [Amended COMAR 01.01.1973.08]

PART D. Council Membership:
(i) Council membership rotation plan:

Members are appointed by the governor in accordance with the Developmental Disabilities Act for terms of five years beginning July 1. In the event that an appointment has not been made to fill a vacancy resulting from expiration of a term, the incumbent member can continue to serve until such time as a new appointment is made. Members may be reappointed. Members cannot serve more than two consecutive terms, unless one of their terms was less than five years. In such instances, a third term may be granted but the total number of consecutive years served may not exceed 10 years.



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(ii) Council Members:

	Last Name	First Name	MI	Agency Org. Code	Agency/Org. name	Appt. date	Appt. Expired Date	Alt/ Proxy for State Agency Rep Name
1.	Franczkowski	Marcella		A2	MSDE/IDEA	11/2/15	6/30/19	C. Brown
2.	Bayliss	Patricia		A3	DOA			R. Hanratty
3.	Oliver	Rebecca		A4	DHMH	4/27/17	6/30/19	
4.	Greenspoon	Marni		A5	DRM	1/12/17	6/30/19	
5.	Smith	Christopher		A6	MCDD	11/2/15	6/30/20	
6.	Derx	Lisa		A7	Family Health Adm	9/27/16	6/30/19	
7.	Hargett	Kathy		B2		1/12/17	6/30/19	
8.	Miller	Jed		A8	Family Health Administration, DHMH	4/27/17	6/30/21	
9.	Beatty	Carol		A9	MDOD	11/2/15	6/30/17	
10.	Simons	Bernard		A9	DDA	11/2/15	6/30/17	
11.	Briggs	Damon		B1		9/17/13	6/30/18	
12.	Cannady	Jamal		B1		11/2/15	6/30/20	
13.	Kaufman	Aaron		B1		7/1/12	6/30/17	
14.	Gomes	Harold		B1		4/27/17	6/30/20	
15.	Oluwatobi	Ojo		B1		4/27/17	6/30/20	
16.	Shipps	Ruth		B1		11/2/15	6/30/20	
17.	Barnhart	JoEllen		B2		9/27/16	6/30/21	
18.	Cole	Eric		B2		7/1/12	6/30/17	
19.	Dockery	Sharon		B2		7/1/12	6/30/17	
20.	Jones	Meghan		B1		4/27/17	6/30/18	
21.	Randall	Julie		B2		5/5/14	6/30/18	
22.	Young	Russell		B2		5/5/14	6/30/18	
23.	Herbert	Teresa		B2		9/27/16	6/30/20	
24.	Vanderhook	Adam		B3		5/5/14	6/30/18	
25.	Han	Kay		B2		4/27/17	6/30/21	
26.	Brown	Kalani		B2		4/27/17	6/30/20	
27.	Lay	Amanda		B1		8/8/12	6/30/17	
28.	Mercado	Miguel		B2		1/12/17	6/30/18	



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Part E. Council Staff

#	Position or Working Title	FT	PT	% PT	Last name of person in position	First name of person in position	MI
1	Executive Director	X			Cox	Brian	
2	Deputy Director	X			London	Rachel	
3	Director of Communication & Information Management	X			Mason	Krista	
4	Director of Public Policy Initiatives	X			Sparks	Teri	
5	Administrative Coordinator	X			Bell-Boulware	Faye	

SECTION II: DESIGNATED STATE AGENCY

The DSA is:

Agency Name: The Maryland Department of Disabilities
 DSA Official's Name: The Maryland Department of Disabilities Address
 217 E. Redwood Street, Suite 1300
 Phone: 410-767-3660

Fax: 410-333-6674

Email: mdod@maryland.gov

Direct Services

Does it provide or pay for direct services to persons with developmental disabilities?: No

Describe DSA Roles and Responsibilities related to Council:



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Supplies support services and assurances; receives, accounts for and disburses funds; provides fiscal control and accounting procedures, record access, financial reports and non-federal share; assists in getting SP assurances and ensuring consistency with state law.

Memorandum of Understanding/Agreement:

Does your Council have a Memorandum of Understanding/Agreement with your DSA? N/A or No Agreement

Calendar Year DSA was designated: 1987

SECTION III: COMPREHENSIVE REVIEW AND ANALYSIS INTRODUCTION:

In December 2014 staff briefed Council members on the State Plan process and the role that the Council would play in helping to provide, collect, and review information as well as to provide input and make decisions regarding all aspects of the State Plan. A State Plan Committee was formed by Council members to help guide the process closely, and a workgroup formed to review data on disparities and make a recommendation on targeted disparity efforts. The workgroup recommended a targeted disparity objective addressing employment barriers to people with IDD living in rural areas. However, due to growth by 134% of MD's Hispanic population from 2000 - 2013 (currently representing 9.5% of total population) with continued percentage rise projected, routine outreach to Spanish speaking populations will be included in all pertinent Council activities. Overall, there is inadequate information across systems in Maryland to support data-based conclusions about disparities among minorities with developmental disabilities. To ensure the Council reaches and benefits a diverse consistency, we will consider racial, cultural, ethnic and geographic diversity when implementing all State Plan objectives. The Council has identified diverse organizations to assist with this (noted in the Collaboration section). Note: Federally assisted state programs, plans and policies, as well as other broader issues are included in Parts A - D of the CRA. The following steps were taken to ensure a methodical and comprehensive approach to gathering data and input needed to inform the CRA.

- 1) The Executive Committee reviewed and approved the overall work plan and timelines for development of the State Plan.
- 2) In partnership with the UCEDD, a comprehensive public input needs assessment survey was developed in both English and Spanish, and distributed widely with both digital and traditional paper distribution methods. Specific efforts were made to extend survey outreach to minority &



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rural communities. The liaison to Hispanic families through Parents' Place of Maryland (MD's Parent Information & Training Center) was enlisted to help distribute surveys to Spanish speaking stakeholders. Outreach efforts were also made with the Governor's Commission for Hispanic Affairs. The survey was available from May 15 through July 31, with 475 respondents. The UCEDD compiled a report for review.

3) Focus groups were held with people with developmental disabilities in three regions of the state: rural Southern MD, rural Eastern Shore, and Central MD.

4) Council staff leveraged involvement with the 23 commissions, task forces and coalitions on which staff serve, many of which have people with developmental disabilities and family member representatives, in addition to other stakeholders. These served as ongoing opportunities to learn about, discuss and analyze issues, challenges and responses to priority issues in Maryland; and thereby inform development of the State Plan.

5) Staff drafted Issue Briefs using survey and focus group input, as well as extensive knowledge of the state of the state and information and data from the US Census, the Department of Health & Mental Hygiene & the Developmental Disabilities Administration (DOA), Maryland State Department of Education (MSDE) & the Division of Rehabilitation Services (DORS), the Maryland Department of Planning, the Maryland Department of Transportation (MDOT), Maryland Family Network (MFN), the Administration on Community Living, and other sources.

6) Staff found that data on minorities with disabilities was lacking, primarily for adults. Specific inquiries were made to DOA for data on minorities with developmental disabilities in the state; little to no data was available to help assess minority disparities in access to long-term services/supports.

7) Council staff facilitated input from the UCDD (MCDD) and P & A (ORM - Disability Rights Maryland).

8) Committees reviewed and revised Issue Briefs, including information on past Council accomplishments, existing and emerging opportunities, and issues needing attention. Committees then made recommendations and developed priorities for Council approval.

9) After full Council approval of the priorities, staff drafted goals, objectives, strategies and outcomes based on the recommendations. Staff met with ORM and MCDD to brief on the drafted state plan and identify areas in which to collaborate and work in partnership.

10) A Council workgroup was formed to examine existing data on disparities in Maryland and make a recommendation to the Council for adoption of the targeted disparity objective.

11) The Council reviewed, revised, and voted on the goals, objectives, strategies and outcomes.

12) The draft goals, objectives and outcomes went out for public comment.

13) Public comments were summarized for review and consideration by the Council; after consideration of the feedback, the Council voted to finalize the State Plan.



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PART A. State Information

Racial and Ethnic Diversity of the State Population:

Race/Ethnicity	Percentage of Population
White, alone	52 %
Black or African American alone	30.5%
American Indian and Alaska Native alone	0.6%
Asian alone	6.5%
Native Hawaiian and Other Pacific Islander alone	0.1%
Some other race alone	0.3%
Two or more races	0%
Hispanic or Latino (of any race)	9.5%

(Poverty Rate: The 2009 estimated poverty rate in Maryland is 10.1 %.)

State Disability Characteristics

a) Prevalence of Developmental Disabilities in the State:
88,339 (Using the national prevalence rate of 14.9 people per 1000 and U.S. Census Population Data.)

b) Residential Settings:

Year	Total Served	A. Number Served in Setting of <6 (per 100,000)	B. Number Served in Setting of >7 (per 100,000)	C. Number Served in Family Setting (per 100,000)	D. Number Served in Home of Their Own (per 100,000)
2012	176	92	5	38	34
2013	217	135	7	37	37
2005	138	131	7	37	39

c) Demographic Information about People with Disabilities:

People in the State with a disability	Percentage
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Population 5 to 17 years	5%
Population 18 – 64 years	8.4%
Population 65 years and over	32%

Race and Hispanic or Latino Origin of people with a disability	Percentage
White alone	11.3%
Black or African American alone	11%
American Indian and Alaska Native alone	14.3%
Asian alone	5.4%
Native Hawaiian and Other Pacific Islander Alone	0.1%
Some other race alone	4%
Two or more races	10.6%
Hispanic or Latino (of any race)	5.2%

Educational Attainment Population Age 25 and Over	Percentage with a disability	Percentage without a disability
Less than high school graduate	22.5%	8.9%
High school graduate, GED, or alternative	33.3%	24.4%
Some college or associate's degree	24.4%	26.2%
Bachelor's degree or higher	19.9%	40.4%

Employment Status Population Age 16 and Over	Percentage with a disability	Percentage without a disability
Employed	25.4%	69.4%
Not in labor force	69.4%	24.9%

Earnings in Past 12 months Population Age 16 and Over with Earnings	Percentage with a disability	Percentage without a disability
\$1 to \$4,999 or less	15.4%	9.2%
\$5,000 to \$14,999	17.7%	12.2%
\$15,000 to \$24,999	13%	11.1%
\$25,000 to \$34,999	11.4%	11.3%

Poverty Status Population Age 16 and Over	Percentage with a disability	Percentage without a disability
Below 100 percent of the poverty level	17.2%	8%
100 to 149 percent of the poverty level	10.5%	5.1%



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At or above 150 percent of the poverty level	72.4%	86.8%
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PART B. Portrait of the State Services

Health/Healthcare

Access to Quality Health Care:

Children and adults with developmental disabilities can access health care services in Maryland through private or public insurance programs. The number of children and adults with developmental disabilities served by these programs is not known.

Many people with developmental disabilities rely on Medicaid for their health insurance. Medicaid is a program that pays the medical bills of people who have low incomes, cannot afford medical care, and meet other eligibility requirements. In Maryland, health care for Medicaid recipients is provided by Maryland's Dept. of Health and Mental Hygiene (DHMH) managed care program, known as HealthChoice. Eligible Medicaid participants enroll in a Managed Care Organization (MCO) of their choice and select a primary care provider. MCOs must meet specific standards for treating people with special needs, including children with special health care needs and people with developmental disabilities. Everyone who receives money through Supplemental Security Income (SSI) or Temporary Cash Assistance (TCA) automatically receives Medicaid.

Within HealthChoice, Medicaid recipients with specific rare and expensive conditions are eligible for the Rare and Expensive Case Management Program (REM). REM participants receive fee-for-service benefits and case management services, and may receive an expanded set of benefits.

If the person does not qualify for HealthChoice (e.g., because he or she is also Medicare eligible, eligible for Medicaid through spend down, or eligible in a long-term care facility), he or she will still receive Medicaid services, but through a "fee-for-service."

One of the major challenges for people with developmental disabilities is finding doctors who accept Medicaid because the reimbursement rate is relatively low.

Another major issue that people with developmental disabilities and their families face is the shortage of health care professionals, which is especially acute in the rural areas of the state. Lack of, or limited access to, health care services is compounded for people with developmental disabilities who need specialty care. Geographic areas receiving the designation of "medically underserved" include the



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lower Eastern Shore, Garrett and Allegany Counties, and parts of Baltimore City. Telemedicine is beginning to fill some of the voids where specialty care is not available.

Other factors impacting health care delivery include: 1) inadequate health insurance coverage that results in high out of pocket expenses and 2) the lack of coordination of services and supports.

The Maryland Children's Health Program (MCHP) provides full health benefits for children up to age 19 who are not eligible for Medicaid, whose modified adjusted gross income is at or below 300% of the federal poverty level, and who are uninsured. MCHP enrollees obtain care through MCOs under the Maryland HealthChoice Program.

The Model Waiver for Medically Fragile Children allows children with complex medical needs who would otherwise be hospitalized and are certified as needing either hospital or nursing facility level of care to receive medically necessary and appropriate services in the community. As a result, individuals enrolled in the program can continue to live at home with their families.

The Home and Community Based Options Waiver, Community First Choice Program (CFC), and Medical Assistance Personal Care Program (MAPC) are long-term supports that provide assistance with activities of daily living to Medicaid recipients who have a chronic illness, medical condition or disability. Services are provided in the eligible person's home or community residence. Other services in each program vary. The CFC and MAPC Services may be provided in the workplace.

In 2012, the MD General Assembly established the Habilitative Services Workgroup, of which the Council was a member, to determine if children who are entitled to habilitative services are receiving these benefits; if those children are not receiving the services, to determine the reasons why; the ways to promote optimum use of these services; and the costs and benefits associated with expanding habilitative services coverage to individuals under the age of 26 years. At the same time, the Autism Technical Advisory Group was created and charged with determining the medically necessary and appropriate use of habilitative care services for the treatment of autism, including Applied Behavioral Analysis (ABA). As a result of recommendations from both workgroups, regulations changed to ensure that all medically necessary habilitative services for children younger than 19 diagnosed with autism or autism spectrum disorder include: behavioral health treatment, including ABA psychological care, including direct or consultative services and psychotherapy; and therapeutic care, including speech therapy, physical therapy, and occupational therapy.

Access to dental care is a critical component to maintain good physical health. The Maryland Healthy Smiles Dental Program is available for all Maryland Medicaid enrollees under age 21, pregnant women,



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and adults over age 21 with Rare and Expensive Case Management coverage. As of 2009, DentaQuest handles the coordination of all dental-related customer service for Maryland Medicaid enrollees participating in the Healthy Smiles Dental Program. All HealthChoice MCO's provide limited dental services to adults.

The Maryland Medicaid Advisory Committee advises the Dept. of Health and Mental Hygiene in the implementation, operation, and evaluation of the Medicaid program.

The National Core Indicators is a survey of Marylanders who receive services and support through Developmental Disabilities Administration funding. Several measures of the survey look at health and wellness.

Of those surveyed: 85% reported having a physical exam, 77% a dental exam, and 49% an eye exam or vision screening in the past year. 70% reported having a hearing test in the past 5 years. 82% of women reported having a Pap test in the past 3 years, 81% of women reported having a mammogram in the past 2 years (40 & older), 6% of men reported having a colorectal cancer screening in the past year (50 & older), 50% reported taking at least one medication for mood disorders, anxiety, behavior challenges, and/or psychotic disorders.

Prevention/Wellness:

The Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT) promotes access to and assures availability of quality health care for children, teens and young adults younger than 21 years of age. The preventive care component of the EPSDT Program, known as the Healthy Kids Program, provides services for early identification and treatment of health problems before they become medically complex and costly to treat. All children who receive Medicaid and MCHP get EPSDT services.

The Office of Genetics and People with Special Care Needs within DHMH works to improve the early identification of children with special health care needs through newborn screening for metabolic diseases, sickle cell disease, chronic diseases, birth defects, hearing loss, and developmental problems. In 2014, the Office launched an online Resource Locator, a searchable database for Maryland families and providers which is accessible in over 50 languages. One of popular tools for families is the My Health Care Notebook. The notebook provides a way to organize information about health care and is being promoted to youth who are transitioning to adult health care to support greater independence in self-management of health and wellness.



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The Maryland Department of the Environment (MDE) enforces laws that reduce the risk of lead exposure in rental units built before 1950. MDE also keeps a list of inspected rental units and monitors the trends in blood lead levels in children. Local health departments manage cases of elevated blood lead levels in children, investigate instances of high lead exposure, enforce the standards required of lead inspectors, and provide information to educate parents, renters, landlords, homeowners, and health care providers. Sixteen percent of people with developmental disabilities taking the National Core Indicators survey report engaging in regular, moderate physical activity. The survey indicates that approximately 61% of adults are overweight or obese. These measures suggest that people are not participating in regular, physical activity.

Health Disparities:

Most developmental disabilities are caused by a variety of factors. Some of these factors include genetics, low birth weight, parental health and behaviors (such as smoking and drinking) during Pregnancy, complications during birth, and exposure of the mother or child to high levels of environmental toxins, such as lead.

Babies born with a low birth weight are at increased risk for serious health complications, including neurological and developmental disabilities, compared to babies with a normal birth weight. Maryland's rate of 8.6% in 2014 is higher than the national average of 8.0% and does not meet the Healthy People 2020 goal of 7.8%. At the county level, the rates in Baltimore City, Dorchester, Charles, and Prince George's Counties have been higher than other counties. Black infants have a substantially higher incidence of low birth weights than other infants. In 2013, the percentage of low birth weight infants was 6.8% for white infants, 12.1% for black infants and 7.3% for Hispanic infants. The incidence of very low birth weight (birth weight <1,500 grams) was 1.7% overall, 1.2% for whites, 2.7% for blacks and 1.3% for Hispanics.

Exposure to lead is the most widespread environmental hazard for children in Maryland. The percentage of children with elevated blood lead levels in Baltimore City has been the highest. In 2012, 219 children in Baltimore City were identified with elevated blood lead levels, or about 60.2% of total children identified in the state.

Lower cognitive performance is associated with poorer health and functioning throughout the lifespan and disproportionately affects children from lower socioeconomic status populations. One in 10 Marylanders lives in poverty. The 5 jurisdictions with the highest poverty rate are: Baltimore City, Somerset, Allegany, Wicomico, and Dorchester Counties.

National & State Initiatives and Opportunities:



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The Maryland Health Benefits Exchange is a public corporation and independent unit of state government established in accordance with the Affordable Care Act. It is responsible for the administration of Maryland Health Connection, which is the State's health insurance marketplace for comparing and enrolling in health insurance, as well as determining eligibility for Medicaid and other assistance programs, federal tax credits, and cost-sharing reductions.

Medicaid Matters! MD is a statewide coalition of organizations that advocates preserving and protecting Medicaid by informing policymakers and supporting consumer advocacy. It has been active in the expansion of Medicaid benefits for families with children, increased funding and access to dental care, and support of people who want to live at home in the community rather than nursing homes. The Council is a member.

The Maryland Community of Care Consortium for Children with Special Care Needs (COCC) is a stakeholder group funded by a grant from the federal Maternal and Child Health Bureau. The COCC works to create systems of care that promote optimal health, functioning, and quality of life for Maryland children with special health care needs and their families.

Employment

Background:

Marylanders with disabilities and their families clearly express their desire for jobs in the community, earning living wages with benefits, and with opportunities for career advancement.

The primary state agencies in Maryland that provide short and long term employment supports for adults with developmental disabilities are the Developmental Disabilities Administration (DDA), the Division of Rehabilitation Services (DORS) within the Maryland State Dept. of Education (MSDE), and the Dept. of Labor and Licensing's American Job Centers (One Stop Career Centers).

The DDA funds long-term supports for people with developmental disabilities to obtain and maintain work successfully in the community. Supports may include a career exploration and assessment process, job development, on the job training, ongoing job coaching, assessment of assistive technology needs, benefits awareness, and management and operation of an individual's own business. One of the most important sources of funding relative to employment is "transitioning youth" funding in the DDA budget, which helps students with developmental disabilities who leave school at the age of 21 to transition to employment and other day services. Transitioning youth funding is at the discretion of the governor but has been fully funded under the past four governors.

DORS provides short-term services to people with disabilities who want to work and meet eligibility



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criteria, including career assessment and counseling, job training, assistive technology, job placement, job coaching, and higher education. Anyone who receives Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI), or ODA funded services is presumed eligible for DORS services. Maryland's One Stop Career Centers provide a range of assistance to job seekers with and without disabilities including training referrals, career counseling, job listings, and other employment-related services.

New requirements in the federal Workforce Innovation and Opportunity Act (WIOA) will help further advance employment of people with disabilities by requiring coordination with all partners to provide high quality services and supports. In addition, there is an increased VR role in transition for students from school to adult, limitations on sub-minimum wage, and a requirement for formal cooperative agreements between vocational rehabilitation and state Medicaid and IDD agencies.

In addition to agencies mentioned above, the Maryland Dept. of Disabilities (MDOD) functions as the state coordinating entity to improve the delivery of services to individuals with disabilities and advocates for the delivery of services in the most integrated setting, including employment.

Maryland is moving forward, in conjunction with stakeholders, to finalize and implement an Employment First plan that outlines why and how people with developmental disabilities will get and keep community-based jobs, earn income, and have meaningful days when not working. In 2016, the General Assembly passed legislation that requires the phase out of subminimum wage by 2019. The DOA, MDOD, and stakeholders will develop an implementation plan and track and analyze data. In addition, supplemental plans for employment are required for each person currently being paid subminimum wage.

Local school systems play a vital role in preparing youth with developmental disabilities for employment because transition planning takes place when developing a student's Individualized Education Program. A transition plan must reflect a student's individual choices, preferences, and needs in the areas of education and training, employment, adult living arrangements, and community experiences. In MD, transition planning and the delivery of transition services begins during the school year in which the student turns fourteen.

The Council, in partnership with state agencies and other stakeholders applied for the Partnerships in Employment grant through the Administration on Community Living, (ACL) in July 2016. The goal of Maryland's project is to improve employment outcomes for youth with intellectual and developmental disabilities, ages 18-21. These outcomes would be achieved by 1) increasing inclusive dual enrollment programs in Maryland 2) reviewing, revising and implementing state policies to establish competitive



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employment as the desired outcome for youth with ID/DD 3) increasing the knowledge, skills and expectations of these youth, their families, and the Local Education Agencies and 4) developing a statewide tracking system to evaluate employment outcomes.

The Governor's Interagency Transition Council for Youth with Disabilities coordinates and implements interagency planning for the delivery of services to improve the post-secondary school outcomes of youth with disabilities.

The Employed Individuals with Disabilities Program allows people with disabilities to work and qualify for (or keep) Medical Assistance. It gives people with disabilities an incentive to work by ensuring health coverage even when earnings are substantial.

Data, Diversity & Disparities :

In collaboration with stakeholders, the Maryland Supported Employment Leadership Network implemented a statewide employment outcome data collection system for the DDA in 2013. The data system is designed to provide longitudinal data that support Maryland's goals to improve both participation in integrated employment and the quality of employment outcomes. Data is collected on approximately 11,600 people who receive day and employment services funded by the DDA. The data has limited application because it is collected during a two-week period in the spring and fall and does not necessarily capture where people spend the majority of their time.

Employment data from 2014 indicates that 33% of the people receiving day or employment services have integrated jobs. Seventeen percent (17%) have individual competitive jobs, work an average of seventeen hours/week, and earn an average of \$8.91 per hour. The DDA does not have ethnic or racial minority statistics available for the people funded by the agency. A study of employment outcomes of Maryland youth with ID/DD showed only 14.2% were engaged in integrated, competitive employment within one year after completing high school. In 2015, eight of Maryland's 23 counties still had more transition-age youth with ID/DD in facility-based employment than in competitive, integrated employment. Nineteen of the 23 counties had some youth in sheltered workshops. There is no standard data collection method/measurement system that captures employment outcomes of youth with ID/DD.

The 2013 American Community Survey estimates a 28% employment rate of Marylanders with ID aged 21-64. This number includes people who are employed in the community and people who are paid in sheltered workshops. The employment rate for working-age adults without disabilities is 76%.

In comparing regional data, rural areas of MD, particularly the Eastern Shore region, have poorer employment outcomes than the rest of the state. Over 37.7% of people with developmental



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disabilities in Central Maryland have integrated jobs compared to 33.2% in Western Maryland, 32.1% in Southern Maryland, and 16.7% on the Eastern Shore. Geographic disparity is evident between rural areas and other regions of the state.

Available data from the Division of Rehabilitation Services (2015) indicates that out of a total of 26,931 people served, 50% were Black/African American, 44% White, 3% Hispanic or Latino, 2% Asian, and 1% American Indian or Alaskan Native. The data suggests a lower participation rate for the Hispanic/Latino population.

Results from the 2013-14 National Core Indicator Adult Consumer Survey indicate that of the people who receive DDA-funded supports and do not work, 60% want to have a paid job in the community. Despite wanting a job, only 39% have integrated employment as a goal in their service plans.

Forty-three percent (43%) of respondents in Maryland who attend a day program indicated they wanted to go somewhere else or do something else during the day.

To remove barriers to integrated employment, Maryland needs to:

1. Increase provider capacity and support innovation that leads to people transitioning from facility-based day programs, including sheltered workshops, to more inclusive community-based alternatives. Agencies want and need training and technical assistance regarding: organizational change, strategic planning, customized employment, and fiscal policy.
2. Ensure that Individual Plans reflect a person's desire for integrated community employment and/or community engagement and the services must be provided to reach his/her goals.
3. Implement state policies, programs and funding that support and prioritize integrated community employment and meaningful community-based alternatives.
4. Develop and implement, in collaboration with other stakeholders, a comprehensive strategic communication plan that increases families' awareness, understanding and support for community employment.
5. Increase the number of students with developmental disabilities who leave school and transition to work and other supports in the community.

Informal and Formal Services and Supports



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Supports to Children & Families:

There are approximately 51,000 children under 22 with developmental disabilities in Maryland. Many of them continue to struggle to obtain the formal and informal support they need. The DDA is the primary state agency that funds Home and Community Based Services (HCBS) for families with a child with a developmental disability. However, the demand far exceeds available funding so many families wait for Low Intensity Support Services (LISS) and Family Support Services (FSS).

The LISS program allocation is approximately \$4.5M annually and provides low-cost, short-term supports, capped at \$2000. In 2012, 97% of respondents to a Developmental Disabilities Council survey said LISS is an important program; 56% said it is "critical." In response to recommendations from a DD Council Stakeholder Workgroup, the DDA revised statute and regulations to improve LISS program access and operations.

The DDA-funded Family Support Services (FSS) are designed to enable a family to provide for the needs of a child with developmental disabilities living at home. FSS funding can be used for services and items that enhance the quality of life, preserve family unity, and promote family stability. FSS can provide the same services and items as LISS without the cost cap and other limitations. In FY14, 8259 individuals and families received support services through the DDA but the number of people waiting for services has grown. As of January 2016 there were over 4400 people under age 22 with developmental disabilities on DDA's waiting list, with 28 in the Crisis Resolution and over 455 in Crisis Prevention. Respite care is one of the most frequently requested services but it is only available to a limited number of families through DDA, OHR and Office of Genetics.

The Autism Waiver currently serves 1000 children and is administered by the Maryland State Department of Education (MSDE). It provides access to Medicaid, service coordination, respite care, in-home supports, behavioral supports, intensive therapeutic integration, family consultation, and other services. Children with autism are eligible until the end of the school year in which they turn 21. More than 4000 children are on the Autism Waiver registry waiting for services. Only fifty to seventy-five slots become available each year. Many children age out before they ever receive service. The Autism Waiver has one thousand slots with \$18M in state funds matched with federal funds. In 2012, the Maryland Commission on Autism issued a final report with recommendations for an integrated system of training, treatment and services but no action has been taken since.

A Habilitative Services Workgroup in 2012 developed a guide for parents about habilitative service, now distributed at IEP meetings. All medically necessary habilitative services for children with autism now include behavioral health treatment, including ABA.



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In 2014, DDA requested the Council's partnership in implementing a Community of Practice for Supporting Families (CoP). The tools used by the Community of Practice can be infused within the system of formal supports that plan with families as well as help create and maintain informal supports for families. CoP will help people think about what a good life means to them, what life experiences help point them in that direction and provide resources that support families, their needs and the needs of people with developmental disabilities. The DD Council and DDA will expand CoP in upcoming years, with the DD Council taking a lead role in facilitating the expansion.

Informal supports vary across the state. There are local parent-led groups, including five local affiliates of National Down Syndrome Society and six Autism Society chapters. Families also find informal supports through local Arcs. The Parents' Place of Maryland, the federally mandated Parent Information and Training Center, also offers supports to families through information and referral, training, programs and other formal and informal supports, including four parent leadership programs.

Supports to Adults:

Most people with developmental disabilities are supported by their families, not formal services. Braddock et. al. estimate that over 69,000 Marylanders with developmental disabilities (75%) are supported by a family caregiver. For individuals with developmental disabilities in Maryland who do receive formal supports and services, the majority are funded by the DDA. DDA-funded services are delivered by licensed service providers, most of which are non-profits and are paid through the Medicaid Waiver, Community Pathways. Community Pathways includes nineteen different types of services to assist individuals to live and work in the community, including the option to self-direct their services and are based on individual assessed need. Currently, the DDA is undergoing a stakeholder input process to make changes to the Community Pathways Waiver with a stated intent to "create a more flexible, person-centered, family oriented system of supports."

In 2016, the DDA provided community supports to nearly 14,000 people with developmental disabilities in the Community Pathways waiver, including residential and personal supports, day/employment supports, and individual support services. By 2017, the total is expected to increase. As of January 2016, nearly 8000 people were on the Waiting List for ODA-funded community services with 94 in Crisis Resolution, 1,219 in Crisis Prevention, and 6,604 in Current Request. Nearly 1,400 people on the Waiting List have a family caregiver over the age of sixty. Maryland ranks 36th in the nation in terms of commitment to funding services to support people with developmental disabilities in the community ("fiscal effort").

The Community First Choice (CFC) and Home and Community-Based Options Waiver (HCBOW) provide assistance with Activities of Daily Living (ADL's) and accessing the community, to Medicaid



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recipients who have a chronic illness, medical condition or disability. Services are provided in the person's home or in an assisted living facility if the individual is enrolled in the HCBOW. CFC is a "State Plan" service so there is no limit to the number of eligible individuals who may receive services but there are significant waits for services. The HCBOW stopped accepting community applicants and started a registry.

Institutions:

The DDA operates two State Residential Centers (SRCs) for people with developmental disabilities. Currently there are 61 people living at Holly Center and 39 people living at Potomac Center. The annual cost per person at Potomac rose from \$170,000 in 2009 to \$318,00 in 2015. A Written Plan of Habilitation (WPH) is developed annually for each SRC resident to determine the most integrated setting and barriers to achieving it. In 2014-15, community living was determined to be the most appropriate integrated setting for 93% of people living in SRCs, with family opposition the most prevalent barrier. The DDA also operates two facilities for people with developmental disabilities involved in the criminal justice system—an evaluation unit with a twelve-person capacity, and a therapeutic unit with a capacity of twenty and stays intended to not exceed two years. Increased attention to diversion lessened the demand on these facilities.

Outcomes:

National Core Indicators assesses the outcomes of services through a sample of about four hundred people receiving DDA services. Here is select Maryland data: Fifty percent (50%) said they chose where they live and who they live with. Seventy percent (70%) said they decide or have input in choosing their daily schedule, and 90% said their staff treat them with respect.

Relationships:

Research shows that friendships can have a major impact on health and well-being and that our relationships are a significant reason for happiness. Maryland National Core Indicators data reveals that 72% of respondents reported that they have friends other than family or paid staff. However, 40% of those surveyed reported feeling lonely at least half the time. Despite the importance of having enriched relationships, developing and maintaining relationships often gets little, if any, attention in our service system.

Disparities:

Data from the DDA is not consistent and comprehensive enough to draw credible conclusions about disparities among people on the waiting list or people receiving services. A significant number of people (18% on the waiting list) are categorized as "other" or "unknown" with regard to race/ethnicity and Hispanics are not separately categorized, despite being the fastest growing sub-population. Thirteen percent (13%) of students with disabilities are Hispanic compared to 9% of Maryland's overall population.



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Four percent (4%) of Autism Waiver enrollees are Hispanic compared to the 10% of students diagnosed with Autism Spectrum Disorder.

Interagency Initiatives

The Council takes an active role and has a high degree of involvement in many initiatives and related coalitions, committees, and councils. These interagency initiatives seek to improve and enhance community services and supports and other assistance to Marylanders with developmental disabilities and their families.

The Council serves on all of the groups listed below:

The Home and Community Based Services (HCBS) Community Settings Rule Transition Team is made up of the Department of Health & Mental Hygiene DHMH, people with developmental disabilities, family members, Disability Rights Maryland (DRM), The Arc Maryland, and providers. The Transition Team advises DHMH regarding implementation of the State's HCBS transition plan.

The Quality Advisory Council represents the DDA, Maryland Department of Disabilities (MDOD), Medicaid, people with developmental disabilities, family members, Maryland Association of Community Services MACS, The Arc, DRM, and providers. The Quality Advisory Council provides input and recommendations on implementation and enhancements to the DD waiver and quality management system. The Chair is a person with a developmental disability.

The Maryland Interagency Transition Council for Youth with Disabilities includes representation from the Maryland Department of Disabilities, the Maryland State Department of Education, the Developmental Disabilities Administration, the Mental Health Administration, the Department of Human Resources, the Department of Labor & Licensing Review (DLLR), and parents. This body conducts activities to promote interagency collaboration related to transition, and recommends policies and resources that support a seamless transition process to the governor.

The Autism Waiver Advisory Council is made up of representation from MSDE, DHMH, and families of children with autism. This Council advises MSDE on issues and policy regarding the Autism Waiver and supports for children and their families.

The Office of Child Care Advisory Council is made up of representation from MSDE, DECD, and DSE/EIS, the Maryland Family Network, and the Governor's Office for Children. The OCCAC advises on issues and policy regarding licensed child care.



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The Special Education State Advisory Council has representation from MSDE, local school systems, parents of students with disabilities, IHE, DHR, and Dept. of Juvenile Services. This body advises MSDE on special education policies and practices, including the disproportionate representation of students in special education from minority racial/ethnic backgrounds.

The Early Childhood Advisory Council has representation from MSDE, DHMH, the Governor's Office for Children, Maryland Family Network, child care state associations, and early childhood education providers. It identifies strategies for making the greatest gains in early care and education, and advises the State. The ECAC also examines school the readiness gap for English as a second language learners.

The State Interagency Coordinating Council, made up of MSDE, the Governor's Office for Children, MDOD, DHMH, and parents of children with disabilities, advises the Maryland Infants & Toddlers Program, ensuring collaboration among participating agencies and communication to local coordinating councils. The SICC also reviews racial and ethnic data to identify inequities.

The Office of Child Care Advisory Council includes representation from MSDE, DECO, Maryland Family Network, and the Governor's Office for Children.

The OCCAC advises on issues and policy regarding licensed child care and inclusive practices.

The Maryland Community of Care Consortium for Children with Special Health Care Needs includes the Parents' Place of MD, the Office of Genetics & Children with Special Health Care Needs, and parents of children with disabilities. The Consortium implements strategies aimed at achieving an integrated, community-based system of services for children with special health care needs.

The Saylor Alliance Steering Committee includes MDOD, DDA, the MD State Police, the Police & Correctional Training Commissions, DRM, community organizations, people with developmental disabilities, and family members. The Steering Committee focuses on preparing & supporting people with developmental disabilities to train law enforcement.

The Maryland Coordinating Committee for Human Services Transportation (Dept. of Transportation, DHR, DHMH, MDoA, DLLR, MDOD, Dept. of Veterans Affairs, DORS) examines the transportation needs of seniors, people with disabilities, and low-income citizens. The committee also coordinates Maryland's effort to provide quality transportation services.



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In addition to serving on all of the above groups, below are listed other interagency initiatives that the Council follows and serves in an advisory capacity as needed or called upon:

- Maryland Money Follows the Person Advisory Committee (Medicaid, DDA, MHA, PWD, DRM) advises the State in its efforts to re-balance the system toward community services.
- Maryland Access Point (MDoA, MDOD, DHMH, DHR, CILs) focuses on providing streamlined access to information and resources involving long term supports and services.
- The Maryland Caregivers Support Coordinating Council (MDoA, DHMH, OHR, MDOD, family members) coordinates statewide planning and implementation of family caregiver support services.

Diversity:

Although numerous entities include family members from minority backgrounds, only two (HCBS Transition Team & Quality Council) include a person with developmental disability from a minority background. People with developmental disabilities are typically represented on committees by People on the Go, and both of POG's two staff are white. Not only is more diversity needed to reflect the state's demographics, but more entities, including those focused on children's issues, should have members with disabilities.

Quality Assurance

The Office for Health Care Quality (OHCQ):

OHCQ licenses and monitors community programs and state institutions through annual surveys and incident reports about abuse, neglect, financial exploitation, and other issues. Chronic staffing shortages and an increased workload challenge the Office's ability to meet its goals. In FY2014, the agency completed 36% of annual re-licensure surveys, falling short of the intended 45%. OHCQ has implemented a targeted survey process that has increased the number of surveys completed. Ultimately the agency's goal should be to complete 100% of annual re-licensure surveys, consistent with its statutory mandate.

Maryland's Protection & Advocacy group: Disability Rights Maryland (DRM):

DRM was until recently the Maryland Disability Law Center (MDLC). DRM works with OHCQ, DDA and MD Medicaid to identify and address systemic problems within community agencies. DRM asserts that while OHCQ monitoring and investigation of DDA provider agencies has improved in capacity and quality in recent years, there is still inadequate disciplinary action for those provider



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agencies that systematically fail to comply with regulations to ensure individual health and safety. DRM maintains that too often the provider agencies consistently failing to comply are not closed. As a result, DRM identifies a problem with monitoring and enforcement in the regulatory structure. While many DDA regulations are protective of individual autonomy and rights, such as the individual planning regulations, other regulations are inadequate to ensure systems of support meet individual needs with monitoring and enforcement of behavior support services of particular concern. However, DRM knows of no incidents of seclusion and it appears that providers generally comply with Maryland's strong protections regarding restraint. Specific concerns involve reports of individuals with inadequate behavior support services, who experience psychiatric ER visits, hospitalizations, other 911 calls and arrests. Restraint, seclusion and other trauma are the norm in hospitals, jails and prisons.

In studying the DDA behavior supports program, DRM finds that competent and experienced provider agencies are deterred from serving people with intensive behavior support needs because of changes in DDA reimbursement practice. Other, less qualified and experienced agencies are agreeing to serve people whose needs are beyond the provider's capabilities and who have inadequate support from DDA's behavior support system. DRM asserts that people may be at risk of serious harm and long or short term institutional confinement due to inadequate behavior supports and lack of oversight to ensure compliance with regulations.

National Core Indicators Data:

Maryland implements the National Core Indicators and approximately 400 surveys are conducted. The tool is not intended to be used for monitoring individuals or providers; instead, it assesses system-wide performance. The following statistics are NCI survey participation relative to the percentage of the state population: 2% of those surveyed were Asian (6% of MD pop is Asian); Hispanic 1% (9%); Black 35% (29%) and White 61% (53%).

Self-Advocacy:

Maryland's statewide self-advocacy movement for people with developmental disabilities is led by People On the Go of MD (POG), which is sponsored by the Council and the Maryland Center on Developmental Disabilities. There are 11 self-advocacy groups currently affiliated with POG and 3 known independent self-advocacy groups. The Council has a long history of supporting the self-advocacy movement. Since the late 1980's the Council has supported local and statewide groups to: 1) become more knowledgeable about their rights; 2) impact issues important to them; 3) develop skills in order to participate more actively in advocacy and the political process; 4) provide training; 5) and build their memberships. As a result of these projects, advocates have become more active participants in working for change, and POG is readily recognized and respected in the General Assembly.



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From 2003- 2010, the Council supported the Cross Disability Rights Coalition, a collaboration between POG and Maryland ADAPT. In 2010, the Council shifted support to focus only on POG in order to build momentum on key DD issues. Challenges related to self-advocacy in Maryland include: 1) increasing the number of people who remain active in the self-advocacy movement and help lead, including young adults; 2) the need to improve training for facilitators/support ; 3) inadequate transportation to meetings and advocacy events; 4) the need for more support from providers. POG reports that its membership is under-represented from different races and cultures.

Leadership Development:

The Council funded and supported Partners in Policymaking (PIP) for 10 years at \$100,000/yr. In 2004, the Council stopped funding PIP and instead funded the development of a new leadership development program, called Leaders in Disability Policy (LDP), which trained people for two years. PIP and LDP did not continue after Council funding ended. A survey of graduates from seven MD PIP classes found 42% rated their advocacy skills good or excellent prior to PIP compared to 100% after graduating. There have been no other leadership development programs in the state of the magnitude of PIP and LDP for people with developmental disabilities or family members. However, far less-extensive programs have periodically been held, sometimes with Council small grant support. Examples include Special Education LEADers conducted by Parents' Place of MD and the Youth Leadership Forum.

Priority Issues include:

- 1) Training the next generation of leaders so more people with developmental disabilities and family members impact issues at local and state levels; .
- 2) Developing approaches that are affordable, sustainable and result in ongoing engagement of graduates;
- 3) 3) Reaching under-served areas & people from diverse racial & ethnic groups;
- 4) Enlarging the pool of people with developmental disabilities & family members who are prepared to fill staff, board and other roles.

Education/Early Intervention

The Maryland Infants & Toddlers Program (MITP):

MITP provides early intervention services for more than 17,000 infants and toddlers and their families annually, a 78% increase over the last ten years. State funding was last increased in 2009 to \$10.4M, where it remains today. There has been a 20% increase in the number of children eligible for MITP services, resulting in a 17% decrease in state funding per child. MITP services are provided through



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twenty-four local ITPs. Early childhood programs are now required to conduct developmental screenings. Each local ITP submitted a written plan to the Maryland State Department of Education (MSDE) to ensure the provision of year-round services.

In 2009, Maryland became the only state to offer families the choice to continue to receive early intervention services (EIS) up to the beginning of the school year following the child's 4th birthday if the child is eligible for preschool special education. Sixty-seven percent (67%) of families with an eligible child chose the extended option.

About 12,000 children, ages 3-5, receive pre-kindergarten special education with an IEP. Fifty-six (56%) attend a regular early childhood program and receive the majority of their services in that program. Nineteen percent (19%) attend a separate special education class, school or facility. Maryland received a \$15M pre-kindergarten expansion grant to further expand high quality preschool programs.

Education: K- 12 and Transitioning Youth:

MSDE serves about 92,000 students with disabilities ages 6-21. MSDE has a strategic plan to narrow the achievement gap and improve results. MSDE is now using a framework to supervise and engage with local school systems (LSS) and provide resources, funding and technical assistance (TA). Supervision and interventions are increased if a LSS is not meeting the needs of children with disabilities. More data is being collected to inform the decisions and actions of the LSSs.

Maryland now applies the principles of Universal Design for Learning (UDL) in the development and provision of curriculum, instructional materials, instruction, professional development, and student assessments.

In 2014, students receiving special education services demonstrated a 3.4% improvement in graduation rates, as compared to a 1.4 % increase for all students.

In 2012, Maryland was one of four states to begin participating in the SWIFT project. Four schools in four LSSs now receive technical assistance to bridge general and special education through academic and behavioral supports for all students. SWIFT helps school systems to create learning opportunities for all students and helps to engage all partners, including families and community members.

The Developmental Disabilities Administration's (DDA) Transitioning Youth Initiative (TYI) is for young adults with developmental disabilities who exit school at age twenty-one and require supports to



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integrate into work, college and/or other activities. In FY 2015, approximately six hundred students received supports through the TYI.

From 2007 - 2012 several school systems in Maryland participated in the Maryland Seamless Transition Collaborative. Implementation of the model resulted in improved post-school outcomes for youth with disabilities. As a result, local transition councils were established and a few of the LSS's embraced the model, implementing it county-wide.

The Governor's Interagency Transition Council for Youth with Disabilities (IATC) coordinates and implements interagency planning for the delivery of services to improve the post-secondary school outcomes of youth with disabilities.

In 2013, the Maryland Legislature created a task force to study the expansion and availability of credit and noncredit courses for students with intellectual and developmental disabilities at colleges and universities. A report with eighteen recommendations was released January 2016. In 2012, the Maryland Department of Disabilities (MDOD), the DDA and the Division of Rehabilitative Services (DORS) began a SUCCESS program (Students United for Campus Community Engagement for Post-Secondary Success) at the University of Maryland Baltimore County. The SUCCESS program was Maryland's first four year college program for students with intellectual disabilities. However, students are no longer being accepted into that program and it will end. In August 2015, a Maryland collaborative applied for a Transition and Post-Secondary Programs for Students with Intellectual Disabilities (TPSID) grant but did not receive it.

Maryland has established the College & Career Readiness Standards and new assessments to ensure students are meeting federal standards. New assessments were fully implemented in the 2014-2015 school year with accommodations available to students with disabilities. Beginning in the 2015-2016 school year, an assessment for students with the most significant intellectual disability was implemented.

Data, Diversity & Disparity:

In the last two years, there has been a 7% increase in Hispanic families in the MITP and a 6% increase in students with disabilities (3-21) who are English Language Learners. Hispanic children receiving early intervention services are less likely to be ready for kindergarten and are more likely to receive services in a more restrictive environment.

There is a disproportionate representation of students in special education from racial/ethnic backgrounds. LSSs are required to report on this and MSDE monitors and provides guidance.



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The placement rate of students with disabilities into general education classrooms has steadily increased. Maryland currently serves 68% of students with disabilities in the general education setting, at least 80% of the day. However, 13.3% of students with disabilities are served in general education classrooms less than 40% of the day and 6.9% are in separate schools. Students with disabilities from racial/ethnic minority backgrounds are more likely to be placed in separate classrooms/schools.

Housing

Background:

Policies, financing strategies and programs in Maryland that address affordability have improved as a result of persistent advocacy, but most low-income people with disabilities still find housing unaffordable. National and state data confirm that low-income people with disabilities are experiencing severe housing affordability problems. It is virtually impossible for people with disabilities receiving Social Security Income (SSI) to obtain affordable and accessible housing in the community unless they receive rental housing assistance.

The 2015 SSI payment in Maryland for an individual is \$733/month, equal to 14% of the statewide area median income (AMI). Income below 30% of AMI is considered "extremely low income" by the Department of Housing and Urban Development (HUD). According to the federal standards, housing is considered affordable if it consumes no more than 30% of a household's income. Using this standard, an individual whose sole source of income is SSI can afford \$220 in monthly rent. However, the statewide Fair Market Rent (FMR) for a one bedroom apartment in Maryland is \$1,049, with a range of \$537 to \$1,307 depending on the area.

It is commonly believed that the answer to the housing affordability gap for people with disabilities is employment. National Housing Wage data makes it clear that when people with disabilities move from the SSI program to employment, many are still likely to experience housing affordability problems unless they make significantly more than minimum wage. The "Housing Wage" is the hourly wage a person would need to earn to pay the Full Market Rent in Maryland. Currently, the "Housing Wage" for Maryland is \$20.16 for a one-bedroom apartment, spending no more than 30% of income on housing costs. Comparatively, SSI payment in 2015 is equivalent to an hourly wage of \$4.23.

Housing Resources - Essential but Limited

Efforts in Maryland to address affordability for people with disabilities at extremely low incomes generally fall into these categories:



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1. **Rental Assistance:** Housing Choice Vouchers are the most common rental assistance. Recipients pay 30% of their income toward rent and the voucher covers the balance. There are extremely long waiting lists in most counties.
2. **Bridge Subsidy Program:** Provides short-term rental assistance while people await permanent housing assistance. The latest iteration is for people served through the Money Follows the Person (MFP) initiative.
3. **State Housing Finance Programs:** The Department of Housing and Community Development (DHCD) has resources that help developers lower their debt if they set aside rental units for people with disabilities at lower incomes. To reach people with extremely low incomes, rental assistance is typically also needed.

The Weinberg Foundation has contributed \$4M to date toward the development of integrated rental units for people with disabilities, affordable at SSI-level income through an innovative initiative. Weinberg subsidizes building costs to allow units to be offered at rents affordable to people with disabilities between 15-30% of the Area Median Income. This is believed to be the first state-foundation partnership of its kind in the nation and was initiated by Maryland Dept. of Disabilities (MDOD) and the Council.

MDOD has taken a lead role in developing a strategic plan to enhance existing housing programs and ensure sustainability of Maryland's vision that people with disabilities will have affordable, accessible, integrated housing of their choice.

Disparities:

There is no Maryland-specific data collected that identifies disparities based on disability. Surprisingly, DHCD's "Housing Analysis" in its "Consolidated Plan" notes that all types of households had substantial housing needs without substantial difference due to household size, makeup, race, or other factors. However, U.S. HUD's 2015 "Worst Case Housing Report" notes that nationally 14.1% of rental households with "worst case housing needs" included at least one non-elderly person with a disability. Relative to race/ethnicity, worst case needs affected 44.1% of Hispanics and 44% of non-Hispanic White renters with very low incomes but a significantly lower proportion, 35.5%, of non-Hispanic Blacks.

In terms of geographic location, we know that people in areas of high cost housing (particularly Montgomery and Howard counties) have a harder time affording housing and people have a harder time finding accessible housing in areas with older housing stock like Baltimore City.



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Transportation

Accessible, available, affordable, and reliable public transportation is critical in supporting independent living for people with developmental disabilities. Inadequate levels of service times, geographic coverage, and insufficient accommodations for people with disabilities lead to a system of public transportation that is often cited as being an obstacle to finding and keeping gainful employment and for full participation in all facets of community living. The Maryland Department of Disabilities (MDOD), has prioritized working toward improved access to public transportation for people with disabilities in their strategic plan, addressing many barriers of concern to people with developmental disabilities. MDOD's efforts include improving on-time performance of the MTA, increasing the number of accessible taxis in the greater Baltimore region, increasing Travel Training opportunities, and streamlining cross-jurisdictional travel allowing transportation routes to cross County lines.

Overview of Public Transportation in Maryland:

The Maryland Transit Administration (MTA) is a part of the Maryland Department of Transportation. The MTA provides both fixed route and demand- response options for people with disabilities.

Fixed Route: In the Baltimore metropolitan area, fixed route public transportation service is operated by the MTA. Services include buses, subway, light rail, and trains. All buses have wheelchair lifts and/or kneeling capability and utilize stop announcements. Subway access is through level boarding with mini-high platforms to access light rail. In metropolitan areas, fixed route services run seven days a week with evening hours.

Outside the Baltimore metropolitan area, fixed route and demand/response is overseen by Locally Operated Transit Systems (LOTS). A county's LOTS service varies in relation to the jurisdiction's size and population density. Some jurisdictions have extensive fixed-route service; others offer demand-response with door-to-door service. Some offer limited or no fixed route options on weekends, with some jurisdictions lacking evening service. Travel training is provided for people with developmental disabilities through mobility management, providing individualized training leading to the ability to ride a fixed route service safely and independently.



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Demand Response: MTA operates Mobility/Paratransit "origin to destination" with lift-equipped buses for people with disabilities who are not able to ride fixed-route public transportation. Door-to-door service is provided where possible, with decisions made through paratransit plans at the local level. Mobility/Paratransit service operates within $\frac{3}{4}$ mile of any fixed route. This is problematic for people with disabilities living outside the service area without a safe and accessible way to travel the distance needed to be inside the service area. If pick up/drop is outside the service area, paratransit may not serve that location.

Call-a-Ride: A shared ride service, Call-a-Ride is available throughout the service area 24/7, from the first exterior door of the pick up or destination. It is a demand/response service limited to the Baltimore metropolitan area. The service is for MTA-certified Mobility/Paratransit customers meeting eligibility requirements and is provided by participating taxicab and sedan companies. Call-a-Ride does not require advance registration, operates 24 hours a day 7 days per week with a discounted rate and up to three additional passengers riding free of charge. All applicants must be capable of boarding, riding, and exiting vehicles either independently or with the assistance of a companion. A limited number of wheelchair accessible taxis and sedans are available to eligible individuals with mobility impairments who use motorized or non-folding wheelchairs.

MetroAccess: MetroAccess is a shared ride service provided by Washington Metropolitan Area Transit Authority (WMATA) for people with disabilities unable to use fixed-route public transit throughout the Washington Metropolitan region. WMATA provides service to two capital region Maryland counties: Montgomery and Prince George's. Rides are offered in the same service areas and during the same hours of operation as Metrorail and Metrobus.

Disparities:

The MTA does not collect data on ethnicity, race, age, or gender. People with developmental disabilities and advocacy groups identify excessive travel, wait and hold times, and limited availability of accessible vehicles as barriers to access and use of transportation. In rural areas, limited fixed route options in evenings and weekends as a result of lack of funding make access to work or recreation during evenings and weekends virtually impossible. The Maryland P&A, Disability Rights Maryland (DRM), reports that people with disabilities complain of unfavorable bias from MTA employees. DRM is involved with litigation on behalf of riders who have been determined to be ineligible for Mobility/Paratransit or have experienced prohibitive hold times when attempting to schedule a ride.

Child Care



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A 2012 Council report noted that 72% of families had difficulty finding and keeping child care for their child with a disability. Fifty-three percent (53%) of families removed their child from a program because the provider was not adequately trained to support their child; ninety-two percent (92%) of child care providers reported willingness to receive more training to help them serve a child with a disability. Almost all 15 recommendations the Council included in the report regarding needed change in Maryland have been implemented.

There are about 1580 licensed child care centers with the capacity to serve 163,370 children; 7100 licensed family child care programs with the capacity to serve 53,710 children, and 1760 licensed before after school programs in Maryland. In addition, there are a total of 1000 head start and public prekindergarten locations. The Office of Child Care (OCC) within the Maryland State Department of Education (MSDE) licenses and monitors all programs. The OCC also administers Maryland's child care subsidy program for working families and administers the state's Child Care Credentialing System and other training programs for child care staff.

Most of OCC's funding is federal through the Child Care and Development Fund (CCDF) which subsidizes the cost of child care for eligible families through vouchers. The minimum spending requirement for quality initiatives will rise from 4% to 9% over the next five years and incrementally thereafter. The current CCDF State Plan requires the State to allocate funds for quality improvement and for services for infants and toddlers and school-age child care. In addition, DECD has identified the following priorities to improve access to and the quality of child care: 1) access to child care for children who are medically fragile, 2) professional development, and 3) resource and referral services. The next CCDF State Plan is being drafted with recommendations made by a workgroup that the Council participated in.

In 2011 Maryland was awarded a federal Race to the Top - Early Learning Challenge Grant. This grant provided \$50M over five years and funded ten projects designed to improve the quality of early childhood education. The largest project was Maryland EXCELS, a quality rating and improvement system for child care programs. Participation in Maryland EXCELS is mandatory for child care providers receiving subsidies and voluntary for others. The Council helped develop Maryland EXCELS and remains on the advisory committee. The quality standards include measures related to children with disabilities and inclusive practices. The Maryland EXCELS website includes information and resources about children with disabilities and inclusive practices for both child care providers and families.

The OCC modified the credentialing program for child care providers that has been in place since July 2001. It is a voluntary program that recognizes child care providers who go beyond the



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requirements of licensing regulations. There are six credential levels and four administrator levels, each recognizing a child care provider's achievement of a specified number of training hours, years of experience, and professional activities which lead to quality child care programs. The modifications require training about children with disabilities, inclusion, and the ADA. Less than 40% of child care providers participate in the program. By 2016, all child care providers will have to receive a specific training about the ADA and Inclusive Practices developed by the OCC, in conjunction with stakeholders, and mandated by Maryland regulations. All child care courses and workshops must include information on how the subject areas apply to children with disabilities. The tool used to rate each training before it is approved provides that all content address "special needs and inclusionary practices (using person first language) and ADA" regardless of the training. The Council advocated for these requirements.

Parents can find information and referrals for licensed child care with Maryland Family Network's LOCATE: Child Care Service, funded by the MSDE. Additionally, LOCATE: Child Care Special Needs Service provides enhanced services for families of children, birth - 21 years old, with disabilities or special needs. In 2014, LOCATE provided information to families of 811 children with disabilities and/or special needs.

As a result of the Council's advocacy and partnership with the OCC and others, policies and practices have become more inclusive of children with disabilities and their families. Despite progress, families of children with disabilities still face obstacles to finding and keeping high quality, inclusive child care and before and after care.

The Division of Early Childhood Development (DECD) within MSDE is responsible for early care and education in Maryland. The DECD's mission is to improve early education in Maryland so that children are well prepared for school. In 2014, the state updated the standards to evaluate readiness and implemented a new kindergarten readiness assessment to align with Maryland's new PreK-12 College and Career Readiness Standards. This data is collected by Kindergarten teachers each year and reported to the local school systems as well as MSDE. MSDE compiles statewide and jurisdictional school readiness data that is released annually.

MSDE data from 2015 reveals that 47% of all students entered kindergarten fully ready to learn, yet only 20% of kindergarteners with disabilities entered kindergarten fully ready to learn compared to 49% of their peers without disabilities. Data also reveals that where a child receives his or her care prior to kindergarten matters--only 33% of children at home and informal settings are ready.

National & State Initiatives and Opportunities:



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The Early Childhood Advisory Council (ECAC) created by Executive Order, brings together stakeholders to develop, implement, and oversee a statewide early childhood system and improve school readiness. Since being codified into law in 2014, the Council is a required member, and an assessment of the availability of high quality, inclusive child care where children with and without disabilities learn and play together is now required to be completed.

The Dispute Resolution Workgroup was designated in 2013 to make recommendations to the State Superintendent regarding rules and regulations to establish a uniform and timely dispute resolution process to resolve claims of discrimination by a child care provider based on a child's disability. The recommendations included a process for families to make a complaint when their child has been discriminated against by a child care provider based on their disability. Despite the recommendations, the OCC has not yet established a formal process. The workgroup's recommendations requiring training about the ADA and inclusive practices was completed.

MSDE and the Maryland Higher Education Commission are required to work together to develop a master plan to increase professional development for early childhood educators. One requirement is to include a plan ensuring students receiving bachelor degrees in early childhood education also learn about young children with disabilities.

The CCDF funding for quality initiatives will begin to increase by 1% annually beginning next year. This will result in more CCDF funds to be used by Maryland for quality enhancement in early child care and education programs. The CCDF funding will not increase as a whole.

Diversity Data:

17% of kindergartners are Hispanic. Almost 16% are English Language Learners (ELL). 28% of children five or younger have at least one parent who speaks a language other than English. Fifty-seven percent (57%) speak Spanish. There has been a 6% increase of children with disabilities who are also ELLs in the last 2 years. Only 21% of ELLs are prepared for school compared to 50% of English proficient students. Fewer Hispanic children (27%) are ready for kindergarten. Many initiatives under Race To the Top are geared toward ELLs and their families.

PART C. Analysis of the State Issues and Challenges

Criteria for eligibility for services



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The analysis of eligibility criteria used to determine access to specialized services provided by state agencies indicates that the following programs exclude some or all individuals with developmental disabilities from receiving services:

Waiver for Children with Autism Spectrum Disorder:

These services support children ages 1-21 with autism spectrum disorder in their homes and community. Children and adults with other developmental disabilities are ineligible, as are adults with autism spectrum disorder. Over 4000 children are on the registry, waiting for services. The waiver is capped at 1000 children per year. This waiver is administered by the Maryland State Department of Education.

Community First Choice (CFC) & Home & Community Based Options Waiver (HCBOW):

These inter-related programs provide services and supports to enable older adults and people with physical disabilities who are Medicaid eligible to live in the community and includes personal care, activities of daily living, and support for community access. The age criteria is 19-64 for CFC and requires institutional level of care. The age criteria for HCBOW is 18-64 and requires nursing facility level of care. People outside of this age range are not eligible. Individuals with disabilities who do not meet the level of care determination criteria are not eligible. These programs are administered by the Department of Health and Mental Hygiene, Office of Health Services.

Waiver for Individuals with Brain Injury:

Services include residential and day habilitation and supported employment for adults with brain injury ages 22-64. People with other types of disabilities are ineligible, as are people who acquired their head injury after age 17. In addition, only people in specified facilities are eligible; people living in private nursing facilities or at home who need and want these waiver services are not eligible. This waiver is administered by the DHMH, Mental Hygiene Administration.

Maryland Money Follows the Person:

While individuals with developmental disabilities residing in institutions are eligible for the MFP initiative, only people residing in nursing facilities are offered peer outreach and support and options counseling.

Affordable Rental Housing Opportunities Initiative for Persons with Disabilities:

Individuals with disabilities between the ages of 18-62 receiving SSI or SSDI and at 15-30% of area median income are eligible. People with disabilities that fall outside these parameters are not eligible.

Maryland Department of Disabilities (MDOD) Section 811 Project Rental Assistance Program:

Medicaid recipients with disabilities between ages 18-62 are eligible. Others are not.



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Division of Rehabilitation Services (DORS):

DORS offers short-term programs and services that help people with disabilities go to work or stay independent in their homes and communities. DORS is required by federal law to serve people with the most significant disabilities first. To comply with this law, DORS determines the severity of the disability of individuals who are eligible for services as follows: Most Significant Disability (Category 1), Significant Disability (Category 2), and Non-severe Disability (Category 3). People who receive SSI or SSDI or people who are eligible for DDA funding are presumed to be eligible for DORS. Because funding for rehabilitation services is limited, individuals with the most significant disabilities are served first without a wait. Even if eligible, people with less significant disabilities may not receive services. DORS is now required to use 15% of its federal funds to support pre-employment services to students with disabilities. Services are available beginning at age 14. Currently, over 3,175 people are on the DORS waiting list. DORS is part of the Maryland State Department of Education.

Analysis of the barriers to full participation of unserved and underserved groups of individuals with developmental disabilities and their families

Barriers to full participation of unserved and under-served groups are associated in Maryland primarily with geographic distinctions (rural vs. suburban and urban areas) and differences in ethnicity/race.

Under-served rural areas include the Eastern Shore, Western, and Southern MD. The Eastern Shore covers 34% of Maryland's land, while only 8% of the population lives there. Western Maryland covers 15% of the land with only 4% of the population. Barriers to full participation in these regions include lack of health care providers, inadequate access and availability of public transportation, higher unemployment rates, fewer adult service providers resulting in less choice of provider and limits in types of services and supports available. There are also limited opportunities for learning about best practices and networking.

Employment outcomes reflect disparities. 37.7% of people with developmental disabilities in Central Maryland have integrated jobs compared to 33.2% in Western Maryland; 32.1% in Southern Maryland, and 16.7% on the Eastern Shore.

Increasing paid employment opportunities in the community was the number one priority indicated by people in rural areas who responded to the Council's State Plan survey. Also a significantly higher number of respondents from rural areas indicated there was a lack of access to information in general and reliable, affordable transportation.



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In these less populous regions, people with disabilities and their families also experience a lack of health care professionals, especially specialists. In order to access specialists many families travel to Baltimore or Washington, D.C.

Hispanic families of children with developmental disabilities are another underserved population in Maryland. Data from the 2015 Kids Count provides a snapshot of the growth of Maryland's Hispanic community over the past five years--the number increased by 15%. In 2009-2010, the Council funded a study to determine the extent to which Hispanic families with a member with a developmental disability have the same access to information and resources as other people with developmental disabilities and their families in Maryland. The study revealed that many Hispanic families need assistance with understanding and navigating the service system. The DDA does not collect data on the number of Hispanic people served, and therefore the extent to which these families are accessing DDA-funded services is unknown. Examination of DDA data about people on the waiting list and receiving services indicates that whites and blacks are proportionately represented based on the census. Asian Americans may be under-represented but a valid conclusion cannot be arrived at because the ethnic/race data for nearly 10% of people is "unknown."

In identifying these underserved groups, the Council reviewed and analyzed data and information from a variety of sources, including the U.S. census, National Core Indicators, state agency reports, research, and surveys. Too often there was inadequate data to draw valid conclusions. Collected information was compared to data about groups of people who traditionally have more access to services and supports, as well as activities already in place to address identified barriers. Questions considered were: 1) Is the disparity already being targeted by another Maryland leader? 2) Is the disparity a result of a failure from within various organizations to meet needs? 3) Is the disparity a result of outside factors? and 4) Do we have valid data to demonstrate a disparity?

After Council review, a workgroup was formed for further discussion and analysis. With critical analysis of data, state plan survey results, and other information combined with input from the workgroup, the Council identified people with developmental disabilities living in rural areas as the underserved population in Maryland to focus on, particularly in light of solid documentation of employment outcomes significantly lower than in more populated areas of the state.

The availability of assistive technology

A variety of assistive technology (AT) services are available in Maryland for people with developmental disabilities. The Administration on Community Living (ACL) funds Maryland's



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Technology Assistance Program (MD TAP). MDTAP provides AT services across the state. Services include equipment demonstrations, short-term device loans, an online equipment exchange program providing people with access to gently used AT, statewide AT training, and public awareness initiatives. MDTAP also administers the AT Loan Program and Work ABILITY Loan Program. These programs allow qualifying Maryland residents with disabilities and their families to receive low-interest loans to buy AT to help them live, work, and learn more independently. Additionally, MDTAP supports an AT cooperative buying program providing discounts on AT products for people, families, and education entities.

The Maryland Division of Rehabilitation Services (DORS) offers AT support to prepare people with disabilities to work and live independently. Other AT services are provided by the Workforce & Technology Center which offers career assessments, skills training and job placement. In FY15, DORS authorized purchases for AT services and devices in excess of \$2.3 million for adults with disabilities. The average cost of the AT device per adult was approximately \$2,225.00.

The Johns Hopkins University Center for Technology in Education (CTE) partners with MSDE to research, advocate, and disseminate information about effective policies and practices supporting use of AT. The CTE trains educators on how to assess the learning needs of their students with disabilities and to how to implement individualized AT services aiding in the process of removing achievement barriers in academic settings.

Disability Rights Maryland (DRM) -- Maryland's P&A (previously known as the MD Disability Law Center) assists Medicaid-eligible individuals with disabilities to access AT devices and services including augmented communication devices. An average of 35 people a year from FY2011-2015 benefited from the project. DRM advocates for children receiving special education services to ensure AT needs are met, including students transitioning from school to adult services.

The Council partnered with the P&A (DRM) and People on the Go (Maryland's self-advocacy group) to educate Coordinators of Community Services on AT communication devices and how to support people with developmental disabilities in the Individual Plan process. Efforts resulted in the first person with a developmental disability in the state to be approved for an iPad as a communication device through Medicare.

Through grant funding, the Council provided training on the use of AT to over 100 families and professionals who work with people with developmental disabilities in Western MD, and supported the creation of credit and non-credit professional development courses at Frostburg University on a variety of AT topics. In partnership with Judy Centers and Head Start, 140 home and center-based



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child care providers were taught how to create low-tech adaptations and implement accommodations to include children with developmental disabilities in typical child care settings.

Gaps:

- 1) There is a lack of knowledge that Medicaid will pay for medically necessary AT for students who receive Medicaid. Additional outreach and education is needed for individuals, families, schools, speech and language professionals, and service coordinators.
- 2) There continues to be a lack of qualified speech and language pathologists to perform assessments for individuals covered by Medicaid. The few that exist are almost exclusively located in the Baltimore/DC/Metro area.
- 3) Medicaid/Medicare continues to deny purchasing iPads for Augmented Alternative Communication (AAC) applications. DORS and Autism Waiver services have proven to be an alternative source for funding the iPad with the recommended AAC software. The Council will sustain the relationship with DRM to continue addressing this policy barrier so more people can obtain AT supports and services needed to better communicate wants and needs.
- 4) According to DRM, outreach to and education of AT vendors is needed on how to obtain payment for AT when people transition from nursing facilities to community services. There is a mechanism in place when an individual is expected to transition within 90 days; however, most providers and mid-level state Medicaid staff are not aware of the process.

Waiting Lists *

Numbers on Waiting Lists in the State

a.

Year	State Pop. (100,000)	Total Served	Number served per 100,000 state pop.	National avg. served per 100,000	Total persons waiting for residential services needed in the next year as reported by the state, per 100,000	Total persons waiting for other service as reported by the state, per 100,000
2012	58,918	8049	137	142	69	0
2013	59,387	12,908	217	251	72	78
2014	59,764	13,042	218	0	95	0

b. Entity who maintains wait-list data in the state for the chart above



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Case Management Authorities Providers Countries State Agencies **X** Other

c. There is a statewide standardized data collection system in place for the chart above

Yes No **X**

d. Individuals on the wait-list are receiving (select all that apply) for the chart above:

No Services Only case management services **X** Inadequate services

e. To the extent possible, provide information about how the state places or prioritizes individuals to be on the wait-list

** Comprehensive services but are waiting for preferred options

** Other

Use space below to provide any information or data available related to the response above

Transitioning Youth

f. Description of the state's wait-list definition, including the definitions for other wait lists

The DDA Waiting List includes children and adults who have a current need for services, including those in crisis situations. Individuals who have a future need (more than three years) are placed on a separate "Future Needs Registry." People are eligible for all service categories funded by DDA (residential, day/employment and support services) if they have a developmental disability as defined in state law. A person has a developmental disability if they have a severe chronic disability caused by a "physical or mental condition" other than a sole diagnosis of mental illness that is manifested before the age of 22, that is likely to continue indefinitely and as a result the person cannot live independently without continuing assistance and the need for services that are individually planned and coordinated. If an individual does not meet the full definition of developmental disability but has a severe, chronic disability caused by a physical or mental condition (other than a sole diagnosis of mental illness) that is likely to continue indefinitely, he or she is eligible for support services only (not day/employment or residential services).

g. Individuals on the wait-list have gone through an eligibility and needs assessment

X Yes No

Use space below to provide any information or data available related to the response above

A person applies for DDA by completing an application, which is followed by an in-person interview conducted by DDA personnel or contracted Coordinators of Community Services within specified timelines. Eligibility and priority determinations are completed by DDA based on the application information, interview, and supporting



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documents and records. When the application process is complete, the applicant receives a letter indicating his or her priority category. Eligibility and priority decisions can be appealed. A person can request a review of his or her priority status at any time. DDA assesses each request for change in priority status and notifies the person of the determination and appeal rights.

h. There are structured activities for individuals or families waiting for services to help them understand their options or assistance in planning their use of supports when they become available (e.g., person-centered planning services)

Yes No

i. Specify any other data or information related to wait-lists

As of January 2016, the DDA waiting list totaled 7917 people in the following priority categories: Crisis Resolution: 94 people, Crisis Prevention: 1219 people, Current Request: 6604 people. Over half of the waiting list are people under age 22. They total 4419 with over 3200 eligible for comprehensive services and nearly 1200 eligible for support services only. Over 4000 people have a "caregiver" age 41-60; nearly 1200 have a caregiver age 61-80; and over 230 have a caregiver older than 80. Over 400 people in crises resolution and crisis prevention have a caregiver over age 60.

j. Summary of Waiting List Issues and Challenges

Other than serving all Transitioning Youth (TY) every year, the waiting list remains relatively constant due to a shortage of funding. Rarely are people in the Crisis Prevention (CP) category served (other than TY) and never those in the Current Request category, leaving a mostly crisis-driven system. From 1998-2004 a WL initiative funded 9,000 people. There has been no multi-year initiative since then to significantly lower the number of people waiting for support. In 2007 \$10 M was allocated for the WL and another \$15M in 2012 through an alcohol tax. The latter reached everyone in Crisis Resolution and provided services of a short duration to a portion of those in CP. Recently, tens of millions of dollars have been diverted from the waiting list and other needs when DDA has reverted unspent funds to the state treasurer and has had to re-pay Medicaid for disallowed billing. DDA has had a practice of designating young children eligible for "supports only" (SO), resulting in many families ineligible for family support services because it requires DD eligibility (see above). DDA has committed to changing this policy. Children and adults found eligible for SO had received case management while on the WL and historically some came off the WL and received services. People who are SO eligible do not qualify for the Medicaid waiver. Due to funding constraints, DDA withdrew case management services and has established a policy to only fund people through the waiver. This means SO eligible people have no chance of ever receiving services through DDA. An inter-agency response is needed to ensure these individuals are well-informed and referred to other resources, and that the gaps are addressed.



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Analysis of the adequacy of current resources and projected availability of future resources to fund services

DD Community Services:

The Developmental Disabilities Administration's (DDA) FY17 community services budget totaled \$1.1B, a 6% increase over FY16. The State of the States 2014 report ranks MD 36th nationally in terms "fiscal effort" based on the proportion of total statewide personal income devoted to financing DD community services. Community provider rates have increased over the past two years and the rate system is being restructured. The overall cost is not yet known.

Millions of dollars become available annually when people leave services but most go to fund additional supports for people already in the waiver. New funds must be allocated each year for people to come off the 8000 person waiting list. From FY2006-17 funding was allocated for people in the top priority category only half of the time. In addition, a special fund, the Waiting List Equity Fund, only funds approximately 25 people annually, which won't increase until the remaining institutions are closed. The vast majority of services in Maryland are already federally matched. It is likely that a capped supports waiver will be developed to serve more people. There are several strong indicators that DD community services remain among the top state funding priorities, including: transitional youth services have been funded for the past twenty years, even in the worst budget times; there has always been bi-partisan support for the budget; fiscal conservatives consistently name DD services as one of the top two priorities and the DD community has strong legislative champions on the budget committees.

Even as additional funding is made available, the need will continue to far exceed available resources. It will be essential to explore mechanisms like a Supports Waiver.

Education and Other Child-Serving Systems:

MSDE serves approximately 100,000 students with disabilities ages 6-21. School systems receive a basic per pupil funding amount. Supplemental aid is based on students with special needs, including students with disabilities. Decreased state funding for students with disabilities would require more supplemental funding by federal IDEA funds. Maryland offers discretionary grants to local school systems to further the inclusive education of students with disabilities but since federal and state resources are at risk, it is possible that less money will be dedicated to ensure students with disabilities are educated in the least restrictive environment.

Early intervention services (EIS) are available at no cost to families. Ten million in state funds are allocated for EIS - level funded since FY09. The state portion cannot exceed 20% of the total cost. There has been a 20% increase in the number of children eligible for EIS since FY09 with a 17% decrease in state funding per child. The vast majority of funding is from the counties. Dedicated funding is necessary to ensure sustainability and quality of services. In 2009, MSDE received \$14.4M in ARRA funds to create a birth-5 early childhood intervention and special education system of services that extended EIS to kindergarten age if the child is



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eligible for preschool special education services. Maryland now uses discretionary funding to continue to offer this option to children until the school year after their 4th birthday.

In FY14, funding for the Autism Waiver increased to \$18.2M for 1000 children (adding 100 slots). This is still inadequate with over 4000 children waiting. An additional \$1.5M in state funds is required to generate the federal match to increase the waiver by another 100 slots. Although CMS has approved the increase in slots, there has been no further appropriation. The Child Care Subsidy Program began a waiting list in 2011 due to funding reductions but received an increase in funding this year to support 18,610 children. About 3200 eligible children are waiting to be enrolled. This will grow until new funds are allocated.

Maryland received \$50M from Race to the Top Early Learning Challenge grant funding, which ended in 2015 but was used to expand resources to ensure high quality early learning programs for all children. Maryland also received a \$15M federal pre-K expansion grant in 2015, which must be matched with state funds, to provide services to 3800 additional children from economically disadvantaged backgrounds.

Analysis of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are in facilities receive

Maryland's Developmental Disabilities Administration operates two state institutions for individual with intellectual disabilities (ICF/IIDs) - Potomac Center and Holly Center. In addition, DDA operates two Secure Evaluation and Therapeutic Treatment (SETT) units, an evaluation unit with a 12-person capacity and a treatment unit with the capacity to serve 20. The SETTs are primarily for people who are or may pose risks to themselves or the community and are incompetent to stand trial or not criminally responsible. The SETTs are not licensed as ICF/IIDs because they do not meet the criteria. Maryland has no community-based ICF/IIDs.

The Office of Health Care Quality (OHCQ) is the agency within the Department of Health and Mental Hygiene charged with monitoring the quality of care in Maryland's State Residential Centers/SRCs (ICF/IIDs). Annual surveys have taken place within the past year. In the most recent annual surveys of the SRCs conducted by OHCQ, violations were cited in the areas of medication administration, nutrition, physical and chemical restraint, as well as physical plant maintenance.

Holly Center currently has 61 residents compared to 86 in 2011. Potomac Center currently serves 39 people compared to 55 in 2011. However, the Council, DRM and other advocates remain concerned at the slow pace of moving residents from ICFs/IID to community based services despite state reports that virtually all can live in the community and the fact that many already do receive day services in the community.

Per DRM, which monitors the ICF/IIDs, Holly Center appears to have improved the quality of services after being the subject of repeated Department of Justice investigations years ago. Per DRM, Potomac Center has experienced high-level professional staff turnover and OHCQ has reported numerous serious deficiencies in



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regulatory compliance with nursing regulations, so DRM is concerned that Potomac Center is not maintaining necessary standards for safe medication management. DRM has also been concerned that, at any given time, a small number of individuals at Potomac Center are frequently chemically restrained. This typically does not continue for long periods of time for most individuals.

The SETT facilities were a subject of intense focus by DRM, the Council and other advocates when the state proposed to build a new 60-bed facility. DRM noted at that time a number of problems with the SETT and civil rights violations, including that the state process for determining competency to stand trial was too lengthy, that determining whether a person with ID was competent and restorable should usually be relatively prompt, and as a result, people were being detained in the SETT for far longer than was necessary. The state agreed not to build a larger SETT and the process for determining competency and restorability now results in lengths of stay in the SETT that are far shorter. The SETTs have remained below capacity for several years.

Although it has not monitored recently, DRM remains concerned about previous observations that individualized programming was lacking, people were not able to learn or practice skills, people did not have access to pre-employment and employment services, residents were shackled and handcuffed for transportation to physician visits which was limiting their access to health care by doctors who objected, and the SETT was not providing all medically necessary care. In its most recent survey, which occurred in the past year, OHCQ found violations in safe hiring practices for both SETT facilities.

To the extent that information is available, the adequacy of home and community-based waivers services (authorized under section 1915(c) of the Social Security Act(42 U.S.C. 1396n(c)))

Autism Waiver:

The Waiver for Children with Autism Spectrum Disorder serves 1000 children. More than 4000 are on a registry waiting for services but only 50-75 slots become available each year due to turnover. So, even though early intervention is important, children spend years on the registry waiting for services, with many children aging out before they ever even receive services. Once a child with autism enters this waiver, services are individualized and comprehensive. Services have been more costly than originally anticipated, causing Maryland State Department of Education (MSDE) to seek additional state funds to cover deficit spending, rather than funds to increase slots. Centers for Medicaid & Medicare Services (CMS) has approved an increase of 100 slots per year but these have not been state funded so there has been no resulting expansion of the waiver.

Developmental Disabilities Home & Community Based Service (HCBS) Waiver:

As of May 2016, there were 13,895 people enrolled in the DD waiver, Community Pathways. With over 8,000 people on a waiting list, this is far from adequate. A multi-year waiting list initiative is needed, as well as a new Supports Waiver to significantly increase the number of people receiving some degree of support. Fortunately,



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funding is allocated each year for all transitioning youth as they exit the school system. As of May 2016, only 494 people were self-directing their services, with DDA's goal to expand this number significantly.

DDA is revamping the individual planning process to ensure a more person-centered approach and will be training Coordinators of Community Services to better support people to maximize self-direction and self-determination. Wages remain low, which affects the ability to attract and retain qualified staff, thereby impacting quality of services.

DDA has solicited stakeholder input and engaged external consultants to identify a wide range of waiver improvements and enhancements and has begun a process of waiver amendments. Far too much of the service system remains wedded to traditional models of service delivery but the HCBS Settings Rule is proving to be an impetus for significant change. As the system transforms, inadequacies in funding and capacity, coupled with DDA policies and practices, have made it increasingly difficult for families to find providers willing and able to meet the needs of people with the most significant needs.

More service providers have begun to recognize the need to transition to more integrated services, especially employment, and have begun the transition. Quality and innovation varies dramatically and more must be done to implement best and promising practices on a broader scale.

Other Waivers:

The Model Waiver Program, capped at 200, serves children with complex medical needs and is always at or near capacity. Because of improved health care and advances in technology, children with these complex needs are living longer, and their families' needs are changing over time. They would benefit from services not currently available from this waiver, including home accessibility modifications and respite care.

The Home and Community Options Waiver (HCBOW) recently combined the Older Adults Waiver and the Living at Home Waiver. It serves people with physical disabilities ages 18-64, who have a nursing facility level of care. For people in nursing facilities paid by Medicaid who want to move to their own homes, there is no waiting list. However, over 13,000 people in the community are on a registry for the HCBOW. Community First Choice (CFC) provides similar services to HCBOW and offers assistance to eligible people who would otherwise require a nursing facility or intermediate care facility care. There are no caps on enrollees, yet enrollment has been slow and difficult.

Medical Day Care Waiver participants must meet the nursing facility level of care and be at least age 16. There were approximately 5,000 in this service as of March 2015.

The Traumatic Brain Injury Waiver serves adults diagnosed at age 17 or older who want to leave certain types of facilities. The capacity is 200 but only about 140 people are supported. It is underutilized due to stringent eligibility criteria.

PART D. Rationale for Goal Selection*



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The Council prioritized issues to be addressed in the State Plan through a comprehensive process that included:

- 1) a critical analysis of broad stakeholder input;
- 2) consideration of past experience including successes and lessons learned;
- 3) assessment of potential systemic (vs. limited) impact and sustainability;
- 4) identification of known and potential partners;
- 5) discussion of opportunities and challenges;
- 6) review of the current and expected efforts of other entities in Maryland;
- 7) review of other states' efforts and sustained impact;
- 8) and Council human and fiscal resources.

We determined priority issues based on the need for more advocacy and leadership and where our strengths and resources could be applied with the greatest likelihood of positive impact. For some key systemic issues, we decided to apply our advocacy and leadership, but not our grant funds. This was a strategic decision made because experience has taught us that funding does not always have the desired long-term impact. Other issues deemed a priority by some stakeholders were not included because we determined that the Council would have limited sustainable impact given our available resources. We will remain informed about these issues and will assess them when we review the State Plan each year.

The Council's mission is "to advance the inclusion of people with developmental disabilities in all facets of community life." A few years ago, we translated our mission statement into three strong, descriptive words that speak to the values informing our vision for all people with intellectual and developmental disabilities and their families in Maryland. Those words are empowerment, opportunity, and inclusion. The three State Plan goals and their objectives established through this plan are inter-related and will help us realize this vision and accomplish our mission.

Goal 1: People with developmental disabilities effectively advocate for themselves and others and influence issues that are important to them.

Objectives focus on: Supporting self-advocacy (personal advocacy and group/systemic advocacy)

Rationale: Promoting and supporting self-advocacy in Maryland remains a priority because at its core, the Council believes that people with developmental disabilities must actively participate in and lead advocacy on issues that impact their lives. The Council has supported self-advocacy in Maryland for many years and the movement is stronger as a result--People on the Go (POG) has stronger operational structure and a more established leadership. As a result, POG is continuously sought out as a partner on many initiatives in the state. In 2016, POG led a legislative effort for the first time--to end sub- minimum wage--and was successful. In the process, it became widely evident that POG is recognized and respected by legislators. This is a direct result of the work POG has conducted over the years through support from the Council. To build on this, POG



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must continue to have organizational support to exist and operate. More needs to be done to build the skills and influence of advocates with disabilities at the state and local level, increase cross-disability work, and identify and support new leaders. The Council has determined that its support financially and in other ways is crucial to the success of the statewide group. Fortunately, for the first time in over 10 years the Council is able to reduce our investment without a negative impact because two other entities have started providing funding.

Goal 2: People with developmental disabilities and their families are empowered to lead the lives they want and transform communities.

Objectives focus on: Increasing knowledge and skills, training and leadership development for people with intellectual/developmental disabilities and their families.

Rationale: People with developmental disabilities and their families need information on a broad array of ever-changing, complex issues if they are to have a chance of 1) obtaining the services and supports they need, 2) influencing issues important to them, and 3) individually and collectively increasing opportunities. Individuals with ID/DD and their families are at a disadvantage compared to professionals in terms of access to information, training and support, even though they are the ones who should be at the forefront. So many adages apply here, including "knowledge is power" and "nothing about me without me."

As noted in the Critical Review and Analysis section, a survey of Partners in Policymaking graduates from seven Maryland PIP classes found 42% rated their advocacy skills good or excellent prior to PIP compared to 100% after graduating. However, there has not been a leadership development program of the magnitude of PIP since 2004 in MD. This is a priority again because there has been a dearth of new advocates and leaders emerging to help the self-advocacy and parent advocacy movements in significant ways. In addition, the Council and other organizations need a larger pool of people with developmental disabilities and family members prepared to fill staff, board, and other roles.

Similarly, a survey in 2016 by the Council reinforces prioritization of this goal's activities - 76% of respondents said that gaining information about the DD service system is a high priority for them and others they know. Numerous activities under this goal address this.

This priority provides new opportunities to implement approaches that are affordable, will result in ongoing engagement of people with developmental disabilities and family members, and will reach people from diverse racial/ethnic backgrounds and geographic areas.

Goal 3: Children and adults with developmental disabilities meaningfully participate in all facets of community life, and are valued and supported by their communities.



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Objectives focus on: Increasing expectations; increasing access to informal and formal services and supports; increasing inclusion in various aspects of community life; increasing employment; and impacting related policies, practices, regulations and laws.

Rationale: This goal is multi-faceted because it addresses issues across the lifespan in different systems as is necessary for people to lead meaningful lives. Data, public input, and experience demonstrate the critical need to improve policies, regulations, and laws and to build capacity; the Council's leadership and engagement is needed to produce results. The key to building capacity is in raising expectations. We have heard repeatedly that low expectations create significant obstacles related to inclusive education, employment, and in how families plan for a good life for their child with ID/DD. We want families to envision a future free of institutions, sheltered workshops, and larger residential settings. Instead we want them to demand of the system a provision of individualized support that leads to employment, typical living situations, and enriching personal relationships.

Comprehensive Review and Analysis (CRA) information and data that support this goal:

- A comprehensive Council report noted 72% of families had difficulty finding and keeping child care for their child w/disabilities and 53% had removed their child from a program because the provider was not adequately trained. 92% of child care providers reported that additional training would help;
- There is an estimated 28% employment rate of Marylanders with ID aged 21-64. This includes people who are paid in sheltered workshops. The employment rate for working-age adults without disabilities is 76%;
- Only 14.2% of youth with ID/DD are engaged in integrated, competitive employment within one year after completing high school; only 50% of people receiving DD services said they chose where they live and who they live with.
- 40% of people supported by DDA said they feel lonely at least half of the time.
- More than 4000 children are on the Autism Waiver registry waiting for services but only 50 to 75 slots become available each year;
- Nearly 8000 people are on DDA's Waiting List for community services.
- Nearly 1400 of them have a family caregiver over age 60; and
- Maryland ranks 36th in the nation in terms of commitment to funding services to support PWDD in the community.



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Collaboration

As a Network:

The Council, Maryland Center for Developmental Disabilities (MCDD/UCEDD) and Disability Rights Maryland (DRM/P & A) will work together to develop and widely disseminate materials that explain critical aspects of the DDA service system in a way that is easily understood and usable by people with developmental disabilities and their families (Obj. 2.2). This objective was agreed upon after each organization engaged in information-gathering, analysis, and priority setting. We met to discuss shared priorities and to identify opportunities for a formalized, measurable collaborative goal and activities based on available staff and fiscal resources. This is in addition to the many ongoing collaborative activities undertaken by our organizations in numerous arenas.

The goal of this collaborative initiative is for people with developmental disabilities and their families to understand essential information about the Developmental Disabilities Administration (DDA) system in order to make informed decisions and advocate for their needs and wishes. Examples of topics include: eligibility for services, process for applying for services, rights and responsibilities, service types--essentially "how the system works." Our plans were reinforced when the Council conducted a survey to identify webinar topics and over 200 people responded. "All about the DDA System" was the highest ranked topic by far, with 76% of respondents indicating they thought it was a priority and would tell others about it. Our intent is to expand to other topics and systems in future years if this is effective.

Our initial planned activities include:

- 1) Identify topics;
- 2) Develop branding for consistency and to be recognized as the "go to source" for understandable materials;
- 3) Develop materials from existing documents and information;
- 4) Translate materials into Spanish;
- 5) Post online and update as needed;
- 6) Widely disseminate; and
- 7) Gather feedback and evaluate the impact.

Our initial defined roles, which will evolve and change as we implement the initiative and learn more, are as follows:



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Council: 1) Participate on steering committee to oversee and contribute to each listed activity and outcome; 2) Contribute topical expertise; 3) Contribute funding for someone to write the materials; and 4) Contribute to the cost of translation.

DRM: 1) Participate on steering committee to oversee and contribute to each listed activity and outcome; 2) Contribute topical expertise; and 3) Provide documents and information that will be translated into a widely understood format.

MCDD: 1) Participate on steering committee to oversee and contribute to each listed activity and outcome; 2) Provide interns to assist with coordination and review of materials; 3) Professionally design the materials; 4) Assistance with branding through marketing department; and 5) Contribute funding for someone to write the materials.

The network partners will establish mechanisms to include people with developmental disabilities and family members at each stage of the process to ensure the outcome meets their needs. The steering committee will guide and coordinate the project. Dissemination of materials will be coordinated to ensure consistent and clear messaging and will identify all three organizations. All key decisions will be made collaboratively, including whether to expand to other systems based on the evaluation.

With each other:

(e.g. Describe the plans the Council has to collaborate with the UCEDD(s). Describe the plans the Council has to collaborate with the P&A.)

The three entities share information, strategize, and collaborate on multiple activities. Regular formal communication occurs through Council meetings and the MCDD's Community Advisory Committee, which all three organizations serve on. In addition, formal collaboration occurs between the Council and DRM via the DD Coalition and Education Advocacy Coalition. These are supplemented with informal, as-needed communication via issue-specific emails, calls, and meetings.

With DRM: As described in the annual work plans, we will work closely with DRM to improve the ability of people with ID/DD to advocate for themselves (Obj. 1.4); advocate for a state child care dispute resolution process (Obj. 3.3); advocate for improvements in education policies (Obj.3.3) and employment policies (Obj. 3.5); and advocate for improved services and increased funding (Obj. 3.7). In addition, the Council collaborates with DRM extensively through our joint work on the Developmental Disabilities Coalition and Education Advocacy Coalition (Obj. 3.7), which entails advocacy focused on policy, regulations, and legislation (Obj. 3.7).



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With MCDD: The Council collaborates with MCDD most significantly in support of the statewide self-advocacy group, People on the Go (Obj. 1.1, 1.2, 1.3). We jointly fund POG, formalized with an award letter with MCDD/POG. We also have a formal inter-agency MOU with DDA, which formally outlines POG/MCDD requirements related to funding DDA provides for a special self-advocacy training project called Project STIR. Collaboration with MCDD also includes working to increase access to post-secondary education (Obj. 3.4).

With other entities: (e.g. network collaboration with other entities in the state, including both disability and non-disability organizations, as well as the state agency responsible for developmental disabilities services)

To ensure effective implementation of the plan and broad sustainable outcomes, the Council will continue to collaborate with a wide range of entities and has committed to developing partnerships with new and more diverse individuals and organizations. This will be done in collaboration with our DD network partners when related to the focus areas they are also involved in. This will help us engage and impact a diverse constituency and involve more entities outside of the disability arena, which is critical to our core focus on inclusion and opportunity. The Council reviewed the new objectives and identified new entities to pursue for collaboration. This will be a dynamic, evolving process with more focus infused in all our work. Council, work team, and staff meetings will be used to identify appropriate and needed collaborators at key decision points, such as the development of a new RFP or formation of a policy position.

Examples of existing and potentially new collaborators identified by the Council in addition to DRM and MCDD, as related to the new State Plan objectives and activities include:

Obj. 2.1 - Leadership Development: foundations; non-disability local and state leadership programs; county disability commissions; Parents Place of Maryland (PPMD - Parent Information's & Training Center); DD Coalition; Education Advocacy Coalition; DDA; DOD; Centers for Independent Living (CILs); entities that support ethnic/racial minorities; and local self-advocacy and parent groups in all geographic areas. Collaboration will occur through an advisory group and individualized outreach.

Obj. 3.2 - Community of Practice for Supporting Families: PWDD and families; PPMD; state and local Arcs; family support providers; organizations interfacing with ethnic/racial minorities; CILs; local Health Depts.; MD Board of Physicians; DOD; MSDE, DORS; DDA; Dept. of Aging; and the governor's ethnic commissions. Collaboration will occur through meetings of the leadership team and CoP members, training events, joint communications to all stakeholder groups; likely an annual gathering and possibly small joint-funding initiatives as the project evolves.



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Obj. 3.5 - Increase employment opportunities: Chamber of Commerce; AmeriCorps; Jr. Achievement; large employers headquartered in MD; providers, NACCP; Urban League, Appalachian Region Commission ; DD Coalition; local school systems; community colleges ; Dept. of Labor, DDA, DORS, DOD, and MSDE. Collaboration will occur through meetings, trainings, coordinated communications and events; jointly-funded initiatives; and combined strategic planning.

Obj. 3.7 - Increase access to services and supports: On all key DD system issues, the Council works very closely with the DD Coalition, including DRM, POG, The Arc MD, and the state provider association. We will continue to hold regular meetings, meet with the DDA to advocate and collaborate on specific issues, hold DD Day at the Legislature and collaborate during legislative sessions. On many key education issues the Council collaborates with the Education Advocacy Coalition, comprised of over 30 members, including parents, local and statewide advocacy organizations across disabilities and Legal Aid. Collaboration occurs through information-sharing and strategy meetings of the coalition; meetings with MSDE and joint action on policy, regulations and legislation.

Numerous other potential collaborators were identified by the Council for other objectives, including Towson University and St. Mary's College of Maryland; MD Higher Education Commission; local governments, MD Out of School Time Network; MD Family Network; ACLU, and Best Buddies, among others.

Potential collaborators identified to help us ensure our work is inclusive and diverse: NACCP; Urban League; Rural MD Council; Gov's Office of Community Initiatives; Gov's multiple ethnic commissions; organizations and media outlets specializing in support and outreach to minorities; and faith-based groups.

PART E. 5 Year Goals

Goal #1: Self-Advocacy

Description

Promoting and supporting self-advocacy in Maryland remains a priority; people with developmental disabilities should be fully engaged in debates, discussions, and initiatives that impact their lives. The Council has supported self-advocacy in Maryland for many years and the movement is stronger as a result--People on the Go (POG) has an established leadership recognized and sought after for input and ideas, and with a more secure structure. This goal and corresponding objectives will ensure past



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progress will be leveraged for even more impact, statewide presence, and effectiveness moving forward.

Expected Goal Outcome

People with developmental disabilities lead the lives they want and policies and support systems help make this happen.

Objectives

Objective 1. Support People on the Go of Maryland and local self-advocacy groups to be strong, effective, and influential.

Objective 2. Support opportunities for people with developmental disabilities to provide leadership training to other individuals with developmental disabilities who may become leaders.

Objective 3. Support and expand participation of people with developmental disabilities in cross-disability and culturally diverse leadership coalitions.

Objective 4. Improve the ability of people with developmental disabilities to advocate for what they want through meaningful participation in the individual planning process.

Goal #2: Engaged in Transforming Communities

Description

Leadership development program is a priority especially now because there has been a dearth of new advocates and leaders emerging to help the self-advocacy and parent advocacy movements in significant ways. Meaningful and positive community transformation happens as a result of robust engagement and involvement of people with developmental disabilities and families. Moving forward, the Council and other organizations need a larger pool of people with developmental disabilities and family members prepared to fill staff, board, and other roles. This goal will increase knowledge and skills, training and leadership development for people with intellectual/developmental disabilities and their families, supporting full engagement in transforming communities.

Expected Goal Outcome

People with developmental disabilities and their families have the information and skills to flourish and create change in their communities.



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Objectives

Objective 1. Increase knowledge and skills of people with developmental disabilities and families through education and training.

Objective 2. MDDC, Disability Rights Maryland (DRM), and Maryland Center for Developmental Disabilities (MCDD) will work together to develop and widely disseminate materials that explain critical aspects of the DDA service system in a way that is easily understood and usable by people with developmental disabilities and their families.

Objective 3. Increase knowledge and understanding of issues of importance to people with developmental disabilities and their families.

Goal #3: Full Participation & Community Support

Description

Increasing expectations; increasing access to informal and formal services and supports; increasing inclusion in various aspects of community life; increasing employment; and impacting related policies, practices, regulations and laws--This goal is multi-faceted because it addresses issues across the lifespan in different systems as is necessary for people to lead meaningful lives. Data, public input and experience demonstrate the critical need to improve policies, regulations and laws and to build capacity - the Council's leadership and engagement is needed to produce results. We include raising expectations because we have heard repeatedly that this is a significant obstacle related to inclusive education, employment, and in how families plan for a good life for their child with ID/DD. We want families to envision a future free of institutions, sheltered workshops and larger residential settings. We want them to demand of the system: provision of individualized support that leads to employment, typical living situations, and enriching personal relationships. Completion of this goal in five years will significantly support these efforts.

Expected Goal Outcome

People with developmental disabilities achieve their full potential in all facets of community life side-by-side people without disabilities.

Objectives

Objective 1. Increase the expectations that family members, providers, educators, and others have about people with developmental disabilities.



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Objective 2. Increase access to informal and formal support for families of people with developmental disabilities across the lifespan.

Objective 3. Increase access to inclusive opportunities in early childhood care and education, school, and out of school time activities.

Objective 4. Increase access to inclusive post-secondary education opportunities for people with intellectual disabilities.

Objective 5. Increase community-based employment opportunities for people with developmental disabilities, including people with significant support needs.

Objective 6. In collaboration with people with developmental disabilities, their families, and stakeholders, increase opportunities for people with developmental disabilities living in rural areas to find and maintain employment by reducing barriers in rural areas.

Objective 7. Increase access to community-based services and supports.

Evaluation Plan

Continuous Quality Improvement: A Multi-Method Approach:

Over the course of the next five years, the Council will implement a multi-method approach to ensure the needs addressed by Council goals and objectives are being met and results are being achieved. The methodology will include both formative and summative evaluation of our goals. Formative evaluation methods are primarily for internal use or use among a close network of stakeholders as a means of continual quality improvement. Through formative evaluation methods, Council members and staff work to continually strengthen and improve by (1) identifying, analyzing and overcoming challenges as they arise; (2) pivoting in response to internal and external factors contributing to barriers;(3) assessing impact of factors that may impede progress; and (4) identifying what works well to inform continued progress.

Process and Progress Evaluation:

Two types of formative evaluation approaches will be used: process and progress evaluation. Process-based evaluation measures the extent to which a critical project activity is implemented as planned and proposed, and if changes or adjustments are needed. Progress evaluation measures how well outputs and outcomes are achieved as the Council seeks to obtain its five-year goals and objectives. Summative evaluations will be conducted to determine whether an initiative's intended



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outcomes have been achieved, allowing the Council to judge the overall effectiveness, merit, and significance of its work.

The evaluation will incorporate qualitative and quantitative methods to answer the following questions:

- To what extent were objectives achieved?
- What strategies contributed to achieving the objectives?
- What factors facilitated or hindered progress? What factors resulted in progress?
- What outcomes were achieved?

Assessment of Effectiveness:

Assessment of the effectiveness of strategies used that contribute to achieving the goals of the State Plan will rely both on formative and summative evaluation methods.

The summative evaluation involves the collection of data measuring intended project outcomes. Outcomes for the evaluation of Council activities will be measured through multiple methods including quarterly and annual collection of performance measures from grantees. Staff engaged in activities will report quarterly on relevant outputs and outcomes to determine whether identified targets are met or require further action. For communications-related activities, this will include reliance on data analytics compiled through social media outlets, Google analytics, and Constant Contact.

Measuring Outcomes:

Outcomes for the evaluation of Council activities will be measured through multiple methods including the following:

Face-to-face/telephone interviews will be conducted with some stakeholders, particularly when the stakeholder group is a small and targeted group. In Maryland, interviews will be used to gather information about the Community of Practice for Supporting Families, rural disparity, and employment. Interviews will collect data not only on stakeholders' perceptions of outcome attainment of the specific objective, but also on the needs groups have for information, education, training, technical assistance, policy revision, etc., in better serving people with developmental disabilities and their families. In the case of interviews with individuals with developmental disabilities and family members themselves, questions will also focus on how our work can better serve them.



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Pre-tests may be used to measure participants' skills/knowledge prior to an intervention. Post-tests or post-intervention assessments measure the gains they make from participating in Council education and training programs. Pre- and post- tests will be designed to demonstrate participants' increased knowledge and skills, changed attitudes, and/or increased motivation in alignment with project specific outcomes.

Satisfaction Surveys will be distributed and administered on a widespread basis to participants of designated Council activities. Standardized survey instruments will be developed specifically to help evaluate both participant degree of satisfaction with Council funded activities, and to obtain demographic data to inform progress in outreach to and participation of ethnic/racial minorities, and to collect geographic data. Surveys may focus on participants' assessments of knowledge and skill gains acquired through participation in the Council activity and intended application of knowledge/skills. Other surveys will measure the extent to which the Council activity enhanced programs'/agencies' capacity to serve individuals with developmental disabilities, and the extent to which project activities have increased stakeholder awareness of diverse issues. Due to the importance of direct data from those participating in Council funded activities, the Council will incorporate orientation to the survey in grantee training and engage in ongoing process evaluation to ensure maximum participation.

Focus groups will be used to gather information from groups of people with developmental disabilities and their families through an interactive, semi- structured, moderated group interview process. The Council will use focus groups to collect data on specific topics.

Monitoring Progress:

Processes and procedures the Council will use to monitor progress in meeting goals include:

- Routine use of DD Suite, a web-based data reporting system that compiles performance measures from all grantees.
- Routine use of a standardized survey for all grantee participants.
- Project-specific evaluation activities. All projects have evaluation activities specific to assessing their accomplishments and outcomes. Project status reports are generated quarterly. In addition, an annual evaluation summary for each project is required for Council activities. The summary has the following components: (1) a brief description of project activities and the degree to which it meets its stated objectives, (2) a summary of the participant satisfaction data, (3) a qualitative description of project accomplishments or impact and (4) a summary of the project modifications, obstacles encountered, and emerging trends that should be addressed with within the project or through new activities. Council members will be assigned to work teams that monitor grants and review this information.



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•Work plan status reports will be reviewed during regularly scheduled Council meetings with quarterly and annual project reports reviewed by staff. Both will be incorporated into the AIDD Annual Program Performance Report template under their respective goals and objectives. The Council review will have several goals:

1. Assess overall progress toward the accomplishment of the annual work plans and five-year plan in meeting identified needs and achieving intended results;
2. Assist in the determination of the status of each goal as achieved, in progress, or not achieved;
3. Make recommendations about modification to the plan in response to emerging trends and needs. The Council findings and decisions will then be incorporated into applicable reports and state plan amendments.

By these methods, the Council will engage in a continuous quality improvement process, where Council staff use data gathered from ongoing evaluation work to identify, analyze, and overcome challenges. Staff will routinely examine internal and external factors contributing to barriers, and make changes to address these factors. Council staff members use the plan, do, study, act (PDSA) approach to measure the impact of changes.

Support of the advocacy movement among people with developmental disabilities in Maryland is a priority as reflected in our level of support and degree of focus in the state plan. In addition to the routine collection of data to inform both formative and summative evaluation methods described above (quarterly and annual reports, use of participant satisfaction surveys, and focus groups) Council staff will meet routinely with leadership of People on the Go (POG) either face-to-face or through phone conference for feedback and assistance as needed in following through with required data collection components.

Data collection requirements include attendance sign-in sheets for meetings and trainings held or facilitated, people with developmental disabilities trained; people with developmental disabilities serving on boards/commissions; people with developmental disabilities providing testimony; number of statute and regulation changes adopted; and numbers measuring growth of POG's list serve/outreach capabilities for information dissemination. The Council traditionally provides support and assistance as needed/requested to problem-solve challenges to meeting performance measures.

In Conclusion:

Assessing information gained from continuous feedback from the Council as well as the ongoing data collection of Council staff will provide a strong review and identification process for emerging trends and needs as a means for updating the CRA.



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LOGIC MODEL

The Logic Model provides an “at a glance” view of how the resources we invest relate to the activities we engage in and lead to the outputs, outcomes and impact we seek

Resources (needed to support activities)	Activities (specific approaches related to objectives)	Outputs (deliverables measured by count or other data)	Short-term Outcomes (changes as a direct result of implementation activities)	Long-term Outcomes (changes as a direct result of implementation activities)	Impact
Federal AIDD allotment DD Act; Program guidance and instructions Grant program – money Grant program – grantee staff, leveraged resources, and time Grant program – people who use the program People with developmental disabilities and their families Council members & staff Collaborative partnerships Websites and technology	Communicate/ conduct outreach Provide/ sponsor education, training, and technical assistance Provide grant funding Support grassroots organizing Support statewide and local self-advocacy groups Understand and address disparities Support implementation of promising/best practices Increase partnerships Advocate for policy and practice improvements and increased funding Increase provider capacity for community-based services and supports Collect data/evaluate impact	Newsletters, Facebook posts, website, other media Education and outreach events Online education and training materials Providers supported Grant awards Collaborative efforts with partner organizations Committees, workgroups, and councils served on Policy and procedure changes Statute and regulation changes Promising/best practices supported Evaluation/lessons learned reports	More people with developmental disabilities and their family members are involved in advocacy efforts Increased knowledge of DDA system and individual planning process Increased expectations of people with developmental disabilities Increased understanding of important issues impacting people’s lives Increased provider capacity to support children and adults with developmental disabilities in their communities Policies, procedures, statute, and regulation changes are adopted Promising and best practices are adopted	More people with developmental disabilities serve in leadership positions More youth with developmental disabilities are educated in an integrated setting with their typical peers More people with intellectual and developmental disabilities attend inclusive college programs in Maryland More people with developmental disabilities are employed in integrated settings Closed sheltered workshops More people with developmental disabilities receive formal and informal supports Rural employment disparities are decreased Policies, procedures, statute, and regulation changes are implemented Promising and best practices are implemented	People with developmental disabilities lead the lives they want and policies and support systems help make this happen People with developmental disabilities and their families have the information and skills to flourish and create change in their communities People with developmental disabilities achieve their full potential in all facets of community life side by side people without disabilities



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Projected Council Budget

GOAL	Subtitle B \$	Other(s) \$	Total
Self-Advocacy	\$223,356.00	\$104,000.00	\$327,356.00
Engaged in Transforming Communities	\$122,521.00	\$0.00	\$122,521.00
Full Participation & Community Support	\$348,497.00	\$108,000.00	\$456,497.00
General Management (Personnel Budget, Financing, Reporting)	\$291,448.00	\$0.00	\$291,448.00
Functions of the DSA	\$12,600.00	\$0.00	\$12,600.00
Total	\$998,422.00	\$212,000.00	\$1,210,422.00

Assurances

Written and signed assurances have been submitted to the Administration on Intellectual and Developmental Disabilities, Administration for Community Living, United States Department of Health and Human Services, regarding compliance with all requirements specified in Section 124 (C)(5)(A) -- (N) in the Developmental Disabilities Assurance and Bill of Rights Act.

Approving Officials for Assurances:
For the Council (Chairperson)

Designated State Agency:
A copy of the State Plan has been provided to the DSA.

Public Input and Review



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Describe how the Council made the plan available for public review and comment. Include how the Council provided appropriate and sufficient notice in accessible formats of the opportunity for review and comment *

Public review of the draft FY 2017- 2021 State Plan was made available for six weeks beginning in March and extending into April 2016. Notices were distributed widely using social media and e-blasts asking recipients to assist in distribution and review. An announcement was also placed on the Council's website with links to the draft State Plan and the survey. Paper copies of the plan with attached paper surveys were distributed as requested, and handed out at a well-attended regional Transition Forum held on Maryland's Eastern Shore, an area typically difficult to reach. Specific outreach was made to Council and coalition members requesting support to encourage maximum input. Input was directly solicited from key stakeholders, including people with developmental disabilities. People were invited to view the draft plan at the office and encouraged to call in comments directly and privately. The State Plan and survey were offered in Spanish and alternative formats by request.

Describe the revisions made to the State Plan to take into account and respond to significant comments *

Summary of Account of Public Input and Results:

Public response to the draft State Plan was overwhelmingly positive, with almost 100% of respondents agreeing or agreeing strongly with the statement: "I like this goal and outcome." For each of the State Plan's goals and planned outcomes, survey participants were asked to indicate their degree of agreement with a statement tailored to that goal. There was space available for comments. In general, the comments made were observations that underscore the importance of the work as outlined in the State Plan. There was no input provided that triggered a red flag to stop and reevaluate our direction. The positive response to the State Plan reflected the high degree of input and involvement people with developmental disabilities, families, and paid professionals had in shaping the plan during the needs assessment process. Results of the public input survey were provided to the Council in the form of a report and presented formally for discussion at a quarterly meeting. The Council did not recommend making any changes to the State Plan as a result. Below details percentage responses, significant comments requiring Council consideration, and Council reflection and response. Specific comments that were supportive and/or already clearly addressed in the plan are not noted here.



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Goal 1:

Ninety-three percent of respondents indicated "agreed" or "strongly agreed" with this goal: People with developmental disabilities effectively advocate for themselves and others and influence issues that are important to them.

Ninety-three percent of respondents indicated "agreed" or "strongly agreed" that: Goal 1 will work and will result in people with developmental disabilities leading the lives that they want.

Comments:

- *"There are many individuals such as my daughter that are unable to advocate for themselves. Where does this leave them?"*
- *"Funds will help a provider agency create and sustain self-advocacy groups."*

Council reflection and response:

The first comment concerns people who are "unable to advocate for themselves" may be a concern rooted in low expectations, an outdated perception that people with significant disabilities may not be "able" to advocate, and a lack of awareness of the important role that family and a strong support team play in supporting an individual's desire to communicate needs, wants, and dreams. The impact of low-expectations for people with significant support needs on desired outcomes is addressed thematically throughout all of our work and in this State Plan. Generalized low-expectations for all people with disabilities has always been at the core of stigmatizing perceptions that create invisible barriers to achievement and personal growth, and is particularly addressed in Goal 3. In reference to the second comment, small grant funds have been--and can continue to be--used to support the start-up of local self-advocacy groups, but Council funds cannot be used to sustain them. The Council advocates that providers and other entities invest in this.

Goal 2:

One hundred percent of respondents indicated "agreed" or "strongly agreed" with this goal: People with developmental disabilities and their families are empowered to lead the lives they want and transform communities.

Ninety-three percent of respondents indicated "agreed" or "strongly agreed" that: Goal 2 will help people with developmental disabilities flourish and create change in their communities.



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Comments:

One comment noted that specific strategies were not included; another asked to partner with the Council.

Council reflection and response:

The draft State Plan for public input did not include specific strategies. The Council asked for input on goals, objectives, and the outcomes. The annual work plans include a host of specific activities and strategies that support planned outcomes, including ones consistent with the comments received.

Goal 3:

One hundred percent of survey respondents "agreed" or "strongly agreed" with this goal: Children and adults with developmental disabilities meaningfully participate in all facets of community life, and are valued and supported by their communities.

Ninety-three percent of survey respondents "agreed" or "strongly agreed" that: Goal 3 will help people with developmental disabilities achieve their full potential side-by-side with people without disabilities.

Comments:

- *"Would be nice but doesn't seem like a reality to me. Funding is short now. How will all these supports and trainings be funded?"*
- *"Should add siblings, grandparents, and extended family members to this list. When elderly parents are no longer able to support their adult children they are looking at the siblings and others in their support system to step in and help."*
- *"People in residential programs remain isolated also. Could a small grant be offered to develop a training module to guide direct care staff (or parents) in starting conversations between people with/without disabilities to help move past being present in but not part of groups?"*

Council reflection and response:

Comment #1: Funding and quality issues are always a concern. The Council is confident that the strategies and initiatives detailed in our State Plan are within our current budget and projected budgets. Many activities will be undertaken through advocacy and public policy strategies that do not require Council funding.

Comment #2: Throughout the State Plan wherever "family" is used, it incorporates siblings, grandparents, and other family members. In addition, the Council worked on a goal in FY2015-16



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specifically to support and build the growth and effectiveness of the Maryland Sibling Network, and will continue to support the education and networking of siblings and extended family members.

Comment #3: The Council will continue the use of small grants in the FY2017-2021 State Plan to support a range of creative ideas and activities that we judge will have a meaningful impact. In addition, the Council will continue to work with the Developmental Disabilities Administration as it works to transform the system of services and supports in alignment with the requirements of the HCBS settings rule, resulting in people with developmental disabilities being more fully engaged and a "part of" the community rather than merely "present."

Conclusion:

Council members and staff are confident that this State Plan reflects input from all key partners and stakeholders, and supports expressed needs, concerns, and interests of people with developmental disabilities and families throughout Maryland.

