


M E M O R A N D U M

November 21, 2018

TO: Health and Human Services Committee

FROM: Linda McMillan, Senior Legislative Analyst 
Carolyn Chen, Legislative Analyst

SUBJECT: **Briefing and Discussion: Report of the Work Group on Meeting the Needs of Residents with Developmental Differences**

PURPOSE: Receive Report

Expected for this session:

Kim Mayo, Department of Health and Human Services
Claire Funkhouser, Parent Representative
Susan Hartung, Parent Representative and Chair of the DD Advisory Committee of the
Commission on People with Disabilities
Susan Ingram, Community Support Services/InterACC/DD
Karen Morgret, Treatment and Learning Centers Outcome Services
Tim Weins, Inter ACC/DD

In December 2017, the Council adopted Resolution No. 18-989, that requested the formation of a work group to report on meeting the needs of residents with developmental differences (developmental disabilities). While the work group requested was not convened because of competing demands, the Developmental Disabilities Advisory Committee of the Commission on People with Disabilities graciously agreed to forgo its regular meetings and take on the task of reporting to the Council. All members of the Advisory Committee were invited to participate, and invitations were sent to the agencies and departments included in the Council resolution.

The Work Group report is attached. It includes:

System-wide recommendations	pages 6-10
Our Stories and Experiences	pages 11-16
Data trends and County Government Funding	pages 17-22
White Papers on individual subject areas	pages 24-73

The Work Group is very concerned about the implementation of the Maryland Developmental Disabilities Administration's Transformation Plan. The Transformation Plan revises the structure of programs and works to bring the State into compliance with new federal

requirements that are included in the Community Settings Rule which create person-centered plans that promote inclusion. DDA's Transformation Plan also includes a rate setting study. There is significant concern that new rates will not adequately compensate service providers, particularly in higher cost areas like Montgomery County. These concerns are reflected in the system-wide recommendations.

The System-wide recommendations are:

1. The Montgomery County Executive and Council must partner with the General Assembly Delegation to receive regular progress reports on the Maryland Developmental Disabilities Administration's (DDA) Transformation Plan. The progress reports should focus on real impacts to individuals, families and providers. Is the Transformation Plan resulting in increases or decreases to the time individuals remain on waiting lists? Is it changing the quality of services provided?
2. The County Executive and Council must carefully monitor the ongoing rate setting study and advocate strongly for rates that reflect the cost of doing business in Montgomery County. Services must be funded in a manner that allows providers to afford to continue to provide services.
3. The focus on opportunity for employment is critical, but the County must advocate with DDA to ensure that new rules truly incentivize employment.
4. DDA should use its full budget allocation to support more people instead of ending the year with surpluses.
5. The County must continue to invest local funds to support providers, increase inclusion in County programs, and provide needed services to County residents with developmental disabilities who are either on a waitlist or not eligible for DDA services.
6. Don't forget about those who are not eligible for DDA services.
7. Residents with developmental disabilities face the same issues as the general population. They are aging, they are more culturally and language diverse, and face barriers to employment if they are ex-offenders.

White Paper Topics include:

- Coordination of Community Services
- Employment
- Health & Wellness
- Housing (non-institutional)
- Law Enforcement and Public Safety
- Recreation
- Respite
- Transitioning Youth
- Transportation
- Waivers

**Report of the Work Group
On
Meeting the Needs of Residents
with Developmental Differences**

**Presented to the
Health and Human Services Committee
November 26, 2018**

In response to County Council Resolution No. 18-989

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Work Group Participants

Gabe Albornoz*, Department of Recreation
Lyda Astrove*, Parent
Kyeshia Barlow, WorkSource Montgomery
Larry Bram, EasterSeals
Betty Bahadori, Parent
Pamela Cooke, Total Care Services, Inc.
Nancy Corr*, Parent
David Cross, Individual, Retired Montgomery County Public Schools
Rosemary DiPietro, Department of Health and Human Services
Whitney Ellenby, Parent
Claire Funkhouser*, Parent
Simone Geness, Montgomery County Public Schools
Susan Goodman, Parent
Susan Hartung*, Chair, DD Advisory Committee of the Commission on People with Disabilities, and Parent
Scottie Holton, Parent
Susan Ingram*, Community Support Services, InterACC/DD and Maryland Association of Community Services
Annette Jolles*, Parent
Vickie Kane, Department of Recreation
John Kenney, Department of Health and Human Services
Shawn Lattanzio*, Department of Health and Human Services
Betsy Luecking*, Department of Health and Human Services, Commission on People with Disabilities
Tom Liniak, Jewish Social Service Agency
Kevin Lowndes, Montgomery County Public Schools
Kim Mayo*, Department of Health and Human Services
Lu Merrick, The Ivymount School
Karen Morgret*, Treatment and Learning Center (TLC) Outcomes Services
Sam Oji*, Department of Transportation
Sarah O'Neil*, MMARS RC, Inc
Marie Parker, TransCen
Shawn Ratliff, Total Care Services
Robin Riley, Department of Recreation
Susan Smith*, Housing Opportunities Commission
John Whittle, Service Coordination, Inc.
Kenneth Vinson*, Department of Housing and Community Affairs

*Participated in four or more meetings

Thank you to Kim Mayo for leading the Work Group meetings and discussions.

Thank you to Judith Pattik, Regional Director (Southern Region), Developmental Disabilities Administration, for her assistance.

Staff:

Carolyn Chen, Legislative Analyst, Montgomery County Council
Linda McMillan, Senior Legislative Analyst, Montgomery County Council
Rebecca Weingarten, 2018 Montgomery County Council Summer Fellow

Introduction

A developmental disability (or developmental difference) is a condition attributable to a mental or physical impairment that results in substantial functional limitations in major life activities. It is diagnosed before the person reaches the age of 22 and it is expected to continue indefinitely. Examples of developmental disabilities include Autism, Cerebral Palsy, Epilepsy, and other neurological disorders. Certain neurological disorders can be caused by traumatic brain injury, but for the person to have a developmental disability the injury would have to have manifested itself before age 22. Often development disability and intellectual disability are discussed together. A person with an intellectual disability usually has an IQ of 75 or lower and significant limitation in adaptive behaviors. It is estimated that about half of the people with an intellectual disability also meet the definition for a developmental disability. Office of Legislative (OLO) Report 2017-13, *Housing for Adults with Developmental Disabilities*, used the "Larson Method" to estimate that there are approximately 7,170 adults (18 and over) and 8,240 children (17 and younger) with an intellectual or developmental disability living in Montgomery County.

In December 2017, the County Council requested a report on issues facing residents with developmental differences. When introducing Resolution 18-989, lead sponsor Councilmember George Leventhal said that he hoped the report would not just provide recommendations, but would inform the incoming elected officials about the breath and complexity of issues that impact residents with developmental differences.

The Work Group called for in Resolution 18-989 was not convened as outlined due to competing demands on Council staff. However, the Developmental Disabilities Advisory Committee of the Commission on People with Disabilities graciously agreed to become the mechanism for this work. All members of the Advisory Committee were invited to participate, and invitations were sent to other organizations listed in the Council's resolution. No one was excluded who wished to participate in one or more meetings. This resulted in over 30 people participating in the process from June to November 2018.

The Developmental Disabilities Advisory Committee will return to its regular committee work starting in January 2019 and looks forward to working with the Executive, Council, and members of the General Assembly to address the recommendations included in this report. The following is a link to the Advisory Committee's website which documents its ongoing work.

<https://www.montgomerycountymd.gov/HHS-Program/ADS/CPWD/CPWDIndex.html>

2009 Workgroup on the Future for People with Severe Developmental Disabilities, including Autism – Call to Action and Partnerships for a Positive Future

In 2009, two reports were released from the Department of Health and Human Services with findings and recommendations from an 18-member Workgroup concerned that residents with severe developmental disabilities were waiting five to fifteen years for services, many with families in crisis and many with aging or elderly caregivers, who may also have disabilities. These reports are attached at Appendix B. The 2009 Workgroup said:

- There is a sense of urgency!
- We must have higher expectations for people with severe developmental disabilities – regardless of an individual's diagnosis.
- Families caring for children and adults with developmental disabilities worry.
- There needs to be a proactive response to people in crisis who are on a waiting list, and advocacy for more services and options.
- Support must be provided for people through service and life cycle transitions, while ensuring they move into activities and services that are meaningful and that enable them to grow.
- Families need increased support across the lifespan.
- The number of highly-skilled, responsive, and adequately paid people who provide direct support, medical, dental, and therapeutic services must be increased.
- The full array of community services and support available to all County residents should promote inclusion and lessen the dependence on specialized services and supports.

URGENCY is STILL NEEDED!

System-wide recommendations of the 2018 Work Group

The current Work Group both agrees with the 2009 recommendations and recognizes how much has changed since the Call to Action was released. The Work Group views this as an opportunity to refresh the 2009 recommendations and provide new findings and recommendations.

Following the 2018 Work Group's system-wide recommendations, this report contains stories from families and providers to help readers better understand the daily challenges, data, and "white papers" which include a discussion of gaps, innovations, **and specific recommendations** on the following topics:

1. Coordination of Community Services
2. Employment
3. Health & Wellness

4. Housing
5. Law Enforcement and Public Safety
6. Recreation
7. Respite
8. Transitioning Youth
9. Transportation
10. Waivers

System-wide Recommendations

Recommendation #1

The Montgomery County Executive and Council must partner with the General Assembly Delegation to receive regular progress reports on the Maryland Developmental Disabilities Administration's (DDA) Transformation Plan. The progress reports should focus on real impacts to individuals, families and providers. Is the Transformation Plan resulting in increases or decreases to the time individuals remain on waiting lists? Is it changing the quality of services provided?

In 2015, DDA announced that it was beginning a "transformation." This transformation is based on the following:

Vision: People with developmental disabilities will have full lives in the communities of their choice where they are included, participate, and are active members.

Call to Action: Create a flexible, person centered, family-oriented system of supports so people can have full lives.

There is no disagreement that these are appropriate and worthy goals. However, the implementation of this transformation has been confusing to individuals, families, and providers. County providers have submitted comments and concerns as new regulations and procedures have been proposed, but they do not believe that their concerns have been listened to or addressed. Each time there is a delay it is unclear whether providers will be able to accept new clients or how they will be able to continue to serve current clients. Families are unclear about how services will be provided to their loved ones, an issue critical for creating and implementing plans for young people transitioning from school to adult services.

Recommendation #2

The County Executive and Council must carefully monitor the ongoing rate setting study and advocate strongly for rates that reflect the cost of doing business in Montgomery County. Services must be funded in a manner that allows providers to afford to continue to provide services.

Providers can only stay in business and individuals can only be served if reimbursement rates are appropriate both in the dollar value and allowable services.

Providers have already voiced concerns about the impact on individuals if only face-to-face encounters are billable. Many individuals just need assistance by phone for things like problem solving with an employer or about transportation. If the new system only allows face-to-face services to be reimbursed, these individuals may suffer negative outcomes, such as loss of a job, when a phone call could have prevented it.

Person-centered planning and the Community Settings Rule, both of which are focused on letting individuals with disabilities have choice and opportunity, will also impact the cost of business. For example, the Department of Legislative Services' report on the FY18 budget for DDA highlights that the Community Settings Rule will mean the average staff to client ratio will have to decrease for community-based services as clients have more autonomy to plan their own day. "For example, if a client wants to go out for the day by themselves, rather than as part of a group, the staff-to-client ratio would be 1:1. Currently, for many day service programs the staff-to-client ratio is 1:8. This increases the cost for day services." There will also be limits on the number of individuals with disabilities that may live together. Although Montgomery County has been a leader in supporting lower ratios for services and housing, it is expected that the new requirements will increase the cost of providing housing. It is unclear that there will be any additional reimbursement to the housing provider.

In 2015, DDA began a rate setting study. The rate setting study was expected to be completed but only Phase 1 has been released. It is now expected to be a three-phase process that will be completed in the start of FY20. The most recent update from DDA says that they have hired another consultant to review the data and assumptions of the original consultant. When the new contractor has completed its work, it will develop a system-wide impact, pilot new rates to ensure accuracy, and obtain additional feedback before final implementation.

At the time of this report, deadlines are still in flux. The ongoing uncertainty of the rate study has been very disruptive. The County must work with the General Assembly Delegation to ensure appropriate rates are approved.

Recommendation #3

The focus on opportunity for employment is critical, but the County must advocate with DDA to ensure that new rules truly incentivize employment.

Maryland is an "Employment First" state. Employment is key to self-sufficiency, self-esteem, and full participation in the community. People with Autism/IDD should have employment choice, be paid a fair wage (not sub-minimum wage) and have the same opportunities for advancement as people without a disability. DDA says it is designing services to facilitate opportunities for full community integration. The Work Group

strongly endorses these goals and in the white-paper on Employment the Work Group calls for partnerships with the Chambers of Commerce, Montgomery County Economic Development Corporation, and WorkSource Montgomery to promote and highlight private business employment of people with disabilities.

However, the Work Group is concerned that some of the proposed specific rules about “meaningful employment” may unintentionally reduce choice, limit some opportunities for volunteer work, and reduce the capacity to place people in jobs. Providers may not be reimbursed for employment support that can be completed by phone or e-mail, a method that is currently used to problem solve. The County should create a vision for meaningful employment and advocate with DDA for implementation.

Recommendation #4

DDA should use its full budget allocation to support more people instead of ending the year with surpluses.

For FY19, DDA has an approved budget allowance of \$1.2 billion from all funding sources.

In FY18, DDA ended the year with a \$27.6 million surplus in General Funds. In FY17, DDA ended with a surplus of \$35.7 million. In FY16, there was a surplus of \$16.8 million.

Some of the reasons behind these surpluses include underestimating the amount of Federal matching funds and longer than expected time for placing individuals in services. Whatever the reason, DDA should not be returning millions in General Funds when \$1 million could provide \$25,000 per year to 40 individuals. This is the capped amount in the Community Support Waiver.

Recommendation #5

The County must continue to invest local funds to support providers, increase inclusion in County programs, and provide needed services to County residents with developmental disabilities who are either on a waitlist or not eligible for DDA services.

State funding is not enough to pay for the programs and services that are needed for residents with developmental disabilities.

Most critically, the County’s support to DD Providers to help them meet annual operating costs, including the County’s minimum wage, must continue. For FY19, the County is providing \$17.5 million to support over 30 organizations. This funding helps providers attract and retain a quality workforce to care for vulnerable adults by

recognizing that this direct work is much more than a minimum wage job and that stability is critical for the person being served. For FY19, organizations receiving this support will pay direct service workers, on average, a wage that is at least 125% of the County minimum wage.

The County's Department of Health and Human Services (DHHS) must continue to be a provider of Coordination of Community Services. Since the transition in 2014 to a fee-for-service system, some of the initial difficulties with transitioning people to private providers have stabilized but it is critical that DHHS continue to be a partner in all aspects of the system that serves persons with developmental disabilities, many of whom have or will access other DHHS services.

County-funded respite is an important service to families who do not receive State-funded in-home supports. Funding should be adjusted annually to ensure that the number of hours are not reduced as wages are required to rise. Rules for use of limited respite should be reviewed to see if it can be more family focused by allowing siblings with and without disabilities to be cared for; however, programmatic decisions must be made in the context of Maryland regulations (COMAR).

Recommendation #6

Don't forget about those who are not eligible for DDA services.

While all children with developmental disabilities are entitled to support services while they are in school, once the individual reaches age 22 or graduates from the school system, the severity of the disability may not meet the criteria to be eligible for any services through DDA. Some individuals whose disability may not qualify them for DDA services may also be dually diagnosed with a behavioral/mental health issue. While many individuals who do not qualify for DDA services may be able to find employment, it will likely not pay enough to cover living expenses and the individual may need supports in scheduling, transportation, and other activities and responsibilities.

These individuals are not on any of the waiting lists but they, and their families and support systems, must not be forgotten. Local supports, such as respite, should be available to assist them in leading full lives.

Recommendation #7

Residents with developmental disabilities face the same issues as the general population. They are aging, they are more culturally and language diverse, and face barriers to employment if they are ex-offenders.

The County must look at the need to increase provider capacity to serve people speaking many languages and with many cultural backgrounds. Clear and easy to

understand information in different languages is critical. RespectAbility recently released a toolkit specifically for Latinx students, their parents and caregivers on the services that are available to help them succeed in school and the workplace.

While for many years there has been a concern that caregivers are getting older, the reality is that the “children” are aging too. Many more people with Autism and other developmental disabilities are reaching middle age or becoming seniors. Services must be tailored to meet the health, housing, and other needs of this aging population, just as the County is working to meet the needs of the general population.

As is the case for the general population, ex-offenders face special barriers to employment and housing. As is also the case for the general ex-offender population, many also have mental health challenges or a diagnosis of mental illness.

*Next,
Our Stories and Experiences*

Our Stories and Experiences

The Transformation Plan's vision and goals are worthy. However, the Work Group recommends carefully monitoring the Transformation Plan to make sure more people will get quality waiver services and providers can continue to do business. There is great concern about the actual outcome. The process of how to merge the regulatory requirements with individual needs is a major challenge.

The Developmental Disabilities Administration's (DDA) vision, as newly stated in their Transformation Plan, is beautiful. But as the saying goes, the proof is in the pudding. I think this is what Annie, my 26-year-old, severely developmentally disabled daughter would say if she could. She loves dessert. It's how it all works out in the end. And, the issue for us, Annie, and many others like her is that navigating the bumps of it, dealing with the many big and little changes, is serious and can even be dangerous. So, beware and proceed with caution. For Annie, a substitute aide, missed routine, or an easy task that is too hard can derail her for weeks. I so want Annie to be included, but I have spent her life re-learning the lesson that steps forward need to be Annie-sized. A rule written too narrowly for this incredibly diverse group of people can take months, even years to circumvent. An effort to include all, or more, can even leave the most challenged at a greater disadvantage. We need our elected representatives to help. We need them to understand these complicated governmental safety nets and advocate for fair, equitable, and realistic solutions.

My daughter has autism, and a bi-polar component to her autism. She can be a lovely helpful child, or "when the switch flips" she is the complete opposite and a danger to herself and others. This has meant complete flexibility in her staffing and program. There have been years when the utmost supervision was required at all times and activities were severely restricted. There was no choice, she ended up in the hospital too many times. But, with the support of her providing agency, staff, and mental health professionals, we have always come out of it and now, for some time, she has been in the community, working two jobs, and happier than she has ever been. What allowed this to happen was the flexibility of the DDA Waiver programs that allowed her program/support, to change immediately when it was necessary. The proposed definitions in the new DDA waiver and corresponding rate changes to take effect in January of 2020, may negatively impact flexibility in her support to work and engage in other activities throughout the day.

I am deeply concerned about how the Transformation Plan will affect severely impacted persons. The recreation discussion is a good example. Presently it is very difficult to find opportunities for this population. My daughter is presently serviced by Community Support Services who has organized activities for their client base to fill this gap. But the new DDA rules included in the rewrite will limit gatherings to four people, despite continuous opposition from

stakeholders. This will call into question a team of basketball players, art sessions, dances or dance classes held "in-house" for groups greater than four participants. The rules are also designed to not permit groups greater than four special needs individuals from different service provider organizations meeting in the community. And this, of course, discourages designing programs that are suited to special functioning levels. I have concerns that this sort of forced integration will cause more problems than solutions, once again, especially for more impacted individuals. At best you can see this as good intentions but hardly practical or, more importantly, fundable.

County funding for respite and other support services is critical.

Four children, two with autism. One day in the midst of this madness that was our family I realized my two neuro-typical children did not know what a waitress/waiter was. The only times they had gone out to eat was in restaurants with ball pits, and fluorescent lighting, and when we were in the car, wee-sing was the only music allowed to be played. Through respite services we not only got to eat out once in a while in "real restaurants" we could attend their sports events without chasing after their siblings, and most importantly, take a once a year vacation. And for me, personally, it was the only time I was able to eat my meal at the same time as everyone else – I always had to feed my son first.

It is hard work for families to support their family member who is not eligible for, or receives limited access to, State-funded services.

JC attended high school in Montgomery County and participated in Montgomery County Therapeutic Recreation clubs. She graduated with a high school diploma but did not qualify for a degree program at Montgomery College. During the last 20 years her family has worked to see that she has opportunities for training and employment. After high-school, she entered a state-funded residential vocation program but was unsuccessful and moved back home. For two years, JC cleaned homes with AmeriCorps and the ARC, with her family providing transportation. After that, for five years she was able to work as a Library Page with job coaching from Santé Group/Rock Creek Foundation. JC used Metro Access/taxi to commute. However, the job coaching program funding ended and she resigned from the library job. JC then entered a training program at the TLC Outcomes Center and applied for a bakery apprenticeship but is turned down. The family started providing transportation again when the library job ended. For a summer, she cleaned at a country club, but the manager required full-time job coaching and funds were not available. In 2013, she was able to receive Division of Rehabilitation Services (DORS) and Low Intensity Support Services (LISS) short-term funds. She was able to secure a job at a grocery store and three months of job coaching and transportation training from Catholic Charities. She continues to work part-time at the grocery store with family support and, after attending Jewish Council on Aging transportation workshops, commutes by bus, Metro, walking, and Uber.

Organizations try to help, even when they are not funded for needed services.

KT is not eligible for DDA services but was eligible for services from the Division of Rehabilitation Services (DORS) that included temporary job coaching. She had been an employee of a grocery store for two years and traveled two hours each way on the bus to and from work. She started with responsibilities in the bakery but did not have the speed to complete all of her tasks. The job coach and KT were able to work with the grocer to get her reassigned as a courtesy clerk. There had been no complaints until she was called to meet with a company representative who asked if she had taken food items without paying for them. She said she had, and while she knew it was wrong she was hungry and didn't have the money to pay for them. She was told she owed about \$31 and could pay the next payday. The next payday, after all her auto-deducted bills had been paid, she only had \$8.19 in her account. KT shared that her shifts had been cut back and she makes less than \$500 per month. She pays \$250 in rent, \$50 for a cell phone, \$100 for food, and the cost of transportation. The grocer gave her time to pay but she was also suspended without pay until corporate human resources made a decision. KT ended up losing her job. Treatment and Learning Centers (TLC) is trying to help by connecting her with job openings even though they are not funded to do so, a situation that happens all the time. How did TLC and KT connect again? The grocer had an employee with DDA funding and remembered that TLC had supported KT in the past. KT is going to have to reapply to DORS to see if she is eligible for services.

Reliable transportation is critical and is a safety issue.

My son Corey is verbal, has a great memory and uses a wheelchair. He does not read or write, and he cannot use a cell phone. Corey uses Metro Access to get to physical therapy on Tuesday and Thursday afternoons. The office is located on the second floor. In one instance Metro Access arrived to pick him up but no one knew they had arrived. Although Metro Access has the phone number of the physical therapist and his caregivers, they did not call. Physical therapy staff cannot just take him down and wait for Metro Access. New arrangements had to be made for his transport. Another time, Corey had a 3:00 p.m. doctor appointment and Metro Access was scheduled to pick him up at 2:15 p.m., which they did. By 3:55 p.m. he still had not arrived at the doctor's office. As it was the last appointment of the day, the doctor had to leave and we had to reschedule. Perhaps our worst incident was in September. Corey was picked up in Germantown at 12:57 p.m. and dropped off in Aspen Hill at 2:45 p.m. Metro Access confirmed these times and at first said there were no other passengers in the vehicle at the time. Metro Access later confirmed that another passenger was picked up at 1:37 p.m. in Rockville and dropped off and then a second passenger was picked up and dropped off. Why did it take 1 hour 40 minutes to go approximately 16 miles on a sunny weekday during non-rush hour? Corey told his physical therapist that they drove around. Despite his physical and intellectual disabilities, Corey has superb hearing, knows what's going on, and is completely verbal. Although he is fully toilet trained, due to this lengthy ride, Corey had a urine accident. This alone made him upset. I believe he knew it was taking substantially longer than usual, and that something was not right; and it was this trauma that led to the accident. An added difficulty is that Metro Access' policy is that the driver cannot help anyone get on or off their electronic

wheelchair. Most recently, in October, Corey was to be picked up at the Wheaton Mall between 3:20 p.m. and 3:50 p.m. It took Metro Access until 6:35 p.m. to remedy the situation and have another driver pick him up. This event also impacted another individual who is supported alongside Corey.

The process for transitioning from school-based services to adult services is broken and it is difficult to be prepared for what it may really mean.

Most people think the college transition is one of the most complex and stressful transitions a family experience. The college transition process cannot even compare to the impersonal, confusing, frightening, and stressful process parents experience when their disabled child transitions from school age to adult services. Our transition with our daughter with disabilities was a nightmare that would drag on for two years affecting our whole family's health, finances, and emotional well-being. We thought we were proactive and prepared for the transition process. We did all the things the "transition specialist" recommended parents to do. I was a special education teacher. I know about programs and practices that are proven effective in educating youth with disabilities. Our disabled daughter had attended the Ivymount School since she was three years of age. Her complex needs were supported by a highly skilled team of educators, therapists (speech, occupational, physical) and nurses, in small, inviting, educational classes. Our daughter even had a one-to-one aide to attend to her individual needs. What we knew from our experience was that for 18 years, our daughter had experienced this family-like learning environment.

In contrast, the transition process was far from a sense of togetherness. It was scary and unknown, as if you were falling off a cliff into a dark tunnel. In our first transaction with our daughter's transition coordinator, she explained at the end of the transition process, one of your three choices of adult programs may accept your child, but it's not guaranteed. This was not the welcome I was expecting. It is frightening that program options are limited. It is also a scary reality that people (coordinators and support staff in programs) who don't know your child are placing your child in a program where they will spend many hours. You also struggle with entrusting program staff who most likely are not trained in the complexity of your child's unique set of needs. (My daughter can't move, eat, do anything for herself, has very limited speech, and is confined to a wheelchair as well as having very complex medical needs that require emergency trained staff.)

A parent who hasn't gone through the transition process doesn't understand the difference between school-age programs and adult programs. Adult programs are not entitlement programs which all school-aged programs are. You do not really understand the role of the Community Coordinator (CCS) or how the transition process works. You hope you can spend time with this person and try to educate them about your child, so they can advocate your child's needs. You soon learn you are just a name on paper they must process. Our CCS clearly

showed they didn't understand the information I had provided and continued to recommended programs that were not appropriate. Their caseload is too large that there is a high turnover rate, which means that keeping knowledgeable staff is a constant problem. Since the beginning of our transition, we have had five different Coordinators. The CCS are not necessarily knowledgeable to advise families. Our CCS was brand new and couldn't answer most of our questions, so we mostly worked with her supervisor. We were emailed a list a long list of agencies and told to go visit them. The programs were shockingly different from our daughters beloved school. The facilities, the resources, the education of the staff, the ratio of staff to clients, the types and amount of meaningful activities, and the reality of the amount of socialization and inclusion opportunities in the community were all concerns to us. We felt that the environment was not a safe one to deal with our daughter's medical needs, even though she would have her own nurse attending the program with her. Medicaid funding became a disheartening reality of the limitations and the state of most all the adult programs we visited.

Our CCS tried to discourage us from self-direction and instead wanted us to seek a DDA day program. We were advised to get out of the Community Pathways Waiver and enter a Medical Day Waiver. We couldn't believe that our daughter wouldn't have the same rights as all other disabled adults to self-direct her day and services and remain in the community she lived in. Especially since self-directing her services would also allow her to be more flexible in her schedule to meet her health care. We hired a lawyer who informed us that we had been given inaccurate information about our daughter's rights. The more we learned about the process, the more questions we had. Eventually a new CCS was assigned to us. At this time, we had four months until our daughter would graduate and enter adult services.

Suddenly an emergency shifted our priorities. Our daughter was rushed to Johns Hopkins Hospital from merely scratching her scalp at the site of her shunt. For the next three and a half months we stayed with her in the ICU. The transition timelines had to be met. Duties of developing her plan and discussions with the CCS had to be done despite her stay in the ICU. Our daughter was fortunate to recover and was able to come home in time to attend her prom and her graduation. However, two weeks after her graduation, something else about her transition would cause us tremendous stress. We were unaware the compliance coordinator with department of nursing (DON) reviewed files of a group of transitioning youth and determined that these young adults no longer needed nursing. Ironically, they qualified for nursing as school age but now that they had entered adult services, they suddenly no longer qualified. It was also revealed that this time frame coincided with the end of the DON's fiscal year and this practice sometimes occurs in agencies to save money in budgets.

It wasn't until eight months after this review was conducted, that we received a letter stating that DON had determined our daughter no longer qualified for nursing. The letter further said her nursing would be terminated within three weeks' time unless an appeal letter and request for hearing was initiated. Our lawyer and her colleagues were contacted by multiple families

about similar letters at the same time. The lawyers wrote and sent letters to both DDA and DORS and copies to DONS to acknowledge the large group of transitioning youth who all received similar letters of nursing terminations. They warned these agencies of possible crisis in all families if nursing is terminated. Our daughter's Self Direction program couldn't happen if she did not have the level of nursing she needed. DDA did not offer that level of nursing, which was provided by the Rare and Expensive Case Management (REM) program.

My worries were constant ...What if I wouldn't be able to work? Without my income we could not afford our house, our family's healthcare was in jeopardy, as well as my retirement. We had hired a lawyer. Every month our hearing date would get changed. This continued for over a year. Finally, we got a court date and we were prepared for the hearing. We had coordinated a team of doctors that included our daughter's neurosurgeon, neurologist, rehabilitation doctor, and pediatrician. We had so much medical documentation and her nursing care plan was extensive. Then three days before the hearing, the lawyer representing DON sent an email informing our lawyer about a letter that was sent cancelling the upcoming hearing. We received the letter two days later. The letter stated that the DONs had reviewed additional data and was rescinding their decision to discontinue my daughter's nursing. The decision was a relief as the outcome resulted in our daughter continuing her nursing services. However, feelings of anger and frustration were overwhelming from all the stress and pain of dealing with our daughter's transition to adult services. We understand that as painful it is to share our story, we hope sharing will heighten awareness to a process that is in great need of change. We hope that positive change can help the transition process and improve the programs for adults with disabilities.

*Next
Data on Number of Individuals Receiving Services and on Wait Lists
Population Trends
FY19 County Government Funding*

Number of County Individuals Receiving Coordination of Community Services Wait List for DDA Services

Coordination of Community Services is required for all individuals that are receiving services through DDA. The following shows the caseloads at a point in time, the numbers can change daily. The number of providers an individual can choose from has increased over the last two years.

	November 2016	November 2018
MMARS	1,413	1,411
Montgomery County DHHS	498	480
Optimal Health	na	103
Resource Connections Inc.*	na	92
Service Coordination Inc.	na	140
Total Care Services	1,126	1,064
Total	3,037	3,290

Source: DDA *Provider is assigned on a case-by-case basis

Waiting List for DDA Services

	September 12, 2016	August 1, 2018
DDA Waiting List – receiving no services	989	1,058
Crisis Resolution (need services within 3 months)	12	9
Crisis Prevention (need services with a year)	106	59
Current Request	871	757

Source: Annual Reports Commission on People with Disabilities sourcing DDA

Reasons for being in crisis resolution might include being homeless or at risk of homelessness, potential for harm to self or others, or have a caregiver who can no longer care for them (perhaps because of age or illness).

Reasons for crisis prevention can include being at substantial risk of meeting one or more criteria for crisis resolution within one year or having a caregiver who is age 65 or older.

Current requests have been determined to need services, such as employment, housing, or daily living supports but it is not an immediate need.

People who apply to DDA for services but will not need them within the next three years are placed on the Future Needs Registry. This is separate from any wait list.

Population Trend Data

OLO Report 2017-13, *Housing for Adults with Developmental Disabilities*, says that individuals with intellectual/developmental disabilities (I/DD) account for 1% to 2% of the general population but that no national methodology exists to develop estimates of adults with I/DD for service planning purposes. The OLO Report describes the “Boogs and Henney Research Estimate” and the “Larson Method.” Using the Larson Method, OLO estimated that there were 7,170 adults with I/DD and 8,240 children with I/DD in Montgomery County.

The following provides some population trends to consider in understanding the growing need for funding and supports for persons with developmental disabilities.

- From 2013 to 2017, the County population increased by 4.3% while the number of people with a Cognitive Disability increased by 10.9%. Within the age range of 18 to 64 years old, the general population grew by 1.9% while those reporting a Cognitive Disability increased by 3.8%.
- From 2013 to 2017, the County population age 5 to 17 increased by 3.4%. The number of students age 3 to 21 enrolled in Montgomery County Public Schools with Autism increased by 17.9% and with an intellectual disability by 5.3%.
- The Centers for Disease Control report that based on data from eleven research sites, in 2000, the prevalence of Autism in 8-year-olds was one in 150. In 2014, it was one in 59.

Reasons for the increases are not known but may include better and earlier diagnosis, particularly for children whose Autism or disability is on the less severe part of the spectrum. Montgomery County Public Schools may see higher percentages and growth because it is known to have good services and supports.

Montgomery County General Population (American Community Survey)

Age:	2013	2017	% Change
5 to 17 years	173,508	179,391	3.4%
18 to 64	641,576	654,059	1.9%
65 and older	135,583	158,478	1.7%
Total	950,667	991,928	4.3%

The American Community Survey collects data on Cognitive Disability, which is a broader category, defined as, “Because of physical, mental, or emotional problem, having difficulty remembering, concentrating, or making decisions.” Each year, the Commission on People with Disabilities reports on the number of County residents with a Cognitive Disability.

Population with a Cognitive Disability (American Community Survey)

Age:	2013	2017	% Change
5 to 17 years	5,279	5,599	6.1%
18 to 64	13,498	14,019	3.8%
65 and older	8,837	11,027	24.8%
Total	27,614	30,645	10.9%

The Commission on People with Disabilities also reports on the number of students aged 3 to 21 with disabilities enrolled in Montgomery County Public Schools. The categories are taken from codes in student Individualized Education Plans (IEPs).

	2013	2017	% Change
Autism	2,023	2,386	17.9%
Intellectual Disability	620	653	5.3%
Developmental Delay (age 3-9)	2,619	3,282	25.3%
Developmental Delay (extended IFSP*)	154	105	(31.8%)
Traumatic Brain Injury	24	21	(12.5%)
Total	27,614	30,645	10.9%

*Individualized Family Service Plan

In April 2018, the Centers for Disease Control released the report on the prevalence of Autism Spectrum Disorder (ASD) that reported rates based on prevalence in 8-year olds living in eleven regional monitoring sites.

Data Year	Overall Prevalence
2014	1 in 59
2012	1 in 68
2010	1 in 68
2008	1 in 88
2006	1 in 110
2000 and 2002	1 in 150

- The report noted that the most current rate is one in 38 for boys and one in 152 for girls.
- About 70% of children with ASD in the most recent report had borderline average or above average intellectual ability.
- Previous reports showed rates of ASD that were 20% to 30% higher for white children than black children, but the most recent report showed a gap of 7%.
- Maryland (one of the sites) had a higher rate than the network as a whole; 1 in 31 among boys and 1 in 139 among girls.

Montgomery County Government FY19 Funding in Support of Persons with Developmental Disabilities

Montgomery County has long invested County funds to support the providers and system of programs and services that support persons with developmental disabilities, their families and caregivers. The following provides an overview of FY19 funding.

Community Service Network (CSN) \$22,288,023 (total)

DHHS provides a range of services to support people with developmental disabilities. The Community Services Network includes the payment to DD direct service providers, Coordination of Community Services (CCS), and the My Turn program as well as coordination services for children on the Autism Waiver outside of the school day. Costs for payment to providers, CCS, and My Turn are broken out as follows:

Payment to Direct Service Providers (part of CSN) \$17,562,175

The County has a long-standing policy of providing local funds to organizations providing direct service to County residents with developmental disabilities. While the method for determining the amount of the support has varied, in the last couple of years funding has been determined after considering support needed for organizations to pay an average amount above the County minimum wage. In December 2017, the Council enacted Bill 35-17, *Finance – Payment to Service Providers*, which requires the Director of DHHS to recommend to the Executive an amount that would allow organizations to pay, on average, 125% of the County minimum wage. The final amount is subject to appropriation. For FY19, organizations accepting the payment agree that they will pay direct workers, on average, at least 125% of the County minimum wage.

Providers, advocates, and families strongly support this assistance because of the higher cost of doing business in Montgomery County, the need to pay above the minimum wage or State rate to attract the quality of worker that is needed to assist some of the County's most vulnerable residents, and to help organizations reduce turnover which greatly benefits the person being supported.

For FY19, it is expected that 32 organizations will receive a payment from the \$17.5 million appropriation.

Coordination of Community Services (part of CSN) \$1,241,880 (exp) \$ 771,070 (rev)

DHHS is one of five providers of CCS (previously called Resource Coordination or Targeted Case Management) in Montgomery County. DHHS may serve up to 500 persons. The County bills the State for reimbursement that leverages Medicaid. However, the State's reimbursement rate does not fully cover the cost of County employees and a General Fund contribution is required. This report includes a white paper at page 24-28 that provides information and recommendation on CCS.

My Turn Program (part of CSN)**\$353,964**

The My Turn Program serves children aged 3 through 13 who have been diagnosed with a developmental disability but do not receive services through DDA. The program assists families with accessing information, linking to other resources in the community, and providing limited financial assistance for services, activities (including summer camp) and assistive equipment. Most often it serves between 80 and 90 people.

Respite (not included in CSN total)**\$1,362,661 (total)****\$1,048,062 (County)**

Respite provides temporary relief and support for the primary unpaid caregiver who provides ongoing care to frail elderly persons, children and adults with disabilities and/or children with severe medical or behavioral needs. Persons receiving DDA services can request respite as a part of their Waiver Services in their person-centered plan; however, there are many caregivers who must rely on County's respite program. The County's respite program is funded by a combination of County funds and grant funds. In FY18 about 37% of respite hours were used to serve families with a member who has a developmentally disability. In FY17, 46% was used for this purpose. This report contains a white paper at pages 56-59 that provides information and recommendations on respite.

Therapeutic Recreation

Therapeutic Recreation programs are specifically designed for individuals with disabilities. The Department of Recreation offers classes under Aquatic, Fitness and Specialty Programs, including specialized summer camps. Weekend Adult Social Clubs and Dances provide opportunities to interact while developing friendships through like interests. Individuals are encouraged to participate in Therapeutic Recreation and general recreation offerings. Recreation programs are fee supported. The cost for two summer camps, adult swim, and themed dances is about \$25,900. Volunteers support some of the programs. This report contains a white paper at pages 53-59 on Recreation.

Housing Initiative Fund

Each year, the Department of Housing and Community Affairs uses the Housing Initiative Funds to assist organizations with purchasing or renovating housing for special populations, including persons with I/DD. There is not a set amount and it will vary from year-to-year depending on the number of organizations requesting assistance. For FY19, the HIF includes an allocation of \$2.3 million for special needs and non-profit housing for all special populations. This report contains a white paper at pages 42-48 on housing.

Non-competitive Funding

In addition to general financial assistance (Payment to Direct Service Providers previously described), each year, the County provides non-competitive awards to non-profit providers through Community Grants, cost sharing, and contracts in departmental base budgets. For FY19, funding of over \$1.7 million has been provided.

Bender JCC of Greater Washington	\$ 25,000
Best Buddies	34,090
Devenio Inc.	10,000
Ivymount School	70,000
Jewish Social Service Agency	30,000
KEEN (Kids Enjoy Exercise Now)	15,000
Lt. Joseph P Kennedy Institute	659,190*
Madison House Autism Foundation	50,000
Potomac Community Resources	128,580
Red Wiggler	70,000
St. Joseph's House	20,000
Sunflower Bakery	450,000**
TransCen	35,430
The ARC Montgomery	83,960
Treatment and Learning Centers	10,000
UpCounty Community Resources	62,500

*includes \$327,000 for the Community Options Program that was previously included in the general financial assistance to DD providers

* includes \$300,000 Special Appropriation approved November 2018

White Papers

Coordination of Community Services

1. Definition

Coordination of Community Services (CCS) assists people and their family/guardian with the process of applying for services from the Maryland Department of Health, Developmental Disabilities Administration (DDA), conducting an eligibility Comprehensive Assessment, and assisting with planning and coordinating services. CCS is provided to people who are eligible based on a developmental disability, to receive support services from DDA, are placed on a DDA waiting list, or are transitioning from school or institutional services to community services.

CCS has previously been called Resource Coordination and is now a fee-for-service, Targeted Case Management service.

When a CCS provider is conducting the initial Comprehensive Assessment, they are acting on behalf of DDA. If a person is determined to be eligible for services by DDA, the CCS provider they select will then serve as their advocate to obtain needed services from DDA and other sources. Over the lifespan, a CCS provider will assist with the planning from school to community based services utilizing the Medicaid Home and Community Based Services waiver program, develop the person-centered/individual service plan, help the person apply for any needed changes to the DDA support being provided or change the priority category, help to assure a person's rights are protected, and act as an agent for the person as needed to implement the person-centered plan.

DDA approves organizations to be CCS providers in its different regions of the State. CCS providers must meet State and Federal requirements that include training and staff qualifications. CCS providers must also meet Federal criteria for conflict-free case management. In Montgomery County, which is in the Southern Region, people may choose from five private sector CCS providers: MMARS RC, Optimal Health Inc., Resource Connections, Inc., Service Coordination, and Total Care Services. The Montgomery County Department of Health and Human Services (DHHS) also provides CCS to County residents. DHHS has a cap of serving 500 people imposed by the County's approved budget starting in FY16. If a family does not choose a CCS provider, DDA will assign one, (sans DHHS). The person can choose to change CCS providers.

2014 (to FY16) Transformation of CCS

Starting in FY14 major changes were made to CCS (Resource Coordination) in Montgomery County. Prior to FY14, Montgomery County provided all CCS services to County residents and received a grant from the State to pay for the program. In order to better leverage Medicaid funds, the State moved to a fee-for-service requirement and also determined that private provider choice must be available. While the transition was supposed to begin in FY14, private providers did not have the capacity to accept clients and so the transition of clients started during FY15. At first a decision was made to close the program and move everyone from DHHS to private providers because the reimbursement rate was not sufficient to cover the cost of County

employees. Families were extremely confused and upset. Communication from DDA was not clear. People did not know which provider they were assigned to. Serious concerns were raised about turnover and lack of experience by the new providers. People worried about the impact on Transitioning Youth if DHHS were no longer a provider.

The DD Transition Advisory Workgroup was convened and one of its recommendations was that DHHS continue to be a Resource Coordination provider with a cap of 1,100 individuals and the right to decline some referrals. There was concern about the instability of the transition and the importance of having DHHS remain a provider particularly for people that need coordination with other DHHS services. The Council agreed that DHHS should remain a provider understanding that the State reimbursement would not fully cover the cost of County employees. The Council approved FY16 County funding that along with State reimbursement would allow DHHS to serve 500 persons.

2. Eligibility - Applicability

<input checked="" type="checkbox"/> Infants and Toddlers	<2 yrs	<input checked="" type="checkbox"/> Young Adults	18–25 yrs
<input checked="" type="checkbox"/> Pre-K	3–4 yrs	<input checked="" type="checkbox"/> Older Adults	25–49 yrs
<input checked="" type="checkbox"/> K-12 (incl transition)	5–18 yrs	<input checked="" type="checkbox"/> Seniors	50+ yrs

3. Description of Programs and Services

DDA's Guide to Services from January 2018 states that the coordinator:

- Assesses your needs, helps with the person-centered planning, and assists with the development of the initial and annual plan and budget,
- Identifies community resources to help you,
- Verifies that all services are waiver eligible services,
- Verifies that all services are important for the outcomes and goals you want and do not risk your health and safety,
- Monitors that the services are being delivered appropriately and that the funds are being spent correctly, and
- Monitors your emergency backup plan, Provides checks and balances necessary for your health and welfare and overall program integrity.

Review of the private sector's website revealed that Service Coordination also notes that as a part of these services the coordinator will get to know you, will talk to you about your dreams and experiences, and assist you in advocating for what you want. It suggests people talk with a coordinator about where they work and live, what they want to do during the week and on weekends, people who are important, whether you have enough spending money, and what support you need to keep you safe and healthy.

A person may choose to self-direct accessing community services and employment. The DDA Guide to Services says that in this case, the coordinator will help you interview and choose a Support Broker, help you choose a Fiscal Management Services provider, help monitor your

monthly budget, and helps answer questions about your Support Broker or Financial Services Manager.

4. Data and Trends

The following shows the number of residents receiving CCS and their provider. The number of people changes as people are enrolled and leave services. An individual can choose to change providers.

	November 2016	November 2018
MMARS	1,413	1,411
Montgomery County DHHS	498	480
Optimal Health	na	103
Resource Connections Inc.	na	92
Service Coordination Inc.	na	140
Total Care Services	1,126	1,064
Total	3,037	3,290

Source DDA

5. Gaps and Identified Concerns

It is unclear why some people are found by DDA not to be sufficiently disabled to meet the criteria for eligibility for services, especially if they had been receiving services through their school system. There is a perception that DDA is becoming more conservative in their assessment of who is eligible. It would be helpful to have better documentation and definitions. This may be a reason why there seems to be a slowdown in the number of Transitioning Youth.

Families are confused when their child is found ineligible for adult services and there is concern that if the child is on track to graduate with a high school diploma, this becomes an impediment to transitioning to adult services. Families believe that their child should be encouraged to succeed in school and graduate with a high school diploma if possible. Once a person is found ineligible it is unlikely they will receive further services through DDA. Being classified as "Future Needs" is not the same as being on a waiting list. It means that the person is determined eligible but does not have a current need for service.

Beginning Fiscal Year 2017, the implementation of the DDA Transformation Plan has created stress for CCS providers. There is a lack of clarity about the role of CCS and sometimes there are unrealistic expectations regarding the creation and full implementation of person-centered plans. This is frustrating for CCS providers and families.

CCS providers are extremely concerned about the rate setting study and changes to billing requirements. CCS providers would like to be able to spend more time with people but it is unclear whether this will ever be realized due to the increased administrative tasks required of the CCS by the DDA.

There is significant turnover of staff in CCS agencies. Providers report that there are not manuals with policies and procedures and providers that work in more than one region may get different answers to questions. At exit interviews, people say that there is too much stress because things are continually changing, and they are constantly having to relearn their jobs. They want to know what their job is supposed to be. They feel overwhelmed with the time allotted for doing different tasks.

There should be clear standards about staffing ratios. DDA reports that the current budget assumption is a ratio of 1 Coordinator to 45 clients. However, providers report that both a ratio of 1:40 and 1:35 have been discussed by DDA. Based on the required activities thus far in the five-year Transformation, a ratio of 1:35 may be feasible for CCS agencies to be compliant with Federal and State regulations. However, it remains unclear because of the ever-changing role of the CCS. For example, DDA is now requiring that Coordinators have five face-to-face contacts (the previous requirement was four). Staffing ratios and required activities for Coordinators should be clearly defined in writing and taken into account in setting rates.

6. Innovations

Person-centered planning, which is the focus of the DDA Transformation Plan, is considered a best practice. The 2001 document from the National Center for Outcomes Resources, *Practice Guidance for Delivering Outcomes in Service Coordination*, says this is a paradigm change shift **from** management **to** support and that the coordinator ensures that the choices made by the person are actualized in the broader community.

In 2002, New Jersey developed the *Real Life Choices* program. This is a self-directed model meant to support people living at home. Services can include in-home respite, socialization and habilitation, individual supports, and supported employment.

7. Recommendations

- ✓ The Council and Executive should inform the Governor and the General Assembly Delegation that the implementation of the Transformation Plan (paradigm shift) is causing confusion for CCS providers, which is causing stress and disruption for people with Autism/IDD and their families. The Transformation Plan is based on the best practice of being person-centered, but without successful implementation, its goals will not be met.
- ✓ Policies, procedures, expectations, and responses to CCS provider questions should be in writing and available on-line so that all regions have the same information.
- ✓ All CCS providers serving Montgomery County should be staffed at least at the 1:35 ratio. At this time, County Government has a higher ratio (about 1:43) than the private sector providers and higher than either the 1:40 or 1:35 that have been discussed as DDA recommended. CCS providers believe a ratio of 1:25 is appropriate given the

responsibilities with person-centered planning. The Council should review DHHS staffing as a part of the Fiscal Year 2020 budget and fund the necessary positions to adequately comply with family, State, and Federal expectations. DDA should specifically work with CCS providers on strategies to reduce turnover.

- ✓ The Council and Executive should advocate with the General Assembly Delegation for a rate and billing system that appropriately compensates Montgomery County CCS providers for the work that is associated with the required person-centered planning.
- ✓ Montgomery County Public Schools (MCPS) and CCS providers should return to the practice of working together to make sure all children start the Transitioning Youth process at age 14 or younger. Clear information should be given to parents about the different eligibility criteria for school systems and DDA, so they can make informed choices.
- ✓ DDA and Montgomery County should work together to fund a flexible program to provide assistance with accessing resources/information and to provide limited financial assistance for services to adults with Autism/IDD that is similar to the My Turn Program. The My Turn Program provides County children aged 3 to 13 these services. These children have not applied to DDA or were determined not eligible in at least the Current Request priority category. MCPS is open to collaborating on such an effort.

Employment

1. Definition

Employment for individuals with intellectual and/or developmental disabilities (I/DD) is described as “Competitive Integrated Employment” where work is performed by a person with a disability working alongside non-disabled workers and compensated at a comparable and market-driven wage to perform the same tasks¹. More specifically:

- Jobs held by individuals with I/DD in workplaces where the majority of people employed are not people with disabilities;
- Employees with I/DD are paid at minimum wage and are paid directly by the employer who is not the support agency; and
- Employees with I/DD may receive supports by an employment support agency and/or the employer in ways that the employee can learn and perform tasks associated with the job².

The “Sheltered Workshop” model, which is slowly being phased out, is defined as an organization or environment that employs individuals with disabilities as a segregated workforce and typically pays employees less than minimum wage to perform menial and repetitive tasks³.

Maryland’s Developmental Disabilities Administration (DDA) is undergoing a realigning of their services under the *Employment First* national movement from the United States Department of Labor launched on the premise that all citizens, including individuals with significant disabilities, are capable of full participation in integrated employment and community life. Services, systems and values are realigning at the State level to support competitive integrated employment and community participation outcomes and will be designed to provide a ‘flow of services.’

Meaningful Day Services will realign to include Employment Services, Community Development Services, Career Exploration, Day Habilitation Services and Medical Day Care, effective January 1, 2020 and are supported through the Community Support Waiver and Community Pathways Waiver.

Customized Employment Typical Flow of Services:

Discovery → Job Development → Ongoing/Follow-Along Supports
→ Wrap Around Day Supports

As a part of Maryland’s *Employment First*, the use of the sub-minimum wage will end by 2020, there will be a new menu of Meaningful Day services that align with best practices, a rate setting study will be completed, there will be an employment data initiative, technical assistance to

¹“Opening DORS to Employment” brochure. Maryland State Department of Education, Division of Rehabilitation Services.

² <https://dda.health.maryland.gov/Documents/2016/Strategic%20Plan.pdf>

³ <https://nonprofitquarterly.org/2018/03/20/will-subminimum-wages-disabled-finally-end/>

providers, and resources including a website, newsletter, and webinars.
<https://dda.health.maryland.gov/Pages/employment.aspx>

Current providers will need to requalify as provider under the new aligned categories for employment services in order to receive funding from the Community Support Waiver and Community Pathways Waiver.

Individuals with developmental disabilities typically require tailored job skills training, on-the-job one-on-one coaching, supportive career and job search coaching and assistive technology solutions to secure and retain employment. Additionally, since individuals over the age of 18 are most likely receiving Social Security Income (SSI) and/or Social Security Disability Insurance (SSDI), employment services include counseling and coordination of benefits and documentation for the Social Security Administration.

2. Eligibility

<input type="checkbox"/> Infants and Toddlers	<2 yrs	<input checked="" type="checkbox"/> High School	14–17 yrs
<input type="checkbox"/> Pre-K	3–4 yrs	<input checked="" type="checkbox"/> Young Adults	18–25 yrs
<input type="checkbox"/> K-12	5–18 yrs	<input checked="" type="checkbox"/> Older Adults	25–49 yrs
		<input checked="" type="checkbox"/> Seniors	50+ yrs

Eligibility criteria varies depending on program and service.

3. Description of Programs and Services

Division of Rehabilitation Services (DORS)

The Division of Rehabilitation Services (DORS) of the Maryland State Department of Education runs the state's employment readiness programs for individuals with developmental disabilities. Headquartered in Baltimore, there are DORS offices located in Germantown and Wheaton. In order to be eligible for DORS services:

- Individuals must have a physical or mental disability that seriously affects his or her ability to work and must need employment rehabilitation services in order to secure or keep a job.
- Individuals that receive Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI) are presumed eligible.
- For youth programs (ages 14-21), students with disabilities must not have exited, graduated or withdrawn from secondary school or are enrolled in post-secondary credit programs or a national/State-recognized accredited training program and have a disability documented with an Individualized Education Plane (IEP), 504 plan, medical records or a physician's note.

Federal law requires that DORS must serve people with the most significant disabilities first. Counselors determine the severity of the disability of individuals who are eligible for services into three categories:

Category 1: Most Significant Disability – Receive services immediately

Category 2: Significant Disability – Placed on waiting list

Category 3: Non-Severe Disability – No expectation of services

Vocational Rehabilitation (VR) Program – Participants will work with a DORS counselor to secure competitive integrated employment. They receive career counseling and decision making based on interests, abilities and goals, training to prepare for employment, skills training leading to credentials to meet local labor market demands, job search and job placement services, job coaching and supported employment services and assistive technology needs. Participants may be required to pay a portion of the costs of services, based on income.

Pre-Employment Transition Services (Pre-ETS) for ages 14-21 – Students receive job exploration training, work-based learning experiences (in-school or after-school opportunities), counseling on opportunities for enrollment in comprehensive transition or post-secondary educational programs, workplace readiness training to develop social and independent living skills and instruction in self-advocacy.

Nonprofit Service Providers

Nonprofit organizations have offices in the County that provide specialized employment services and programs for individuals with disabilities that accept grant or DORS funding or can be utilized on a fee-for-service basis. Select organizations include but are not limited to: The ARC, CHI Centers, Community Services for Autistic Adults and Children (CSAAC), Community Support Services (CSS), Independence Now, Inc., Jewish Social Services Agency (JSSA), and Treatment and Learning Centers (TLC). Non-profit organizations serve hundreds of individuals each year through their programs. Noted in the section on Data and Trends, in 2018, JSSA served 412 unduplicated clients and TLC served about 350 individuals.

Project SEARCH Montgomery (Ages 18-28)

Project SEARCH is a program dedicated to providing education and training to transitioning young adults ages 18-28 with I/DD that have DDA funding. Up to 12 volunteer interns a year participate in up to three 10-week intensive worksite unpaid internships supported by job coaches from the SEEC (Seeking Employment, Equality and Community for People with Developmental Disabilities). Interns work approximately 25 hours per week and attend one hour of classroom instruction daily with an instructor from the Ivymount School. The onsite team provides daily support and infrastructure to interns and supervisors to ensure overall success in placements in County agencies.

Montgomery County Public Intern Project (MCPIP) for Ages 18+ - Established in 2007 to create flexible and customized work opportunities in County agencies and departments for individuals with disabilities. All County departments have had the opportunity to work with a

customized employment career specialist from the nonprofit provider, TransCen, Inc., to identify tasks and create part-time positions based on the department's need. TransCen recruits and pre-screens potential candidates and works with County Human Resources and medical departments to prepare the candidate to start work if the individual is a good fit. Initial on-site job coaching is provided by TransCen staff and job coach training is offered to employees interested in supporting a candidate. Positions are:

- Temporary and part-time; 2-18 hours/week for 50 weeks not to exceed 900 hours within one year.
- Compensated at \$12.25/hour and can last for a period of no more than 2 years.
- Available based on total hours funded for the program; approximately 13,000 per year.

DORS / Summer Youth Employment (SYE)

Since 2010, TransCen has partnered with DORS to assist eligible youth in Maryland gain work experience and explore career opportunities through a six-week paid summer internship and since 2017, has expanded to a year-round program serving in-school youth that qualify for the Pre-employment Transition Services program through DORS. This program uses Federal Workforce Innovation and Opportunity Act (WIOA) – Pre-Employment Transition Service dollars to create paid work-based learning opportunities for in school youth between the ages of 14 and 21. TransCen staff assist the youth with job search and placement services, short-term job coaching services, outreach to employers, and uses customized employment techniques to target employers based on each youth's interests, skills, and abilities. The youth interns receive on-site, post-placement job supports, and follow-up services.

WorkSource Montgomery (Ages 14+)

WorkSource Montgomery is the County's workforce development entity that coordinates public and private-sector policies and programs with three locations: Germantown, Wheaton and Silver Spring. To qualify, an individual must receive or have:

- Supplemental Security Income (SSI)
- Social Security Disability Insurance (SSDI), and/or
- A physical, sensory, mental, cognitive, intellectual or developmental disability requiring at least one of the following to obtain and maintain competitive integrated employment at or above minimum wage:
 - Significant accommodations,
 - Significant supports, and/or
 - Customization of job responsibilities.

Disability Employment Initiative (DEI) – Through a \$2.5M Federal grant from the US Department of Labor, Office Disability Employment Policy, Anne Arundel and Montgomery counties received funds from the Maryland Department of Labor, Licensing and Regulation to establish the DEI to expand the capacity of the existing American Job Center programs from

October 2016 through April 2020⁴. In Montgomery County, WorkSource Montgomery in Wheaton, MD hired a dedicated Disability Resource Coordinator (DRC) to assist, support and coordinate services for qualified jobseekers, train job center staff, case managers and partner organizations on disability employment issues and implement assistive technology upgrades.

The goal of DEI is to support jobseekers with significant disabilities by improving education, training and employment outcomes by leveraging existing job centers infrastructure and staff at no additional cost. Customized supports and services include enhanced case management, job search workshops, benefits counseling and job placement assistance.

Employer Tax Credits

Maryland Disability Employment Tax Credit – State tax credit that allows employers to claim credit for employees with disabilities hired on or after December 31, 2014. For each taxable year a credit in an amount equal to 30% of up to the first \$6,000 (\$1,800) of wages paid during the first year and 20% of up to the first \$6,000 (\$1,200) during the second year of employment. Employers can also benefit from a tax credit for work-related childcare or transportation expenses paid by the employer.

Work Opportunity Tax Credit – Federal tax credit available to employers who hire and retain veterans and individuals from other target groups with significant barriers to employment. The maximum tax credit ranges from \$1,200 to \$9,600, depending on employee hired.

Disabled Access Credit – Federal tax credit provides a non-refundable credit for small businesses that incur expenditures for the purpose of providing access to persons with disabilities. An eligible small business is one that earned \$1 million or less or had no more than 30 full time employees in the previous year; they may take the credit each year they incur access expenditures.

Barrier Removal Tax Deduction – Federal tax credit encourages businesses of any size to remove architectural and transportation barriers to the mobility of persons with disabilities and the elderly. Businesses may claim a deduction of up to \$15,000 a year for qualified expenses for items that normally must be capitalized.

Noncompetitive Appointment of Persons with Severe Disabilities to County Merit Positions

A Montgomery County Charter amendment was approved that allows for the non-competitive appointment of persons with severe disabilities to County merit positions. If an individual has a permanent, severe physical, psychiatric or mental impairment that substantially limits one or more major life activity and are certified by DORS, meets the minimum requirements for the position and can perform essential functions and passes a background check and physical examination, the individual may register in the non-competitive hiring database to be entered into a pool of applicants who can be considered for openings as they occur, without the County department needing to advertise the position to the general public.

⁴ <https://worksourcemontgomery.com/news-articles/state-grant-to-help-expand-employment-opportunities-to-those-with-disabilities-in-county/>

4. Data and Trends

In Maryland, the unemployment rate for individuals with developmental disabilities is 84.5% compared to 4.6% for people without disabilities; despite priority government programs implemented to address barriers to employment^{5,6}. Montgomery County has the highest employment rate for people with disabilities in the State at 57%.

DDA Data of Montgomery County residents receiving employment services as of August 18, 2018:

- Total Unduplicated: 781
- Community Learning Services (CLS): 336
- Employment Discovery and Customization (EDC): 8
- Supported Employment (SE): 501

DORS currently has more than 2,679 people on its waiting list and individuals can expect to be on the waiting list for as long as 32 months⁷.

TransCen: Montgomery County Public Intern Project (MCPIP) – 120 positions in County agencies have been created since 2007.

TransCen: DORS / Summer Youth Employment (SYE) – the goal is to serve 60 youth in 2018 and 75 youth in 2019.

JSSA: In FY2018, JSSA served 412 unduplicated clients and placed 89 people in 29 full-time positions with 43 placements outside of grocery, custodial and base retail.

TLC Outcomes: For FY18, served approximately 350 individuals between all DDA, DORS and Private Pay programs.

DORS consumers in Job Development/Job coaching services: Served 62 new clients; average wage: \$13.37 hour; average number of hours working per week: 29.

Supported employment (DDA): Served 117 of those served; 107 wanted to work and 104 were working: 97.20%; average wage: \$13.02; average number of hours working per week: 26.

WorkSource Montgomery Disability Employment Initiative (DEI) desired outcomes include 150 individuals served from 2017 to 2020; 60% to enter occupational training in a career pathways program; 75 completing training in a career pathways program; 74 individuals receiving an industry recognized certification; 85 entering unsubsidized employment with a 65% retention rate.

⁵ <https://dda.health.maryland.gov/Documents/2016/Strategic%20Plan.pdf>

⁶ Hananel, Sam. "Too many intellectually disabled are still excluded from the world of work, study says," *The Washington Post*. Feb. 17, 2014.

⁷ <http://dors.maryland.gov/consumers/Pages/waiting.aspx>

5. Gaps

The transition from finishing school to being employed or matched with a program is insufficient. There are waiting lists with no movement. Clear pathways are needed, including a clear pathway from County government intern to full-time employment.

Insufficient State funding means families cannot wait for DDA funding or DORS services and need to private pay for services instead.

An identified concern is that providers are uncertain about the impact of the DDA Transformation Plan on both their ability to sustain their organizations financially and to serve clients appropriately. A decrease in services could negatively impact the client's ability to stay successfully employed. The proposed billing structure means that some people who are employed but need some minimal supports or problem solving that can be done by phone will not be reimbursable services. The DDA transformation could prove a disincentive to employment and an incentive to large group day habilitation.

Gap in data and analysis on who is not being served with the current programs. For example, are there people who need the level of extra supports that could be provided in a sheltered workshop setting who now have difficulty finding and keeping employment? While sheltered workshops had problems of sub-minimum wage and isolation, the model was eliminated without an alternative in place. Previous participants may be on the DDA waitlist for services.

DORS' priority is to serve people that are placed in the highest need category, Category 1, while those in Category 2 and 3 have a disability that is determined to be less severe, and thus, could be more employable.

Trend of older people with I/DD seeking employment services. Both JSSA and TLC Outcomes report that they are seeing more people in the ages of 50+, 60+ and even 70+ seeking employment services as they must continue to work to afford housing and other costs of daily living.

The increase in minimum wage may mean that an employer reduces work hours, a potential impact that is not unique to people with I/DD. However, in some instances, employers are looking to increase productivity by looking for an employee who can complete multiple tasks. A person with I/DD might do an excellent job at one or two tasks but might not be able to take on the additional responsibility that are required for the position.

Youth with Disabilities (YWD) / Young Adult Opportunity Program (YAOP) for Ages 16-24 was created in 2008 to bridge the gap from school to work and serve the "gray-zone youth;" those that do not qualify for adult services. Program has been discontinued due to lack in funding.

6. Innovations

JSSA launched its first paid supported summer jobs program for individuals with I/DD in 2017 and became the largest paid summer jobs program with a private employer in Montgomery County. In the summer of 2018, JSSA served 32 individuals aged 16-21 years old in paid summer jobs working between 12 and 21 hours and 15 unpaid internships for eight weeks. The program expects to serve 50-60 people in summer 2019. JSSA has also worked with employers to institute internship-to-permanent jobs and established a stepped progression program to pharmacy tech jobs. JSSA was named the 2017 Disability Employment Provider of the Year by Maryland Works.

Focus on Sector Strategies. There are growing sectors of the economy such as the hospitality industry (guest services, housekeeping, culinary, banquets), hospitals, eldercare, and government with high potential to employ people with disabilities. Project Search sites in Maryland include Montgomery County Government, MedStar Union Memorial in Baltimore, and the National Institutes of Health. Project Search in New York has a program for eldercare.

There is tremendous potential for people with Autism to be employed in STEM fields, particularly young people. Specialisterne is an international organization with a mission of neurodiversity at work. It seeks to add 100,000 STEM/IT jobs in the United States by 2025. <https://specialisterneusa.com/>

Employment 1st Philadelphia is an initiative designed to support outcomes for people with intellectual disabilities. It has a steering committee that includes individuals, family members, providers, State and county staff. There are six standing workgroups: Capacity Building, Employer Relations/Public Relations, Supports Coordination, Transition, Systems and Policy, and Data.

Vanderbilt University's Initiative for Autism, Innovation, and the Workforce, is developing a strength-based understanding of neuro diversity and is testing the "Nashville Model" of special assessments and community-based approach to employment. <https://my.vanderbilt.edu/autismandinnovation/>

7. Recommendations

- ✓ Undertake a gaps analysis in the County for employment, underemployment and unemployment of people with I/DD with focus on demographics of age range, location and workplace environment. The analysis should look at the continuum of employment supports that are needed for people with severe to mild developmental disabilities. Former participants in sheltered workshops should be surveyed to find out what they are doing now and what employment and community services they need.
- ✓ The County should create its own vision of meaningful employment. Under new rules, paid employment may not meet the State's definition of meaningful employment or

employment choice, even if the individual enjoys their job, is doing well, and is not paid a substandard wage. The County should advocate for its vision.

- ✓ In the transition process, MCPS must do a better job in braiding services with both DDA and DORS.
- ✓ The County Council should create a formal process to promote, highlight, feature, and award businesses with successful programs for hiring people with disabilities. This should be done in partnership with the Chambers of Commerce, the Montgomery County Economic Development Corporation, and WorkSource Montgomery. There should be a focus on sharing employer success stories and information on employer tax breaks.
- ✓ Strengthen the partnership with economic development. Promote the competitive advantages to hiring people with disabilities including: high retention rates, punctuality, brand loyalty, and higher morale for all workers.
- ✓ Invest County dollars in programs that can serve people who will likely not be served even if they are on the DDA or DORS waitlist. Develop solicitations for proposals that can be evaluated based on both the number of clients that can be served and the outcome in terms of placements and continued successful employment.
- ✓ Advocate with the Governor and General Assembly for a rate structure and billing system that will keep provider organizations financially stable and will allow organizations to continue to serve clients without a requirement that every interaction be face-to-face and supports drop-in visits.
- ✓ Advocate for a funding structure that will allow at least the same number of clients to be served and will achieve the wage goals set out for programs.
- ✓ Look at the impact of earned income on public benefits and advocate at State and Federal level for appropriate adjustments. Working too many hours can impact the payment of benefits. However, given the cost of living, people need to earn additional income.
- ✓ The County and MCPS should review insurance liability coverage requirement to make sure that coverage by these agencies is sufficient to place students and interns at private businesses around the County where they may currently be excluded (employers such as WalMart, Best Buy, Party City and TJMaxx). Insufficient insurance can significantly decrease employment opportunities for young people enrolled in MCPS.

Health & Wellness

1. Definition

Individuals with developmental disabilities experience significant health disparities and barriers to health care, as compared with people who do not have disabilities⁸. Health is defined as a state of complete physical, mental, and social well-being, not merely the absence of disease or disability. The term “health care” encompasses physical, mental, behavioral, vision, hearing, oral and dental health care, substance abuse and addiction services, and services and supports that assist in attaining, maintaining, and improving skills, function, and community participation⁹.

Studies conducted on access to health and wellness services in the United Kingdom and the United States have shown that disparities exist across a broad range of access points and health metrics¹⁰:

- Less likely to have a primary care physician that spends enough time with them or to have clinicians who explained things well;
- More likely to have unmet medical needs and less likely than others to have a primary care physician;
- Worse access to care due to struggles with transportation, costs and long waiting lists for appointments;
- More than four times as likely to lack treatment for mental health problems as individuals without disabilities;
- Women with disabilities were more than seven times more likely to have unmet health needs due to the cost of care or medication than men without disabilities.

Additional barriers to effective care include challenges in communication of health care needs, need for personal support for an individual to access care, increased medical issues and lack of provider training and comfort to treat individuals with developmental disabilities¹¹.

2. Eligibility

<input checked="" type="checkbox"/> Infants and Toddlers	<2 yrs	<input checked="" type="checkbox"/> Young Adults	18–25 yrs
<input checked="" type="checkbox"/> Pre-K	3–4 yrs	<input checked="" type="checkbox"/> Older Adults	25–49 yrs
<input checked="" type="checkbox"/> K-12	5–18 yrs	<input checked="" type="checkbox"/> Seniors	50+ yrs

⁸ National Council on Disability. “The Current State of Health Care for People with Disabilities,” September 20, 2009.

⁹ <https://www.thearc.org/who-we-are/position-statements/life-in-the-community/health-care>

¹⁰ <https://www.reuters.com/article/us-health-care-access-disabilities/disabilities-tied-to-worse-access-to-care-poorer-health-idUSKBN1CV390>

¹¹ Harder+Company. “A Blind Spot in the System: Health Care for People with Developmental Disabilities.”

3. Description of Programs and Services

Medical, Dental and Mental Health Services

Montgomery County partners with nonprofit organizations to provide medical, dental and mental health services to residents that are uninsured or underinsured, regardless if they have a disability. Selected providers include:

- MontgomeryCares network of providers accepting Medicaid: Community Clinics, Inc., Community Ministries of Rockville (Kaseman Clinic), Holy Cross Hospital clinics, Mary's Center, Mercy Health Clinic. Mobile Med, and Muslim Community Center Clinic for medical services.
- Catholic Charities, Muslim Community Clinic Dental Clinic, and Department of Health and Human Service's Dental Clinics for dental services. Specialty care for people without dental insurance can sometimes be filled through programs at Howard University and the University of Maryland Baltimore campus.
- Cornerstone Montgomery for mental and behavioral services.

Information on private providers who are sensitive to the needs of people with Autism/DD is generally shared by word of mouth.

Live Healthy – Health, Medical and Prescription Discounts¹²

Montgomery County partners with the National Association of Counties (NACo) or provide the Live Healthy program to provide free prescription discount cards and help residents save money on the cost of dental and health care services. The low-fee Dental Discount program provides discounts on check-ups, cleanings, fillings, crowns, root canals and more. The low-fee Health Discount program provides discounts on vision services, hearing aids and screenings, diabetes supplies and more.

4. Data and Trends

A 2003 report on a Wisconsin Invitational Conference on Health Disparities and Developmental Disabilities, noted that in 2001 a Senate hearing was held based on Special Olympics' observations on vision and oral health for athletes being screened for the Health Athletes Program. Of those athletes:

86% had refractive errors in vision
28% had astigmatism
25% had strabismus
68% had gingivitis
33% had at least one dental decay
15% were referred to an emergency room for acute pain

¹² <https://www.montgomerycountymd.gov/OPI/live-healthy.html>

5. Gaps

No access to dental insurance through Medicaid or Medicare coupled with few dental community clinics in the County.

Limited specialized care in the County for people with developmental disabilities, including physical therapy, speech therapy, behavioral health and occupational therapy.

Lack of centralized provider database for effective health care providers; inclusive individual health care providers are accessed primarily through word-of-mouth.

Lack of flexible funding sources for health services not covered by Medicaid or Medicare, specifically preventive care and providers that accept double-insured individuals.

Lack of providers that are able/willing to serve clients that are dually diagnosed with a developmental disability and mental health issues.

6. Innovations

The Patient Protection and Affordable Care Act led to the Maryland Health Exchange, which filled a medical and dental care coverage gap for individuals with developmental disabilities and pre-existing health conditions.

EasterSeals (DC/MD/VA) has an initiative to increase developmental screening rates for young children through education and outreach efforts with pediatricians and parents in high poverty areas. EasterSeals estimates that only 40% of Maryland children in Maryland are receiving appropriate screenings. This is a coalition that includes EasterSeals, Treatment and Learning Centers, CSAAC, and medical organizations including the Montgomery Pediatric Society.

The Lurie Center for Autism – Massachusetts General Hospital, has established an Autism Care Collaborative. The goal of the program is to ensure that the individuals they see, many of whom have complex medical and behavioral issues, including being non-verbal, can access medical care to promote and maintain health and receive treatment of acute and chronic conditions. The program includes a part-time navigator that helped coordinate care for 200 patients.

In 2013 the WITH (Working for Inclusive and Transformative Healthcare) Foundation provided funding to the Vanderbilt Kennedy Center to create an electronic toolkit for primary care of adults with developmental disabilities. The toolkit is web-based and came on line in 2014. Between January 2014 and mid-August 2018, 171,532 users had accessed the website.

7. Recommendations

- ✓ Increase awareness and education of health and wellness coverage and services as individuals with developmental disabilities age out of the school system to minimize gaps in coverage.
- ✓ Provide educational opportunities for physicians, dentists, psychiatrists, therapists, and medical/dental providers to obtain training on working with individuals with developmental disabilities. Advocate that this issue be included in curriculum for training of medical, dental, and behavioral health providers.

Housing (non-institutional)

1. Definition

Housing is one of the most basic needs for every person. Stable, safe, and appropriate housing is critical to a person's health and well-being, ability to gain employment, and participation in community life. The waitlist for services provided through the Maryland Developmental Disabilities Administration (DDA) recognizes the critical nature of housing as the criteria for Crisis Resolution included being homeless or will be homeless within 30 days and the criteria of Crisis Prevention also includes having a caregiver who is 65 years or older.

Office of Legislative Oversight Report 2017-13, *Housing for Adults with Developmental Disabilities*, estimated that 48% of County adults with I/DD age 18 and over live with their family, 33% live alone or with a roommate, and 19% live in a supervised residential setting. (OLO page 19)

OLO found that about 88% of County adults eligible for DDA services received them in a family home or a home owned or leased by the individual.

The Center for Medicare and Medicaid Services (CMS) is requiring states to implement the "Community Settings Rule" which is focused on self-determination and the most integrated setting. The individual selects from housing options, there is a right to privacy and freedom from coercion, and independence should be optimized. The individual has a lease or other similar protections, their unit should have lockable doors, they have a choice of roommates, and freedom to decorate and furnish their unit. The individual controls their schedule, including access to food. They may have visitors at any time. The setting must be physically accessible. The individual must be able to make separate decision on service providers for services such as employment and community supports.

DDA list the following as its "Guiding Principles" for housing:

- Housing is separate from services.
- New homes are built using universal design principles.
- Individuals live in homes designed to meet their needs throughout the aging process.
- Individuals/families receive services they need where they live.
- Density of homes designed specifically for individuals with disabilities will be considered in the planning of new development.
- Individuals/families are integrated into their communities.
- Individuals/families participate in designing their own homes.
- Individuals/families live in communities that are safe.
- Individuals/families live in homes they can afford.
- Individuals/families make informed choices about purchasing or renting their homes.
- Individuals/families are in control of their home environments.

2. Eligibility

<input type="checkbox"/> Infants and Toddlers	<2 yrs	<input checked="" type="checkbox"/> Young Adults	18–25 yrs
<input type="checkbox"/> Pre-K	3–4 yrs	<input checked="" type="checkbox"/> Older Adults	25–49 yrs
<input type="checkbox"/> K-12	5–18 yrs	<input checked="" type="checkbox"/> Seniors	50+ yrs

3. Description of Programs and Services

DDA Services

Individuals who are eligible for and are receiving funding for residential services can be served through several models:

Supportive Living: Up to 4 individuals can share a residence with up to 4 roommates in a private home or apartment.

Shared Living: An individual and a companion share a residence in either the individual's or the companion's home. Enhanced supervision and supports can be provided in the home. Shared living can also be in a host home. No more than 3 waiver participants may reside in one home. Shared living must be provided for at least 6 hours per day.

Community Living in a Group Home or an Alternative Living Unit: An Alternative Living Units provide services for individuals needing specialized living arrangements which are licensed residential services providing 10 or more hours of supervision per week for up to 3 people. A Group Home provides similar services but previously housed between 4 and 8 individuals with I/DD. New Group Homes will be limited to no more than 4 individuals.

The OLO Report notes that in 2014 Statewide, about 25% of individuals in Group Homes had 3 or fewer people; 50% of homes had 4 people; and 25% had 5 or more people.

For individuals in the Community Pathways waiver, the housing provider can charge an individual up to \$375 for room and board for individuals receiving SSI. If the person is optionally eligible for Medicaid and is able to earn up to 300% of SSI, the amount may be higher. Recipients of SSI can use Housing Choice Voucher or project-based Section 8 as a source of rental assistance. However, a person does not need to be receiving SSI or have an income to get a Housing Choice Voucher or a Project Based Voucher.

Rental Assistance Programs

The following are significant programs that provide rental assistance using Federal funds. Some programs target persons with a disability while the general Housing Choice Voucher does not.

Money Follows the Person Program Bridge Subsidy (State Department of Housing and Community Development (DHCD) subsidy – not Federal)

Eligibility: Transitioning out of institutional setting (not required)
18 years or older
Eligible for Medicaid Long Term Services and Supports (LTSS)
Recipient of SSI or SSDI

Household Income \$19,000 or less annual

Length of Funding 3 years then transition to local housing voucher

Individual Responsibility: 30% of income for rent and utilities

The Housing Opportunities Commission (HOC) has set aside units at Alexander House in Silver Spring for this program.

Section 811 Project Rental Assistance Program (Project Based) (Federal funds are jointly administered by DHCD for housing and Department of Health for services.)

Eligibility: Have a Disability, 18-62 years old at time of lease signing
Maryland Medicaid recipient
SSI or SSDI eligible
Voluntary access to support services

Household Income At or below 30% Area Median Income

Length of Funding 5 years

Individual Responsibility: 30% of income for rent and utilities

Individual must be referred to the program by a qualifying service system/provider entity
In Montgomery County, Independence Now has access to the waiting list.

Housing Choice Voucher (Tenant-based and Project-based)

Eligibility: Citizen or non-citizen with eligible status, 18 years old or older
Registered on Housing Path (HOC online wait list)

Household Income Extremely Low income (\$23,200 for one) or
Very Low income (\$38,650 for one)
At least 75% of HCV must go to extremely low income

Length of Funding no limit

Individual Responsibility: 30% to 40% of income for rent and utilities

Mainstream HCV program for People with Disabilities Vouchers Non-elderly Disabled (NED)

All participants are taken off of the HOC Housing Path wait list. These programs have the same income eligibility criteria except that they are for non-elderly people with a disability. On June 18, 2018, HOC applied for additional NED Mainstream vouchers.

Other Affordable Housing Programs

Homelessness Services

If an individual with I/DD meets the criteria for homelessness or chronic homelessness as defined by HUD, they could be assessed by the Department of Health and Human Services, served through the County's Continuum of Care. If eligible, the person might be served through Permanent Supportive Housing programs. HOC has 316 households of Permanent Supportive Housing funded through Federal McKinney funds or the County's Housing Initiative Program (HIP)

Moderately Priced Dwelling Units (MPDUs)

Moderately Priced Dwelling Units are required in new residential development of 20 or more units. Rents and initial sales prices are affordable to households earning a maximum of 60% to 70% of area median incomes. HOC and qualified non-profit organizations have priority to rent or purchase a portion of the MPDUs in any development. Non-profits and HOC will purchase units that are then used as rental units to serve clients. A recently approved amendment to the MPDU law extends the priority to certain clients referred by the Department of Health and Human Services.

HUD Section 811 Projects

Woodfield Commons is 811 Project Based. It is an 84-unit mixed-income multi-family project with 14% of the units reserved for people with disabilities. It is a partnership between Conifer Realty and HOC. DHCD provides a subsidy so that the household pays 30% of income for rent.

There are 24 units currently in the HUD 811 pipeline in Montgomery County (including the 11 at Woodfield Commons.)

Weinberg Apartments (capital grants for apartment development)

Weinberg Apartments are targeted to people with a disability who are 18-62 years old and are a recipient of or applying for SSI or SSDI. Household income is 10% to 30% of Area Median Income. Individuals are responsible for 30% of income for rent and utilities. In Montgomery County there are 10 units in Takoma Park. Two units are in the pipeline for Woodfield Commons. Flexibility allows an individual to have a live-in caregiver who is a family member and may also receive drop-in services.

Other source of development funds:

Several other sources of funding can assist with the development for affordable housing. Not all these programs are limited to households with a member that has a disability:

- Maryland Community Health Facilities Grant
- Maryland Legislative Initiative Capital Grants
- Maryland Department of Housing and Community Development Group Home Program
- Maryland Department of Housing and Community Development Homeownership for Individuals with Disabilities Program
- Federal HOME Grant
- Montgomery County Housing Initiative Fund
- Group Home Rehabilitation Program (funded by Community Development Block Grant)
- Federal Low-Income Housing Tax Credits

Additional HOC projects underway: (1) HOC is identifying 30 units for Community Choice Homes. HOC will provide units to qualified persons with disabilities for 15 years with a subsidy affordable to a household at SSI levels. (2) HOC is developing a new apartment building at 900 Thayer and has applied for Low Income Housing Tax Credits to allow a set aside for persons with disabilities.

4. Data and Trends

DDA Waiting List information as of August 1, 2018:

Crisis Resolution: 9 total individuals, 9 requested residential services

Crisis Prevention: 59 individuals, 56 requested residential services

Current Request: 757, 724 requested residential

DDA reports that as of August 1, 2018, 862 County residents were receiving Housing Services. In addition, 681 were receiving housing supports (13 through Family Support Services; 92 through individual Support Services; and 576 through Personal Supports)

OLO noted that in 2014 in Montgomery County there were 444 people living in 117 group homes and 408 people living in 194 alternative living units. This was about 40% of the 2,165 County adults receiving home and community-based services through the Medicaid Waiver

Weinberg Apartment - In 2016 there was a waitlist of 1,056 people Statewide for a Weinberg Apartment.

HOC Wait Lists (Housing Path) – There are approximately 30,000 people on the Housing Path overall. About 6,800 people aged 18 to 61 years old qualify for NED subsidies and have a disability.

5. Gaps

Better data is needed on County residents with developmental disabilities who have applied for but not been granted housing resources, not just those eligible for services with DDA.

Affordable housing near transit (Metro and Bus) and within walking distance of jobs and services are needed.

Housing is needed for individuals with developmental disabilities who also have mental health conditions.

Housing is needed for seniors with developmental disabilities, including independent living and assisted living options. Most group homes and apartments are not modified to serve aging residents.

More Moderately Priced Dwelling Units (MPDUs) or other affordable apartments that have two-bedrooms are needed for individuals who have a live-in caregiver. This is especially important in areas easily served by mass transit.

The economics don't work for people with developmental disabilities to pay their own rent. If someone does not have a Housing Choice Voucher (HCV) it is impossible to pay rent based on SSI or SSDI or from the incomes many people with developmental disabilities earn. Even with a HCV it can be very difficult to pay rent and then have sufficient funds left over for food and other daily living costs. DDA pays for the vast majority of services, but it does not include the cost of housing.

Housing for undocumented residents with developmental disabilities who will not be eligible for Federally-funded services.

6. Innovations

Integrated Living Opportunities Initiative (ilonow.org). This program helps families launch young adults with I/DD into the community. Currently there are six young men on the Autism Spectrum, two with DDA services, who are part of the Crossings-Gaithersburg group. There are four other young men moving into their own housing in Bethesda and one young lady living in her own condominium in Germantown.

Main Street in Rockville; Ground was recently broken for Main Street in Rockville. It will be a 70-unit apartment building that is located close to Metro and Rockville Town Center. It will be an inclusive community with 25% of the apartments designed and designated for adults with disabilities. It will have social and educational activities open to all residents. An attached coffee shop will offer employment opportunities.

In September 2018, HUD announced that the Housing Opportunities Commission had been awarded 99 HDVs, valued at \$960,891, to serve non-elderly people with disabilities. The

housing assistance is provided through the HUD's *Section 811 Mainstream Housing Choice Voucher Program* which provides funding to housing agencies to assist non-elderly persons with disabilities who are transitioning out of institutional or other separated settings; at serious risk of institutionalization; homeless; or at risk of becoming homeless.

7. Recommendations

- ✓ More affordable housing for people with developmental disabilities at all stages of life. Reflecting the County's policy on providing affordable housing in all parts of the County and in all types of communities, the County should work with housing providers to make sure that housing is available throughout neighborhoods to avoid clustering of residences. This could require County resources to purchase homes or provide rent subsidies in more expensive part of the County. Housing near public transportation networks should be prioritized.
- ✓ Ensure that people with disabilities who need a 24/7 caregiver are eligible for a two-bedroom MPDU. One-bedroom MPDUs are not suitable for this population.
- ✓ Use new provisions in the MPDU program to allow people with developmental disabilities to have access to renting and purchasing MPDUs during the priority marketing period.
- ✓ Develop residential programs for individuals with Prader-Willi syndrome. These people need 24/7 restricted access to food as a result of this complex syndrome. There are young adults with this syndrome in Montgomery County. Best practices and programs in other jurisdictions should be researched.
- ✓ Support the Housing Opportunities Commission with applying and advocating for additional HCVs for people with disabilities.

Law Enforcement/Public Safety

1. Definition - Issue

Interactions with law enforcement and fire and rescue services can be very different for a person with Autism/IDD.

When asked a question, a person with Autism/IDD might repeat the question back rather than answer directly. A police officer may observe behaviors, such as reaching in pockets or fumbling with objects, that they misinterpret as a threatening action. The person with Autism/IDD might reach toward and officer, not knowing this might be viewed as threatening.

Law enforcement, when responding to a call may not immediately recognize the relationship between a person with Autism/IDD and their caregiver.

Some people with Autism/IDD are able to drive but might not respond as expected if pulled over by a police officer.

Emergency fire and rescue situations are chaotic events for most people, but a response that includes fire trucks, flashing lights, sirens, loud radios, and quickly responding people can be especially stressful for people with Autism/IDD.

Emergency personnel may not be able to quickly recognize that someone has Autism/IDD which may complicate a rescue situation when people cannot make eye contact or interact verbally. The person with Autism/IDD might not react as others to a fire that is burning, smoke in the air, or an alarm that is sounding. The person may not react to hot and cold as expected or be able to tolerate some rescue equipment like an oxygen mask. They may react by running or hiding.

Parents and Caregivers of individuals with Autism/IDD may have to call the police when the individual runs away/wanders or when behavior cannot be controlled. Anecdotally, behavior issues may arise during adolescents.

2. Eligibility - Applicability

<input checked="" type="checkbox"/> Infants and Toddlers	<2 yrs	<input checked="" type="checkbox"/> Young Adults	18–25 yrs
<input checked="" type="checkbox"/> Pre-K	3–4 yrs	<input checked="" type="checkbox"/> Older Adults	25–49 yrs
<input checked="" type="checkbox"/> K-12	5–18 yrs	<input checked="" type="checkbox"/> Seniors	50+ yrs

3. Description of Programs and Services

The Montgomery County Police Department's (MCPD) Autism/Intellectual and Developmental Disabilities, Alzheimer's, and Dementia Outreach Program began in 2004 in response to growing concerns about wandering and elopements by people with Autism or an Intellectual Disability.

The first effort was a program that provided tracking bracelets for wanderers. The program quickly evolved to include Autism/IDD awareness, outreach, education, empowerment, and response. Since 2010, officers have been trained on the dynamics of interactions with law enforcement and the autism community. Trained officers work throughout the districts to respond to calls.

MCPD's program includes self-advocates and an Autism/IDD Ambassador who teaches the classes along with Police Officers. The Ambassador creates scenarios and gives speeches and presentations, so officers can learn directly from someone with Autism.

The MCPD Outreach Unit works with Montgomery County Public Schools (MCPS) to talk to students who will be graduating to create a better understanding of how to interact with the police.

The MCPD Outreach Unit provides training to other departments/organizations including, Ride-On, MCPS, National Institutes of Health, National Children's Hospital, Montgomery College. The Outreach Unit provides about 12-20 presentations per month.

All Maryland law enforcement officers are now required to have recruit or in-service training. Statewide requirements became effective in 2015 in response to the death of Ethan Saylor after a confrontation escalated at a Frederick County movie theater with off-duty Deputy Sheriffs when Mr. Saylor's caregiver was temporarily away.

Montgomery County Fire and Rescue Service (MCFRS) has a presentation on Autism as a part of its Emergency Medical Technician (EMT) class. Paramedic continuing education has training provided on a bi-annual cycle. MCFRS participates in Autism/IDD Night Out.

4. Data and Trends

In 2017, MCPD responded to 1,003 missing and at-risk calls and performed 387 active searches. In 2018 through September 30, MCPD has responded to 778 calls; 237 of these missing at-risk calls have involved a person with Autism/IDD. The Outreach Unit follows up on between 3 to 8 missing and at-risk persons calls per week for people with Autism/IDD.

MCPD's Managed Search Operations Team is staffed with one full-time search manager and seven police officers who are decentralized throughout the district. Under this staffing, a fulltime search manager is only on duty 40 hours per week.

Since 2010, all incoming recruits have received a block of training on how to have positive, effective interactions with the Autism/IDD, Alzheimer's, Dementia, community. This is a four-hour block of instruction. Also, since 2010 Crisis Intervention Team (CIT) participants have received the "Law Enforcement and Autism/IDD Interactions" class.

5. Gaps

Increased education for all public safety personnel on recognizing a person with Autism/IDD and how to de-escalate panic that may occur in emergency situations.

Increased outreach to parents and caregivers on what they need to do and say when calling the police or fire and rescue for assistance. MCPD recommends having a 9-1-1 script if you are calling because your child is in crisis and you need police support.

Alternative to law enforcement when a family member's behavior is not controllable, such as the Crisis Center or mobile crisis team that can focus on behavior and avoid the potential for arrest. There is a particular gap when the individual with Autism/IDD also has a mental health issue.

Additional MCPD Search Operations Team Manager staffing to increase the number of hours a Team Manager is on duty in order to improve the immediate response.

Train more people with Autism/IDD to be able to self-disclose that they have a disability and use tools such as ID bracelets or tee shirts for those who can't self-disclose verbally.

Train more people with Autism/IDD on how to protect themselves when there is a fire, such as how to get low and escape a room with smoke or practicing an evacuation plan.

6. Innovations

The MCPD program is cited as one of the earliest special training/special unit programs, although other Maryland departments, such as Howard County began, soon thereafter.

The MCPD program utilizes "self-advocates" to assist with the instruction. The most notable "self-advocate" is Jake Edwards, the Chief Autism/IDD Ambassador for MCPD. Jake has been co-teaching with the program since 2014. Jake has gone on to teach over 2,000 law enforcement officers throughout the country. Jake and Officer Laurie Reyes were recognized by the White House in 2015 as "White House Champions of Change."

In 2018, Officer Reyes was recognized by the Department of Justice for "Distinguished Service in Policing" for the implementation of the MCPD Autism/IDD, Alzheimer's, Dementia Outreach Program. Officer Reyes was also presented with a Governor's citation.

The Ethan Saylor Alliance was created in 2015 aimed at providing increased training for members of law enforcement and other public service entities on specific needs of those with developmental and intellectual disabilities. The premise of the alliance is that self-advocates take the central role in educating and informing the community about the specific needs of those with disabilities. The Maryland Department of Disabilities is home to the Alliance.

The ARC provides a model for creating a Disability Response Team that addresses issues raised by overrepresentation of people with Intellectual and Developmental Disabilities in the criminal justice system, both as victims/witnesses and suspects/offenders.

7. Recommendations

- ✓ Continue funding that is needed to make sure that specialized training is provided to law enforcement and fire and rescue personnel as a part of recruit school and in-service training.
- ✓ Consider additional funding for MCPD Search Operations Team. Adequate resources are needed to respond to missing at-risk persons calls as well as providing training and making presentations. Ensure funding is available so there is no waitlist for Project Lifesaver.
- ✓ Outreach/education campaign for parents and families on when and how to call the police for help and alternative resources that can be called, such as a mobile crisis team. Assist families with having scripts so they are prepared with what to say. As a part of this outreach effort, inform families when such a call might or might not be referred to Adult Protective Services or Child Protective Services. Families may be scared to call for help, even when a child wanders, if they believe that the call may be referred to Child Protective Services and they could be in danger of having the child placed in foster care.
- ✓ Discuss with law enforcement their experience about transporting individuals with Autism/IDD to hospital emergency room or psychiatric facilities in response to a call for out of control behavior.

Recreation

1. Definition

Therapeutic inclusive recreation is the practice of using purposeful recreation and leisure to address the specific needs and goals of individuals living with disabilities. Therapeutic recreation programs provide accessible leisure, educational and personal development activities through inclusion (mainstreaming) and adaptive programs¹³. Through these specifically tailored programs, participants maximize their self-sufficiency and independence, gain confidence, enhance mental and physical health and wellness, improve motor skills/physical functioning and develop social, communication, emotional, creative, sensory and coping skills that encourages community integration¹⁴.

Examples of therapeutic recreation programs and activities include classes in aquatics, art, dance, drama, fitness, games, music, sports, nature and therapeutic riding. Programs are also structured as membership clubs, community outings, afterschool programs, summer camps and annual social events. These programs and classes typically have a higher staff-to-participant ratio, smaller class size and more structure than general programs and classes.

2. Eligibility

<input type="checkbox"/> Infants and Toddlers	<2 yrs	<input checked="" type="checkbox"/> Young Adults	18–25 yrs
<input type="checkbox"/> Pre-K	3–4 yrs	<input checked="" type="checkbox"/> Older Adults	25–49 yrs
<input checked="" type="checkbox"/> K-12	5–18 yrs	<input checked="" type="checkbox"/> Seniors	50+ yrs

Typically, any individual with a disability who is 5 years or older is eligible to participate in a therapeutic recreation program.

3. Description of Programs and Services

Montgomery County offers therapeutic recreation programs that are County-sponsored and run by nonprofit and religious organizations and educational institutions:

- Montgomery County Recreation’s Therapeutic Recreation program offers year-round classes, group fitness, camps, events, clubs and social activities for individuals ages 5 and up with disabilities. An annual expo is held in the Fall to highlight Therapeutic Recreation programs offered.

¹³ <https://montgomerycountymd.gov/rec/activitiesandprograms/therapeuticrec/>;

<https://www.montgomerycountymd.gov/rec/Resources/Files/publications/TRSummer18.pdf>

¹⁴ <https://www.playfullypractical.com/single-post/2016/12/22/What-Exactly-is-Therapeutic-Recreation-and-Why-is-it-Important>

- Montgomery College's Challenge Program offers enrichment classes for adults with disabilities in life skills, professional development and fitness.
- Examples of nonprofit organizations that serve County residents with disabilities¹⁵: ArtStream, Best Buddies Maryland, Great and Small Therapeutic Riding, Kids Enjoy Exercise Now (KEEN), Montgomery Special Hockey, Potomac Community Resources, Special Olympics Montgomery County, SportsPlus, Spirit Club, Summit Teen Travel, Upcounty Community Resources, and VisAbility Art lab (partnership of VisArts and Madison House Autism Foundation.)
- Examples of faith-based organizations that serve individuals with disabilities: Bender JCC of Greater Washington and Catholic Charities. Bender JCC offers camps that work to educate and boost self-esteem and "Keep Inclusion at the Center" for youth and teens.

4. Data and Trends

The Department of Recreation encourages individuals to participate in both Therapeutic Recreation and general Recreation offerings. Therapeutic Recreation offerings include Camp Apollo (maximum 20 participants), Camp Pines (maximum 20 participants), Adult Social Swim (maximum 16 participants per session), and nine themed dances (for ages 15 and up).

5. Gaps

Insufficient resources to meet requests for inclusion in Excel Beyond the Bell at the Rock Terrace School Pilot.

Insufficient programs for adults with severe intellectual/developmental disabilities who may be functioning at the level of a very young child or toddler. The Department of Recreation does not have staff that can assist with personal care, such as diapering.

6. Innovations

More private business that provide recreation opportunities are working to accommodate people with developmental disabilities. AMC and Regal Cinemas schedule sensory-friendly screenings of kids' films where dim lights stay on, sound is lowered, and families may bring snacks that meet dietary restrictions. Several national amusement parks have undertaken special training and made accommodations to become Autism friendly.

¹⁵ <https://pcr-inc.org/community-resources/community-links/>

7. Recommendations

- ✓ Development of new facilities should be planned intentionally for inclusion beyond the American with Disabilities Act.
- ✓ Provide specialized training people interested in working with people with developmental disabilities in a variety of recreation programs. This will help increase the number of staff with training in how to appropriately and safely handle situations with both children and adults.
- ✓ Explore ways to leverage the use of volunteers. Work Group members recall the availability of preschool programs that, through the use of volunteers, were able to work with children on a one-to-one ratio,
- ✓ Review funding and policies on the cost of fields, ice skating rinks, and pool time. These costs can be the biggest cost for a program and can become prohibitive for serving more people.

Respite Care

1. Definition

Caregiving for individuals with intellectual and/or developmental disabilities is a challenging and demanding job. Caregivers – whether they are parents, siblings, family member or a professional – need occasional breaks or “respite” to handle errands or take personal time so they can return to their responsibilities refreshed and avoid caregiver burnout, which can manifest itself in fatigue, stress, anxiety or depression¹⁶.

Respite programs can provide short-term relief for a few hours, a day, a weekend, or sometimes longer but is not a substitute for ongoing child care, school, work or alternative child care. Caregivers can choose from various respite care venues, including the family home, community and recreational programs, therapeutic camps, and approved respite facilities¹⁷.

2. Eligibility

<input checked="" type="checkbox"/> Infants and Toddlers	<2 yrs	<input checked="" type="checkbox"/> Young Adults	18–25 yrs
<input checked="" type="checkbox"/> Pre-K	3–4 yrs	<input checked="" type="checkbox"/> Older Adults	25–59 yrs
<input checked="" type="checkbox"/> K-12	5–18 yrs	<input checked="" type="checkbox"/> Seniors	60 +yrs

Eligible families in Montgomery County may qualify for up to 140 hours of respite in a fiscal each year. Primary caregivers of a child, adult or senior with developmental or functional disabilities must be a full-time, primary, unpaid live-in caregiver. As of July 1, 2018, to ensure non-duplication of services, individuals/families who receive State-funded, in-home supports are not eligible to receive respite services. This includes services received through Community First Choice, Rare and Expensive Case Management (REM), Community Pathways, Family Supports, Community Supports, and the Autism Waiver. Both the primary caregiver and the individual receiving respite must reside in the same residence in Montgomery County.

Families eligible for respite care can receive a maximum of 10 hours per day or up to 40 hours per month in a home or community setting. Twenty-four hour respite care is only provided in an approved overnight facility.

3. Description of Programs and Services

For the past 22 years, nonprofit organization, The Arc of Montgomery County (The ARC), has administered the County’s respite program on behalf of the Department of Health and Human Services (DHHS). Applicants can visit The ARC website at www.thearcmontgomerycounty.org to print an application or call the respite office at 301-816-9647 to request an application be

¹⁶ <https://my.clevelandclinic.org/health/diseases/9225-caregiving-recognizing-burnout>

¹⁷ <http://thearcmontgomerycounty.org/what-we-do/respite/>

mailed. Once the completed application is received and approved respite staff will contact the caregiver to set up an orientation and work with the family to identify and recommend an appropriate respite provider for the family to choose from. The respite program has a consortium of 100+ Respite Care Providers housed in a central database that the organization maintains for licensure and certification.

In a 2017 presentation to the Developmental Disability Advisory Committee, The ARC said the program has two main goals:

- To prevent or reduce neglect and abuse by contributing to good physical and emotional health of caregivers; and,
- To allow families to successfully continue caring for their loved one at home.

Respite is an income-based program that may provide a full or partial subsidy to pay a Respite Care Provider, but it is not an entitlement. Eligibility for a respite care subsidy is based on income and uses the Maryland Respite Care Services Fee Scale. The subsidy rate for respite care for children and youth age 17 and under is based on the household income, less approved out-of-pocket expenses for the individual. The subsidy rate for adult's ages 18-59 is based on his/her own income, and typically adults with income less than \$30,200 qualify for a full respite subsidy. Seniors are not means tested therefore requires no income verification for eligibility.

Approved respite hours can be used in a variety of venues, including:

- The family's home;
- Community and recreational therapeutic programs;
- Summer camps;
- Adult medical day centers; and
- Approved respite facilities for overnight care.

Applications for respite care can be submitted at any time.

4. Data and Trends

In FY17, The ARC processed 1,900 requests from 410 residents (171 frail elderly, 213 adults/children with intellectual or developmental disabilities, and 26 adults/children with functional disabilities) and reported that the availability of respite services enabled them to maintain social relationships, meet other family obligations, tend to personal needs, reduce stress levels in the home, remain active in their religious life and adequately maintain their homes¹⁸. As of November, 92 applications have already been submitted since the beginning of FY19. In FY17 and FY18 combined, an estimated 120,809 hours of respite care were provided to primary caregivers of people with disabilities and seniors.

¹⁸ Self-reported in Community Grants FY19 Application.

The ARC receives \$1.3 million annually from DHHS (General Funds and Grant funds) to administer the respite program and pay providers. Approximately \$1 million of the budget is used to pay providers directly.

5. Gaps

Transitioning youth 18-21 years of age, who have yet to qualify for state-funded services are a target demographic to apply for respite services at The ARC since their primary caregivers would not have an alternative option for respite care.

Latino families account for only 10% of The ARC's respite program caseload.

Respite care cannot be used for a caregiver to go to work and is not meant to be ongoing. Currently, the Respite Program does not take into consideration families with multiple typical children, which can be problematic for families.

Approved respite facility for children in Montgomery County; current facility that the program partners with is Jill's House in Tyson's Corner, VA, which has a waiting list. Grace's Place in Potomac, MD is slated to be approved as a respite facility for children in the future.

It is a struggle to get providers for people with Autism and behavior issues as the providers generally require a higher reimbursement rate. There is a shortage of providers to work with adults and children with mental health issues.

Need for community respite facility where primary caregivers who have multiple children, with and without disabilities, can drop-off their children.

Need for additional resources for people with profound care needs, including one-on-one nurse care.

Need for a community respite house that serves children with challenging behaviors and intellectual/developmental disabilities.

The Maryland Respite Care Services Fee Scale is not adjusted for the higher cost of living in Montgomery County. Families that do not qualify for full subsidy of respite services but still need care cannot necessarily afford it.

The ARC uses an outdated software system for processing applications, which requires staff to process applications manually. The current application turnaround is 22-30 days. A web-based system that enables families to apply online could expedite the process.

Respite services are included in most waiver programs; however, families are not being referred to respite services in those waivers.

The State sets the rate for Level II (nursing level) respite services. The current Level II is low (\$34 per hour) compared to private providers standard rate, so the ARC is having challenges finding providers that are willing to accept the State's rate.

6. Innovations

The ARC is one of the few respite programs in Maryland that pays Respite Care Providers directly as opposed to paying the families and/or primary caregiver. This allows for efficiency and quality control of the payment from the ARC's respite care program.

The ARC is the only provider that requires family members or neighbors that would like to qualify as Respite Care Providers to undergo pass a Maryland and FBI background check.

The ARC maintains 100+ consortium of Respite Care Providers that is unpublished so that The Arc can ensure that each provider has current licensure and certification. Focus on recruiting diverse agencies with multi-language capabilities.

The ARC is the only provider that offers family and respite care provider orientations to make sure stakeholders understand the respite program.

7. Recommendations

- ✓ Increase flexibility of respite services parameters. Change language for respite eligibility to include "family" to be more family-oriented instead of limiting respite services for the individual with the disability.
- ✓ Support opening a community respite house for children in Montgomery County where primary caregivers that have multiple children, with and without disabilities, can drop-off their children and alleviate the waiting list for the only respite house for children located in Virginia. Respite house should be capable of serving children with challenging behaviors.
- ✓ Move eligibility requirements from income based to individual needs and develop a respite fee scale that is aligned with Montgomery County household income. Conduct a study on how many families are turned away from respite services due to income ineligibility.
- ✓ Develop a Montgomery County Respite Services Fee Scale so it is easier to make adjustments. Address the low State rate for Level II (nursing level) respite services.

The Work Group acknowledges that changes to respite could require changes to State regulation (COMAR), contract changes, or a decision by the County to develop its own rules for County-funded respite in place of relying on COMAR.

Transitioning Youth (TY)

1. Definition

All students need guidance in order to make the “leap” from high school and transition to young adulthood. For students with intellectual and developmental disabilities (I/DD), however, the term “transition” has a very specific meaning. Students with I/DD need more assistance because their leap is that much greater, and “transitioning” is part of the overall Individualized Education Program, or IEP, that defines the move from public school to adult life. The IEP transition plan, as it is called, is required by law for students with developmental disabilities¹⁹.

The IEP transition plan ensures not only that students will be able to function as adults in the real world but to also increase the likelihood they will pursue post-secondary education. The plan goes beyond simply finding a place for students after high school - it provides a personalized course of action based on students’ strengths, desires and dreams for a fulfilling life. Nationwide, only 13 percent of students with developmental disabilities make it to post-secondary education, as compared to 53 percent of the general population²⁰.

A student's transition plan as part of the IEP can begin at age 14 or younger, if appropriate. The student-centered planning process is designed to meet the students educational, employment and independent living outcomes. These outcomes may include:

- Postsecondary education
- Job training
- Employment (supported)
- Continuing and Adult education
- Adult services
- Independent living
- Community participation

Students receive an array of services to help them attain their identified post-secondary outcomes and to prepare them to be college, career and community ready. These services may include, but are not limited to: career education, career exploration, social skills and self-advocacy instruction, career technology education, in-school and community work-based learning experiences, independent living skills instruction, and linkage to community agencies²¹.

2. Eligibility

<input type="checkbox"/> Infants and Toddlers <2 yrs	<input checked="" type="checkbox"/> High School	14–17 yrs
<input type="checkbox"/> Pre-K 3–4 yrs	<input checked="" type="checkbox"/> Young Adults	18–21 yrs
<input type="checkbox"/> K-12 (as needed) 5–18 yrs	<input type="checkbox"/> Older Adults	21–49 yrs
	<input type="checkbox"/> Seniors	50+ yrs

¹⁹ <https://degree.lamar.edu/articles/education/transition-planning-special-education.aspx>

²⁰ <https://www.greatschools.org/gk/articles/transition-planning-for-students-with-ieps/>

²¹ <https://www.montgomeryschoolsmd.org/departments/special-education/programs-services/transition-services-unit.aspx#planning>

In Maryland, a young adult with a disability who is receiving special education services is ENTITLED to a free, appropriate, public education through the school year in which they turn 21 years of age or has met the requirements for a Maryland High School Diploma or Maryland High School Certificate of Program Completion. These services are documented within the student's Individualized Education Plan (IEP) as determined by the IEP team and is funded by the local school system.

A student who exits the school system with a Maryland High School Diploma or Maryland High School Certificate of Program Completion is no longer entitled to services. At this point individuals must apply for adult services to see if they are ELIGIBLE to receive them. In addition to meeting eligibility criteria, funding must be available to receive services and supports from adult service agencies²².

3. Description of Programs and Services

Montgomery County Public Schools' Office of Special Education houses the Transition Services Unit that coordinates services for student with disabilities from birth to age 21. All staff involved in the student's educational program are responsible for preparing students to achieve their post-secondary and employment goals. Special responsibility is assigned to the Transition Support Teacher (TST) who coordinates the transition planning process²³.

Starting at age 14, or earlier if appropriate, the IEP team discusses and plans linkages to post-school services as part of the transition planning process. Each year, as part of the transition plan, the IEP team identifies the services the student may need during the first year following their exit from school. Students must meet eligibility criteria in order to receive services.

Just as important as the identification of the postsecondary goals are the various stakeholders that support the transition process and assist the student in achieving the identified goals. Key stakeholders and selected roles and responsibilities include:

Partner	Roles/Responsibilities
Student	Identify strengths and challenges, express interests and preferences, identify postsecondary goals.
Parents/Guardians	Help student access transition partners, advocate for student's goals, review transition timeline and complete applications to state agencies for services.
Montgomery County Public Schools (MCPS)	Invite partners to IEP meetings, provide instruction and experiences in authentic work environments, provide informational meetings for parents regarding services and document and report student progress and status after exit.

²² Maryland State Department of Education, Division of Special Education/Early Intervention Services. "Transition Planning Guide for Individuals with Disabilities."

²³ <https://www.montgomeryschoolsmd.org/departments/special-education/programs-services/transition-services-unit.aspx#faq>

Partner	Roles/Responsibilities
Division of Rehabilitation Services (DORS)	Provide Pre-Employment Training Services to eligible high school students age 14-22 in the areas of job exploration counseling, work-based learning experiences, post-secondary education, instruction in self-advocacy and workplace readiness.
Developmental Disabilities Administration (DDA)	Provide long-term funding for eligible individuals upon school exit, contract with Coordinator of Community Services to assist with transition from school to adult world.
Adult Service Providers/Community Rehabilitation Providers (CRPs)	Provide services and supports for DORS and DDA clients to provide job development and job coaching upon exiting high school.
Colleges/Postsecondary Education Training Programs	Provide access and support for campus activities, courses and employment.

Selected age milestones in the transition process include:

- By age 14 – Apply and determine eligibility for DDA services
- Age 18 – Apply for Supplemental Security Income (SSI) and Medicaid Health Insurance
- Year before final school year – Student and family attends local Transitioning Youth Fair; apply for DORS
- Spring prior to final school year – Student and family visit and interview DDA adult services providers
- Fall of final school year – work with Coordinator of Community Services (CCS) to selector a provider for adult services
- Winter/early spring of final school year – DDA regional office reviews service funding plan and informs student and family of start date for services.

4. Data and Trends

MCPS Transitioning Youth

Exit Year	Total Number	Placed in Services	Not Placed
2016	127	114	13
2017	106	86	20
2018	126	56	70 (not yet placed)

Job Site Trends for Alternative Learning Outcome Students*

School Year	Non-School Jobsites	Students
2016-2017	145	468
2017-2018	164	510
2018-2019	174	589

*Jobsite data is collected annually and employment data is collected monthly.

Employment Trend Data for Alternative Learning Outcome Students**

School Year	Students Employed
2016-2017	19
2017-2018	23
2018-2019	17 (as of 10/18/18)

**Employment data is based on Community & Career Connections and Transition Training for Independence teacher self-reporting. Overall employment data is not disaggregated by student disability or program participation, so the actual number of students with intellectual or developmental disabilities who are employed with more than likely be higher than what is report above.

5. Gaps

While transitioning youth services are set to begin on July 1st of each year, there is a delay in getting every student that is exiting MCPS to get matched with an appropriate service provider. Factors contributing to this delay include:

- Uncertainty of service providers from the State on billable rates and eligible services;
- High turnover of coordinator positions at service providers to help families through the transitioning process due to limited training and high caseloads, and;
- Disconnect of parent expectations between entitled services in MCPS and eligible services from the State's Developmental Disabilities Administration (DDA).

Transition plans for youth exiting MCPS do not adequately prepare students to enter secondary education, including Montgomery College due to the need for independent and self-advocacy skills to navigate a college campus.

There is a need for flexible funding sources for services that serve families that are ineligible for services due to immigration status or have language barriers to access services.

6. Innovations

Transitioning youth programs and coordinator with Individualized Education Plans (IEPs) provide a pathway for students to receive education supports and employment preparation and opportunities for experience before exiting MCPS.

MCPS accurately tracks students on IEPs and those that will be eligible for transitioning youth services closely through a Transitioning Services Unit and Transition Support Teachers from when the student enters MCPS.

7. Recommendations

- ✓ Coordinate MCPS transitioning youth employment services with employment programs around the County (WorkSource Montgomery and non-profit agencies) and engage employers directly to be a proactive stakeholder.
- ✓ Integrate transitioning youth planning with person-center planning from non-profit agencies to increase coordination of services when the individual is school-aged to future adult needs. Engage students in the school system earlier (even one year earlier) with state-funded services so that families can work with a coordinator earlier in the transition timeline.
- ✓ Montgomery County Public Schools (MCPS) and Coordination of Community Services (CCS) providers should return to the practice of working together to make sure all children start the Transitioning Youth process at age 14 or younger. Clear information should be given to parents about the different eligibility criteria for school systems and DDA, so they can make informed choices. (This recommendation is also included in the white paper on CCS)

Transportation

1. Definition

Transportation provides a vital lifeline for individuals with disabilities to access employment, education, healthcare and community life and allow individuals with disabilities to live independently within their communities²⁴. Montgomery County offers multiple access points and partners with the Washington Metropolitan Area Transit Authority (WMATA), taxicab companies and nonprofit organizations to provide an array of transportation options. Examples include, door-to-door paratransit services via accessible van or taxicab, public transit buses and commuter rail and escorted transportation. Transit programs for people with disabilities are at reduced fares or free and can include training workshops available by the transportation agency or provider for an individual to learn how to schedule a ride or interpret transit schedules.

2. Eligibility

<input type="checkbox"/> Infants and Toddlers	<2 yrs	<input checked="" type="checkbox"/> Young Adults	18–25 yrs
<input type="checkbox"/> Pre-K	3–4 yrs	<input checked="" type="checkbox"/> Older Adults	25–49 yrs
<input checked="" type="checkbox"/> K-12	5–18 yrs	<input checked="" type="checkbox"/> Seniors	50+ yrs

Students with disabilities that are school-age can access the County's Ride On buses for free Monday through Friday from 2 p.m. to 8 p.m. and those enrolled in Montgomery College need to show a valid student ID card to ride for free year-round²⁵.

Adults with a disability must apply and provide documentation of his or her disability to access reduced fare or free transportation options. Eligibility approval for MetroAccess, the region's primary paratransit service run by WMATA, allows individuals and one companion to ride free on fixed route public transit buses and commuter rail in Montgomery County and the District of Columbia as well as select routes in Prince George's County and Fairfax and Arlington, Virginia. MetroAccess applicants must have their application completed and certified by a healthcare professional and complete an in-person interview and assessment²⁶.

To be eligible for MetroAccess service, an applicant must:

- Have a disability as defined by the American Disabilities Act and be unable to utilize the Metrobus and Metrorail system some or all of the time as a result of their disability; OR
- Need to use a ramp or wheelchair lift to board or exit a public transit vehicle, but an accessible public transit vehicle is not being used at the time, date, and on the route you would travel; OR

²⁴ <https://www.thearc.org/what-we-do/public-policy/policy-issues/transportation>

²⁵ <https://www.montgomerycountymd.gov/dot-transit/kidsridefree/>

²⁶ <https://www.wmata.com/service/accessibility/metro-access/eligibility.cfm#apply>

- Be unable to travel to or from a bus stop or rail station due to a disability, or an accessible pathway to a bus stop or rail station is not available.

3. Description of Programs and Services

Directory of Transportation Providers and One-Stop Transportation Call Center

Montgomery County's Department of Health and Human Services' Commission on People with Disabilities publishes the *Transportation Network Directory for People with Disabilities & Adults 50+*, which serves as a comprehensive community guide to public, private and nonprofit transportation options in the County²⁷. In addition, the County partners with the Jewish Council for the Aging of Greater Washington to provide the Connect-A-Ride Transportation Resource Center²⁸, where individuals with disabilities can call and speak to a Certified Information and Mobility Specialists to help with information, referral, travel training, schedules, benefits and eligibility requirements in Montgomery County, Maryland, and Arlington and Fairfax Counties and the cities of Alexandria and Falls Church in Virginia.

Travel Training

Individuals with disabilities can access free travel training with WMATA and the Jewish Council for the Aging's Connect-A-Ride program. WMATA works with individuals to meet their specific needs, while Connect-A-Ride provides group travel training only. In addition, most nonprofit organizations that provide employment services for individuals with disabilities integrate travel training in their programs.

Transportation Service Types

Public Transportation: County Ride On buses, Bethesda Circulator, Maryland Transit Administration (MTA) Commuter Bus Routes and rails, WMATA Metrobus and Metrorail

Reduced Fair Taxicabs: Abilities-Ride is a program for MetroAccess customers to use on-demand taxi services without sharing a ride at a discounted rate. Regency Taxi participates in this program. Call-n-Ride is a County on-demand discounted taxi service for low-income individuals with disabilities age 18 and older. Same Day Access is a County on-demand discounted taxi service for MetroAccess recipients.

Rideshares: Rideshare companies Uber and Lyft have responded to recent lawsuits to increase access to vehicles that can accommodate individual with physical disabilities.²⁹ Uber and Lyft are not yet an alternative for people who use a wheelchair. In addition, these options may only be appropriate for a person with a mild disability as there is less oversight and regulation of drivers.

²⁷ <https://www.montgomerycountymd.gov/HHS-Program/ADS/Transportation/Directory.html>

²⁸ <https://www.accessjca.org/connect-a-ride/>

²⁹ <https://ride.guru/content/newsroom/rideshare-disability-services>

4. Data and Trends

The following data show the use of Connect-A-Ride, Call-n-Ride, and Metro Access **for all** Montgomery residents, **not just those with IDD**.

Connect-A-Ride	Residents Served
Fiscal Year 2016	3,375
Fiscal Year 2017	3,181
Fiscal Year 2018	3,857

Call-n-Ride	Participants	Number of Trips
Fiscal Year 2016	5,706	122,430
Fiscal Year 2017	5,410	125,595
Fiscal Year 2018	5,209	122,102

MetroAccess	Registrants	Number of Trips
July 2018	8,132	36,978
August 2018	8,098	35,526
September 2018	8,176	38,048

5. Gaps

There is a shortage of taxi cabs to serve the needs of people with disabilities. While some people with developmental disabilities may be able to use Uber and Lyft, they are not equipped to serve people using wheelchairs or who may have other needed equipment.

There are not enough MetroAccess drivers and vehicles to ensure that trips take a reasonable amount of time. When additional riders must be picked up and it is not on, or very near the direct route, it can add a significant amount of time for the individual which can prove very stressful and can result in not arriving on time.

Participants may only get four rides per month through the County's escorted transportation program.

The State is limiting funding for transportation through DDA.

6. Innovations

The CAP program allowed direct service providers to also provide transportation. It was stopped but there was data to show it was successful. Community Support Services participated and found that there was much more consistency on who the driver would be and that the drivers had the skills to drive safely and meet the needs of individual. The State of Maryland decided to stop this program and use WMATA for Montgomery County residents.

7. Recommendations

- ✓ Advocate with DDA to allow the County to reinstate the CAP program or other innovative options that are partnerships with the service provider. This model was reliable and the organization providing the transportation knew the needs of the individual. Determine how many agencies have an interest in participating if the option is reinstated.
- ✓ The County should work with WMATA for better background checks and safety measures to prevent criminal sexual assaults against passengers.
- ✓ The County should work with WMATA to ensure there are enough resources to pick people up on time and deliver them to their destination in a reasonable amount of time.
- ✓ Make sure that any options for senior transportation are made available to seniors with developmental disabilities.

Waivers

1. Definition

A waiver is an exemption from some aspect of a federal health care statute that gives a facility or program the right to deliver care in a manner that varies from published standards. A waiver from the federal Centers on Medicare and Medicaid (CMS) allows states to waive or bend the usual rules to allow Medicaid and other services to be delivered in a different place, to people with different needs, or different income levels. States apply for a waiver and share the cost of services with the federal government. Waivers allow for individuals to receive different care or different circumstances for care in order to shuttle the cost of a program or service.

There are multiple waivers available to individuals in Montgomery County. For children with Autism aged 2 through 21 who are still in school, there is the Autism Waiver. For those who qualify for services through the Developmental Disabilities Administration (DDA), the Community Pathways Waiver provides support and services to the widest range of individuals since those with developmental and intellectual disabilities are eligible from birth through all ages. This waiver intends to allow for individuals to remain in their home and their community. The Medicaid waiver enrollment is set by the state and determined by financial eligibility of the individual not of the parents.

The Maryland Department of Health and Mental Hygiene, Office of Health Services must apply to the Centers for Medicare and Medicaid Services to have waivers approved and they are then monitored by this federal agency. Waivers are approved for an initial period of three years and are renewed for a five-year period. Waiver renewals are based on satisfactory provision of waiver services, meeting state assurances and a written application that describes how services will be provided during the renewal period.

The waivers are intended to allow individuals to choose services in their own community. Individuals are eligible for a waiver if they meet the target group for the specific waiver, any other eligibility requirements, and the state has capacity. If the state does not have available funding for a waiver space, then the individual is put on a waitlist.

2. Eligibility

<input checked="" type="checkbox"/> Infants and Toddlers	<2 yrs	<input checked="" type="checkbox"/> Young Adults	18–25 yrs
<input checked="" type="checkbox"/> Pre-K	3–4 yrs	<input checked="" type="checkbox"/> Older Adults	25–49 yrs
<input checked="" type="checkbox"/> K-12	5–18 yrs	<input checked="" type="checkbox"/> Seniors	50+ yrs

3. Description of Waivers

A. Autism Waiver

Children with Autism aged 2 through 21

Eligibility:

Individuals must be certified as needing an Intermediate Care facility for the Intellectually Disabled. The individual must be enrolled in a publicly funded school and either have an Individual Family Service Plan or an Individualized Education Plan (IEP) with at least 15 hours of special education and related services. The individual monthly income may not exceed 300% of Supplemental Security Income (SSI) and countable assets cannot exceed \$2,000 or \$2,500 depending on the category. The parents' income is waived.

The **goal** is to serve children with Autism in their home, community, and school in place of an institution and so the individual must be able to do so with services and supports.

Services can include respite care, accessibility adaptations, residential habilitation, intensive individual support services, and adult life planning. There are limits to the number of hours that can be received in a week or year. The individual is also eligible to receive medical, pharmacy, home health, and mental health services provided through Medicaid.

B. Community Pathways Waiver

Children and Adults

Meaningful Day, Support, and Residential services

Eligibility:

People (both children and adults) who have been allocated DDA funding and have the "developmental disability" eligibility category may be eligible for the waiver. To be eligible for waiver services, you must demonstrate through a screening process that you need the level of support that people receive in an institution and meet the waiver's financial eligibility requirements.

The goals for the Community Pathways Waiver include providing:

Innovative service options aimed at providing supports that build on the DDA's existing Community of Practice related to Employment and Supporting Families

Participant and family self-direction opportunities

New Supported Living and housing support services to increase independent living opportunities

Transitioning to new Employment Services and provider rates.

Renewal 2018

The Community Pathways Waiver renewal application enhances services and supports for individuals and families

Updates provider and staff qualification standards with national standards

Reflects new rates and payment methods

Provides new opportunities for participants to work toward self-determination, independence, productivity, integration, and inclusion in all facets of community life across their lifespans.

The renewal application includes

The introduction of new services

Revisions to service descriptions

Requirements

Limitations

Provider qualifications

Some new services and changes to existing services will be available and in effect July 2018

Some will transition during the first year (2018-2019)

Others will be implemented July 2019

Three stand-alone Nursing Services will be available July 2020

Enhanced Supports will be implemented in July 2020 - to allow time for development of community setting compliant service providers

Payment systems for direct service providers will transition to Maryland's Long-Term Services and Supports (LTSS) system in January 2020.

C. Family Supports Waiver:

Children birth to 21 years

Various Support Services

Service Cap of \$12,000 annually

The program provides individual and family supports for children birth to 21 with developmental disabilities **on the DDA Waiting List**.

*** DDA expected services under the waiver to start by February 2018, which would reduce the waiting list by 400 individuals.

If on the DDA waiting list:

- No action needs to be taken
- DDA will contact the first 400 individuals on the waiting list based on priority category and date of application
- A DDA Coordinator of Community Services will then assist the individual and family with the waiver application process

The goals for the Family Support Waiver include providing:

Innovative service options aimed at providing supports that build on the Support Families Community of Practice

Individual and family self-direction opportunities

Flexibility for individuals and families to move dollar amounts among line items within their approved person-centered plan to meet the emerging and cyclical needs of the child and family

Short term exceptions to the overall budget caps based on exceptional needs (for example family caregiver support needs, post hospitalization, short term care needs)

D. Community Supports Waiver

Children and adults

Meaningful Day and Support Services

Service Cap of \$25,000 annually

The goals for the Community Support Waiver include providing:

- Innovative service options that support DDA's Community of Practices for Employment and Supporting Families;
- Community-based service options offered under the current Community Pathways Waiver (e.g. Supported Employment, Employment Discovery & Customization, Personal Supports, Respite, Assistive Technology, Behavioral Supports, etc.) with the exception of residential services;
- Self-direction opportunities;
- Flexibility to move dollar amounts among line items within the approved person-centered plan to meet emerging and changing needs; and
- Short-term exceptions to the overall budget caps of \$25,000 based on exceptional needs.
***All services must be provided in settings that meet the federal Community Settings requirements.

4. Data and Trends

An Autism Waiver Overview on the Montgomery County Public Schools' (MCPS) website from 2017 says that:

- MCPS has 255 children approved for services
- Approximately 20 to 30 students exit the program each year
- There are over 4,500 students on the Autism Waiver Registry
- Over 900 students on the registry are from Montgomery County

Waiting List for DDA Services

	September 12, 2016	August 1, 2018
DDA Waiting List – receiving no services	989	1,058
Crisis Resolution (need services within 3 months)	12	9
Crisis Prevention (need services with a year)	106	59
Current Request	871	757

Source: Annual Reports Commission on People with Disabilities sourcing DDA

5. Gaps

There is insufficient funding for the waiver programs. The Work Group in its system-wide recommendations states its concerns that DDA ends the year with surpluses when there are long waiting list for services.

There is confusion about the DDA Transformation Plan and how to apply for waivers during this transition period. Some information on the DDA website is not linking people to the correct applications and descriptions. There may be gaps in services if current providers are not certified to offer services under the new waivers. When the Work Group began meeting, many current providers had not been certified and the process for completing the certification was not clear.

The Transformation Plan implements the Community Settings Rule in addition to implementing new Waivers. There could be gaps in the availability of housing and certain other programs because of new lower limits on the number of people with developmental disabilities that may live together (no more than four) or be together in a program.

6. Innovations

Waivers are established based on state application and approval from Centers for Medicaid and Medicare. A unique “innovation” was not identified during the time the Work Group met. However, the Work Group agreed it would be beneficial to look at other states’ waiver structures to see if there are lessons that can be transferred to improve Maryland’s system.

7. Recommendations

- ✓ The Montgomery County Executive and Council must partner with the General Assembly Delegation to receive regular progress reports on the Maryland Developmental Disabilities Administration’s (DDA) Transformation Plan. The progress reports should focus on real impacts to individuals, families and providers. Is the Transformation Plan resulting in increases or decreases to the time individuals remain on waiting lists? Is it changing the quality of services provided? (This is also a system-wide recommendation.)
- ✓ Evaluate whether the new structure for Maryland’s Waivers, which are more restrictive, is increasing or working against inclusion. Look to the experience of other states to see if Maryland is serving as a model of excellence.
- ✓ The County Executive and Council must carefully monitor the ongoing rate setting study and advocate strongly for rates that reflect the cost of doing business in Montgomery County. Services must be funded in a manner that allows providers to afford to continue to provide services. (This is also a system-wide recommendation.)
- ✓ DDA should use its full budget allocation to support more people instead of ending the year with surpluses. (This is also a system-wide recommendation.)
- ✓ The Executive and Council should receive update on the impacts on program and housing capacity from the implementation of the Community Settings Rule.

Resolution No.: 18-989
Introduced: December 5, 2017
Adopted: December 12, 2017

**COUNTY COUNCIL
FOR MONTGOMERY COUNTY, MARYLAND**

Sponsor: Councilmember Leventhal
Council President Riemer, Council Vice-President Navarro
Councilmember Rice, Councilmember Elrich, Councilmember Katz, Councilmember Floreen,
Councilmember Berliner, Councilmember Hucker

SUBJECT: Work Group on Meeting the Needs of Residents with Developmental Differences

Background

1. Montgomery County is committed to creating an inclusive community for people with disabilities so that they are treated equitably and fairly and can participate fully in the life of the county.
2. While there is no exact estimate of the number of county residents with developmental differences (also called developmental disabilities), the 2016 American Community Survey reports that 29,614 people identify as having a cognitive disability; with about 70% of those being less than 65 years of age. Montgomery County Public Schools (MCPS) reported that for 2016, there were 2,386 special education students with Autism, 3,387 with a Developmental Delay, and 653 with an intellectual disability. Other national models estimate that the county has about 15,000 to 16,000 people with developmental disabilities.
3. In August 2017, there were 1,058 Montgomery County residents on the Maryland Developmental Disability Administration's waiting list. MCPS reported in October 2017 there were 1,070 Montgomery County youth on the Autism Waiver Registry; 246 have a waiver and services, while 824 do not. While not all of the 824 will qualify for a waiver, there is about a nine year wait for services.
4. In July 2017, the Office of Legislative Oversight issued its report, "Housing for Adults with Developmental Disabilities." This report discusses the housing choices needed to support people with a range of developmental differences, from minor financial or daily living supports to long-term care and significant supports for activities of daily living. Federal law and court decisions, such as the Americans with Disabilities Act, the Fair Housing Act, and Olmstead v. L.C., require movement toward a system that gives people choice and the same rights as those without a developmental disability. While focused on housing options, the report highlights many issues, such as the adequacy of Medicaid reimbursements, availability of housing subsidies, importance of access to public transportation, and the significance of increasing employment opportunities.

Action

The County Council for Montgomery County, Maryland approves the following resolution:

The Council directs the Council Administrator to designate appropriate members of the Council staff to form a Work Group on Meeting the Needs of Residents with Developmental Differences.

The Work Group must invite representatives from the following organizations to assist the Work Group:

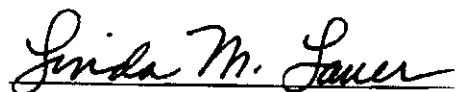
- Department of Health and Human Services,
- Department of Transportation,
- Department of Housing and Community Affairs,
- Department of Recreation,
- Montgomery County Public Schools,
- Montgomery College,
- Maryland Developmental Disabilities Administration,
- WorkSource Montgomery,
- Representatives chosen by the Commission on People with Disabilities that may include consumers of Developmental Disability Administration services and family members or caregivers of a differently abled person.
- Representative from InterACC/DD
- Public at-large

The Work Group must consider information available on the current number of residents with developmental differences and projections based on trends seen in Montgomery County Public Schools, early childhood programs, and other programs that may identify or assess certain conditions, such as Autism.

The Work Group must review and report on current gaps in services including, but not limited to child care, education, discrimination, transition to adult services, resource coordination, housing, transportation, employment, health care, and recreation. The Work Group must report on best practices as well as innovations in each identified service area. If available, the Work Group must provide information on costs associated with programs and services.

The Work Group must provide an interim report to the Council by July 18, 2018 and a final report by October 16, 2018

This is a correct copy of Council action.



Linda M. Lauer, Clerk of the Council



Call to Action:

Strategic Steps for Real Change



2009 Study Results from the
Workgroup on the Future for
People with Severe Developmental
Disabilities, including Autism



+

"Adopt the entire world as
'Our Family' - because when we
do, we will be able to see that,
indeed, everyone is beautiful, and
we all compliment each other
beautifully and we would all be
poorer without each other."

Start Date

+

Action Plan Priorities: What We Can Do

Increasingly, people with severe developmental disabilities and their families in Montgomery County find themselves in crisis, without the services, support and information they require. In a companion document, **PARTNERSHIPS FOR A POSITIVE FUTURE: STUDY RESULTS FROM THE 2008 WORKGROUP ON THE FUTURE FOR PEOPLE WITH SEVERE DEVELOPMENTAL DISABILITIES, INCLUDING AUTISM**, available at <http://www.montgomerycountymd.gov/hhstmpl.asp?url=/content/hhs/ads/disabilitysite.asp>, the *Workgroup on Severe Developmental Disabilities, including Autism* provides detailed information on the situations people face in Montgomery County. Their findings and recommendations are consistent with several recently published statewide and national reports looking at the same issues, which are referenced in the companion document.

Almost all of the recommendations that follow can be accomplished at little or no cost. Those that may require a funding allocation are denoted by the symbol **\$\$\$**. Also, recommendations are organized by suggested implementation priority, and are listed under Year 1 or Year 2 headings.

PRIORITY 1. Respond proactively to people in crisis who are on waiting lists, and advocate for more services and options.

There are urgent needs to provide some level of support to people on waiting lists and to build the service system's capacity. Added capacity would increase the number of children and adults served, enhance the expertise of service providers who work with people with severe developmental disabilities, and expand the ability of community services that serve the general population to successfully include people with severe developmental disabilities.

Recommendation

YEAR 1

- ① Establish a cross-departmental County workgroup, with broad representation of public and private stakeholders and advocates, to develop strategies for addressing the needs of the children and adults who are languishing on waiting lists for services. This workgroup's charge would be to (a) analyze options for employment, therapeutic and recreational support in the County so as to open

doors for people while they are on the waiting list and during gaps in services; (b) advocate with the State to maximize waiver funding, utilize all allocated funds, and reallocate unused funds; (c) maximize the use of existing specialized and general services, introducing universal design to increase accessibility for people with disabilities; (d) advocate with the State to evaluate the waiting list for the autism waiver so that these highly specialized services are targeted to people whose support requirements cannot be met in any other way and so that children need not rely on funding from the adult system, further stretching those limited resources; (e) advocate for insurance coverage for therapeutic support for people with autism; (f) advocate for different caps on autism waiver services to enable the funding to reach more children and families; (g) advocate for adequate funding for students who transition from school to adult services, with incentives for serving adults with severe disabilities; and (h) remove barriers that prohibit many students with severe disabilities from participating in after-school sports and extracurricular activities (e.g., students may be considered academically ineligible by County standards and may require specialized accommodations or supports, which may or may not require funding).



PRIORITY 2: Provide support for people through service and life cycle transitions, while ensuring that they move into activities and services that are meaningful and that enable them to learn, grow and contribute.

There is an **urgent** need to support people with severe developmental disabilities so that they spend their time in ways that are meaningful to them. Also, they require strong support through transitions, especially as young adults exit school, so that they transition into challenging post-secondary education and/or productive employment, with the support, services, and high expectations for active participation in community life.

Recommendation

YEAR 1

- ② Create and implement systems, processes and incentives to ensure collaboration between Montgomery County Public Schools and adult service agencies that serve people with disabilities and their families, with guidance by the County Transition Taskforce.

- ⊙ Expand the number of County staff that support families in navigating the transition process in the Montgomery County Public Schools and Department of Health and Human Services. \$\$\$
- ⊙ Work through local workforce development initiatives to create and/or include employment opportunities for people with severe developmental disabilities within the business community and within County and incorporated city governments.
- ⊙ Create and promote internships for people with severe developmental disabilities and remove barriers to employment within the County and incorporated cities.
- ⊙ Develop partnerships with public and private sector employers to create job opportunities, internships, career explorations, and situational assessments, leading to supported and customized employment.
- ⊙ Identify and advocate for flexible program models that work for people with severe developmental disabilities with flexible funding for services and approaches that allow for a mix of work, education, recreation, therapeutic support, and other activities, redefining current funding formulas to make this possible.
- ⊙ Increase access to continuing education at Montgomery County Community College with supports and accommodations, to increase the likelihood of productive meaningful employment and more independent community living for people with severe developmental disabilities.

YEAR 2

- ⊙ Develop a pilot project to measure transition success for students with disabilities, including employment outcomes, post-secondary education, and how well they were prepared for adulthood.



PRIORITY 3: Increase support to families across the lifespan.

Support is broadly defined and includes increasing the ease of access to timely, relevant information for families, people with disabilities and the people who support them. Support must also address the devastating financial impact on families. Having a family member with a severe disability creates severe economic hardships due to lost individual and family income, out-of-pocket expenses, and increased medical and therapeutic costs.

Recommendation

YEAR 1

- Ⓢ Augment *Info Montgomery* and use Montgomery County's Health and Human Services Regional Center staff and volunteers through the Volunteer Center so that they provide targeted information related to support for people with developmental disabilities and their families, with continuous updating and training for the people who receive calls and requests for information.

YEAR 2

- Ⓢ Broadly advertise and market *Info Montgomery's* capacity to assist families, people with disabilities and the people who support them, with outreach to ensure that people throughout the County know how to access information. \$\$\$
- Ⓢ Develop a formal family-to-family support program to inform and prepare people with developmental disabilities and their families for the realities of transitions across the lifespan. \$\$\$
- Ⓢ Create and support additional before and after school and adult program options, as part of typical inclusive services, in inclusive settings wherever possible, with accommodations and support, to enable parents to maintain employment while offering meaningful activities for their family member with a severe developmental disability. \$\$\$
- Ⓢ Extend the Working Parents Assistance program to age 21 for adolescents with significant disabilities. \$\$\$



PRIORITY 4: Increase the number of highly-skilled, responsive, and adequately paid people to provide direct support, medical, dental and therapeutic services.

The workforce charged with serving people with severe developmental disabilities must be dynamic, diverse and strong. This professional workforce includes direct support staff; mid-level managers; and medical, dental and therapeutic staff.

Recommendation

YEAR 1

- ⊙ Revise current policy/legislative language to develop more customized service options that can be charged to Medicaid, including services such as nutrition, thereby expanding the array of available services.

YEAR 2

- ⊙ Develop a *pro bono* or low cost dental pool for dental services that are not covered by Medicaid or standard insurance.
- ⊙ Design and implement creative approaches for building capacity for therapeutic, medical and dental services and direct support to people with severe disabilities, both to expand the availability of services and the number of providers with expertise in working with people with severe developmental disabilities.
- ⊙ Create incentives or fund subsidies to attract people into therapeutic fields (including speech/language therapy, physical therapy (PT), occupational therapy (OT)). \$\$\$

PRIORITY 5: Identify and utilize the full array of community services and support available to all County residents.

This priority will build community capacity and both promote community inclusion and lessen the current total dependence on specialized services and supports. Accommodations should be provided as necessary.

Recommendation

YEAR 1

- ⊙ Implement House Bill 1411, the Fitness and Athletics Equity Act for Students with Disabilities, which promotes equal access to recreational and physical education

programs for children with disabilities. The bill creates policies and procedures to promote and protect the inclusion of students with disabilities into mainstream physical education and athletic programs, extracurricular activities, and interscholastic competitions.

- ⑥ Identify typical community services and supports available in the County to all of its residents that can be made accessible to people with severe developmental disabilities of all ages, prioritizing these for people on a waiting list for services.
- ⑥ Provide supplemental funding to support capacity-building for typical childcare providers, including training and consultation. \$\$\$
- ⑥ Increase the funding allocation in the recreation department to support therapeutic recreation and inclusion support for people with disabilities. The current allocation for therapeutic recreation is 3.6% , even though the percentage of people with severe disabilities is over 12%.

These conclusions and the recommendations in our companion document, **PARTNERSHIPS FOR A POSITIVE FUTURE : STUDY RESULTS FROM THE 2008 WORKGROUP ON THE FUTURE FOR PEOPLE WITH SEVERE DEVELOPMENTAL DISABILITIES, INCLUDING AUTISM**, are consistent with those of the Arc of Maryland. In their 2008 Public Policy Platform, they advocate for (1) a multi-year Waiting List Initiative to meet the needs of individuals on the DDA Waiting List and Autism Waiver; (2) building the capacity in the community to serve and include people with developmental disabilities; (3) full funding for the Transitioning Youth Program; (4) supports that lead to self-determination and inclusive lives for people with developmental disabilities; and (5) adequate funding to ensure a stable, quality system of community programs, including residential, employment, vocational and individual and family supports (The Arc of Maryland. (2008). 2008 Public Policy Platform. <http://www.thearcmd.org/files/6read-here.pdf>).

For more information about these reports, please contact :
Montgomery County Department of Health and Human Services
Aging and Disability Services
Community Support Network
240.777.1216

Alternative formats of this document available upon request.
For Maryland Relay call 711.

Definitions

Autism Spectrum Disorders (ASDs). This group of developmental disabilities is defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests. Many people with ASDs also have unusual ways of learning, paying attention, or reacting to different sensations. The thinking and learning abilities of people with ASDs can vary—from gifted to severely challenged. ASD begins before the age of three and lasts throughout a person's life. It occurs in all racial, ethnic, and socioeconomic groups and is four times more likely to occur in males than females. (Centers for Disease Control and Prevention (CDC): Autism Information Center, <http://www.cdc.gov/ncbddd/autism/index.htm>).

Developmental Disability. This term (as defined by the Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106-402) refers to a severe, chronic disability of an individual that:

1. Is attributable to a mental or physical impairment or combination thereof.
2. Is manifested before the individual attains the age of 22.
3. Is likely to continue indefinitely.
4. Results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency.
5. Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized support, or other forms of assistance that are of lifelong or of extended duration and are individually planned and coordinated.

Family Support. This term refers to resources, subsidies, services, and other assistance provided to families of persons with disabilities that are designed to support families in their efforts to maintain family members with disabilities at home, strengthen the role of the family as primary caregiver, prevent inappropriate and unwanted out-of-home placement, maintain family unity, and connect families with persons with disabilities who have been placed out of the home, whenever possible. The term includes service coordination, goods, services and financial assistance.

Intellectual Disability. This is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18 (American Association for Intellectual and Developmental Disabilities). Intellectual disability is characterized both by a significantly below-average score on a test of mental ability or intelligence and by limitations in the ability to function in areas of daily life, such as communication, self-care, and getting along in social situations and school activities. Intellectual disability has historically also been referred to as a cognitive disability or mental retardation (Centers for Disease Control and Prevention (CDC): National Center on Birth Defects and Developmental Disabilities, <http://www.cdc.gov/ncbddd/dd/ddmr.htm>, 2005).

Severe Developmental Disability. There is not a single definition for severe developmental disability, as definitions tend to be specific to what a person's unique disability may limit. For the purposes of this report, a severe developmental disability is one that creates significant barriers to one or more of an individual's abilities (such as mobility, learning, communication, self-care, self-direction, interpersonal skills, work tolerance, or work skills) so that the individual requires intensive and continuous long-term support.

Workgroup Members

Lyda Astrove, Co-Chair

Dr. John J. Kenney, Co-Chair

Ronnie Biemans

David Cross

Claire Funkhauser

Paula Howland

Susan Ingram

Amy Kealiher

Joan Karasik

Lauren Newman

Ian Paregol

Neema Rosner

Rebecca Salon

Kristen Secan

Stuart Spielman

Debbie Vanbrunt

Janet Witrol

Special thanks to Amy Kealiher, for her expertise in editing and formatting the reports; to Michele Kirkpatrick, for organizing meetings, managing minutes and documents, and compiling data from surveys and focus groups; and Rebecca Salon, for incorporating the input, data and current research into this document.

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*"Every single person has capabilities, abilities
and gifts. Living a good life depends on
whether those capabilities can be used,
abilities expressed and gifts given. If they are,
the person will be valued, feel powerful and
well-connected to the people around them.
And the community around the person will
be more powerful because of the contribution
the person is making."*

John P. Kretzmann and John L. McKnight

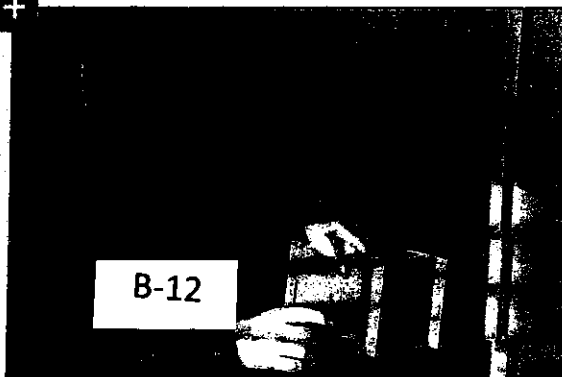
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Partnerships for a Positive Future



2009 Study Results from the Workgroup
on the Future for People with
Severe Developmental Disabilities,
including Autism



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*"... Adopt the entire world as
'Our Family'... because when we do,
we will be able to see that, indeed,
everyone is beautiful, and we all
compliment each other beautifully
and we would all be poorer
without each other."*

Weekly Results from the Workshop

for People with *Stan Dale*

Developmental Disabilities

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Message from the County Executive



As County Executive, I recognize the rich and vibrant contribution each member of our community makes to the total diverse fabric of Montgomery County. In order to preserve and enhance this wonderful gift of our diversity, we must strive to ensure that every resident has access to all services and to the recreational, educational, arts, leisure and community activities in which they wish to participate.

It is with great pride that I introduce a publication that will play an important role in shaping the County's response to the needs of children and adults with severe developmental disabilities. The Report on People with Severe Developmental Disabilities, including Autism is the result of a visionary and collaborative process involving parents, advocates, and representatives from the public and private disability service systems. Through an extensive outreach, data collection and assessment process, we now have a more comprehensive understanding of the needs of the severely developmentally disabled population and the URGENCY to respond to those still waiting for services.

I thank the many people who participated in this process, from those families who willingly participated in the focus groups to those individuals that researched services and data across the country. Because of your efforts, a tangible difference will be made in the lives of many of these individuals who call Montgomery County home.

Isiah Leggett
Montgomery County Executive



Message from the Director of the Department of Health and Human Services



Early in 2008, a group of 18 committed family members, government officials, representatives from the private sector and advocates came together to discuss the unmet needs of the growing number of people with severe developmental disabilities. According to the U.S. Administration on Developmental Disabilities, approximately 4.5 million individuals with developmental disabilities live in the United States. We have learned that developmental disabilities affect approximately 17% of children aged 18 years or younger. These statistics, along with the data documenting over 2,600 individuals on the State waiting list for services, bring home the urgency of our need to develop effective strategies to address the problem.

We are aware that various barriers exist and that children remain on the Autism Waiver waiting list between 4-6 years while adults wait for 5-15 years on the state waiting list. We are sensitive to the fact that families carry an enormous responsibility in caring for their family member(s). This report helps define the scope of the problem and guides us through relevant action steps that can be taken by policy-makers, provider agencies, advocates and families/consumers. A tremendous amount of outreach and research went into the development of the report.

I want to thank each of the members of the Workgroup and the families who so willingly shared their stories and recommendations. We believe this will be an important building block in our County's efforts to address the needs of individuals with developmental disabilities. I encourage you to join us as we continue to work on this very important issue affecting the lives of numerous Montgomery County families.

Uma S. Ahluwalia
Director

Message from the Co-Chairs



A MESSAGE FROM THE CO-CHAIRS OF THE MONTGOMERY COUNTY WORKGROUP ON THE FUTURE FOR PEOPLE WITH SEVERE DEVELOPMENTAL DISABILITIES, INCLUDING AUTISM:

People with severe developmental disabilities of all ages are in crisis. Their needs are intense, continuous, unrelenting, and life-long. We see it every day in our interactions in the community, in requests for assistance made to Montgomery County Government, in collaborations with schools and service providers, and in our day-to-day encounters with families. This two-part report highlights the ***Need for Urgency*** in addressing the needs of people with severe developmental disabilities and their families, and presents a ***Call to Action***, with priorities and recommendations—most of which can be accomplished with little or no cost.

Our thanks to the committed family members, advocates, service providers and County government staff who contributed their time, creativity and expertise in creating this report: **Now** is the time to act — to join forces to support this Call to Action and address the critical unmet needs of people of all ages with severe developmental disabilities and their families.

Lyda Astrove and John J. Kenney, Workgroup Co-Chairs

Addressing a Crisis: The Need for Urgency



Montgomery County residents with severe developmental disabilities, including autism, often languish for years on waiting lists, on average from 5-15 years. Many come from families in crisis; and many have elderly caregivers, some of whom are disabled themselves.

Early in 2008, a group of family members, Montgomery County officials, and private service providers came together to discuss ways to address the unmet needs of increasing numbers of people with severe developmental disabilities. Because of the crisis situations in which families and service providers often find themselves, the workgroup sought to develop proposals and action plans that would increase the capacity of the service system to support people with intensive needs, and provide support to their families and the professionals with whom they work.



*"There are unlimited possibilities
when people are creative and expect
the best."*

The Workgroup



Co-Chairpersons Lyda Astrove and Dr. John J. Kenney convened the Workgroup on Severe Developmental Disabilities, including Autism. The 18-member workgroup included parents, advocates, and representatives from public and private disability services. The workgroup's charge was to determine the extent of the need, define the people most in need of intensive support, and decide which needs should have highest priority. Workgroup members sought input from families throughout the county, examined current policy and legislative barriers, and researched best practices in services and support for people of all ages with severe developmental disabilities.

Findings: What We Learned



In reviewing data from a County-wide survey and focus groups, two overarching and interrelated issues were expressed repeatedly by families, people with disabilities, and service providers.

- 1 There is a need for urgency! We collectively must respond with urgency in addressing the ongoing needs of children and adults with severe developmental disabilities.**
- 2 We must have higher expectations for people with severe developmental disabilities—regardless of an individual’s diagnosis.**

From childhood years onward, a lack of urgency in providing individualized services and the absence of high expectations translate into wasted days and years—resulting in dependent, unproductive lives. We get what we expect. If we believe that a person with developmental disabilities will never hold a job or gain independence, there is little motivation to provide a high-quality education, career counseling or job training. Stereotypes abound about people with the most severe disabilities, most of which serve to limit the opportunities made available to them.

We also heard and learned that people with severe developmental disabilities have very few service options, are socially isolated, have little to no support for becoming contributing members of society, and largely do not participate in the life of their communities.

Who are People with Severe Developmental Disabilities, including Autism?



People with severe developmental disabilities have lifelong disabilities and require continuous support from family members, formal service providers, and other support networks. Severe developmental disabilities create barriers in three or more life areas, —including someone’s capacity for independent living, economic self-sufficiency, learning, mobility, comprehensive and language skills, self-care, self-direction, or the ability to function independently without individually planned and coordinated services. Therefore, people require intensive and continuous long-term support. It is difficult to determine the prevalence of people with severe developmental disabilities because of inconsistent classification and tracking systems.

What is Life Like for People with Severe Developmental Disabilities and their Families?

In the December 2008 journal *Pediatrics*, researchers published the results of a national survey on the impact on families of raising children with special health care needs. Data indicates that parents of children with autism are *three times more likely* to quit their jobs or reduce work hours to care for their children compared to parents whose children have other chronic health care needs. The study showed that the support needs of children with autism place an enormous financial strain on families. In addition to lost income, families pay more for their children's health and support needs, and spend more time providing or arranging for their care.

There is enormous evidence that, with early intervention, challenging educational experiences and the availability of flexible individualized services and support, people with disabilities are most limited not by their disabilities but by *our expectations of them*. It is only in the last decade that we are not surprised to hear of children with Down Syndrome reading at grade level, or adults with autism attending college, writing books, and working as motivational speakers.

However, their unmet needs are staggering. While the number of people diagnosed with severe developmental disabilities increases, needs for services and supports fall further and further behind and the pool of available service providers continue to shrink.

Families caring for children and adults with severe developmental disabilities worry. They worry:

- About the future.
- That they're not doing enough, even though they are exhausting themselves with their efforts.
- That their son or daughter will never get off the waiting list.
- That they are neglecting their other children, their marriage and their health because of the intense demands of caregiving.
- That their son or daughter will always be vulnerable, and they won't be there forever to protect them.
- That they will never get out of debt from out-of-pocket expenses they incur to fill in service gaps.
- That there are too few high-quality service providers from which to choose.
- That their son or daughter will remain socially isolated and friendless.
- That their son's or daughter's life is being wasted due to missed opportunities and low expectations.

DID YOU KNOW...

As of July 2008, 18,024 people were on the waiting list for services from the Developmental Disabilities Administration (DDA). Of these, 94% need services immediately. Many are living with elderly caregivers or are young families with no support. The waiting list grew by 774 in the six months between January and July 2008 (Developmental Disabilities Coalition, 2008).

Although Maryland is the wealthiest state in the nation and has the lowest poverty rate of any state, Maryland ranks 44th in its spending on developmental disabilities services (The Arc of Maryland 2008 Public Policy Platform).

According to Cornell University's Disability Status Report for Maryland (2008), the employment rate for working age people with disabilities was 42.8%. Only 25.9% reported that they worked full-time for the full year. The poverty rate for working-age people with disabilities is 20.1%, compared to 5.5% for people without disabilities.

Guiding Principles



The following guidelines and principles should be applied to proposed solutions, recommendations, and their resulting outcomes.

Nothing about us without us. Planners and service providers should actively solicit input from people with disabilities and their families, and ensure that they have an *ongoing* means for communicating and offering input.

Coordinate services across settings. Support and services need to be systematically coordinated across settings and transitions, with special attention to clear and collaborative communication.

Ensure easy access to information and assistance. Information, transition support, family support, formal and informal services, training opportunities—all these should be easily accessible, well-publicized, and effectively promoted to people with disabilities, their families, and their staff.

Set high standards and provide support for continuous learning through professional development and training. Providers working with people with severe developmental disabilities should have consistent support to develop core competencies and build their expertise through training, mentoring, and higher education.

Provide updated information on best practices. Professionals, family members, and people in the community should have access to current best practices for supporting, working with, and successfully including people with severe developmental disabilities in a variety of settings.

Support and attract providers. Support current community service providers and attract new high-quality providers to deliver direct support and/or medical and therapeutic services



"It's very hard to find your way through the alphabet soup of service while still trying to give your child and your family what they need on a day-to-day basis."

Priorities

The workgroup identified five critical priorities.

PRIORITY 1. Respond proactively to people in crisis who are on waiting lists, and advocate for more services and options.

This is an urgent need for several reasons. The increasing number of people on already long waiting lists puts a significant strain on limited resources. Also, many families have expressed dissatisfaction with the quality of services, both for children and adults, including the inability of many providers to individualize support for their family member.

In July 2008, there were 2,842 Montgomery County residents on the Maryland Developmental Disabilities Administration's (DDA) waiting list, which represents a significant percentage of the 18,024 people on the waiting list statewide (see www.endthewaitnow.com). In October 2008, there were 2,351 children state-wide on the waiting list for autism waiver services, of which 481 were from Montgomery County. Statewide, the Autism Waiver Program has only 900 available slots and is capped at this number.

There also is a lack of collaboration and coordination between agencies and departments, resulting in wasted time, duplication of efforts, and missed or delayed outcomes.

"DDA approved my son's funding but none of the agencies accepted his application. Now DDA took back his funding and he is once again on the waiting list."

PRIORITY 2. Provide support for people through service and life cycle transitions, while ensuring that they move into activities and services that are meaningful and that enable them to learn, grow and contribute.

Many Montgomery County families noted that they encountered a lack of responsiveness in trying to access services or information, which leads to delays or failures in receiving support for their family member. Consequently, many families reported being unprepared for upcoming transitions—lacking adequate

DID YOU KNOW...

2002 U.S. Census Bureau data reports that 32.5 million people (12% of the general population) have a severe disability.

Developmental disabilities affect approximately 17% of children aged 18 years or younger, resulting in substantial financial and social costs (CDC, Monitoring Developmental Disabilities, 2006).

Statewide, the Autism Waiver Program has 900 available slots and is capped at this number. In October 2008, there were 2,351 children state-wide on the waiting list. The current wait time for a child added to the Autism Waiver waiting list is now 4-6 years.

The Infants and Toddlers Programs received 2,255 new referrals in FY 2008 and provided service to 3,632 children and their families, which is an increase from the 1,995 new referrals in FY 2007 and service provided to 3,484.

information to make timely, informed decisions; sufficient lead time; and support in planning and working through the details of the transition.

If people envision a positive future for children and adults with severe developmental disabilities, they are more likely to provide meaningful opportunities and encouragement for growth. Setting high expectations for people with severe developmental disabilities is critical, and is a recurring theme expressed by Montgomery County parents. Their fears and concerns are reflected in national unemployment data as well. People of employment age (21-64) who reported having a severe disability have the lowest rate of employment compared to people with non-severe disabilities or no disabilities at all (US Census Bureau, 2007). In a recent national survey (Easter Seals, 2008), 79% of parents of children with autism were extremely or very concerned about their child's future independence, compared to 28% of parents of children without autism.



"I wish there was a one-stop shop where I could be advised on what options and benefits there are for my daughter as she moves into adulthood."

PRIORITY 3. Increase support to families across the lifespan.

Families are the largest single group of caregivers for people with disabilities—providing a greater quantity and, in many instances, quality of care, especially to people with severe developmental disabilities. In providing this support, care, guidance and education to their family members, they save the county and state millions of dollars. Even when families receive in-home support, personal assistance and community living support, they still provide oversight, quality control, ongoing training for staff, and service coordination. In some instances, depending on the service and funding source, families also recruit, train and supervise staff. For all of these reasons, it is in the best interest of Montgomery County and the State of Maryland to preserve, strengthen and support families.

Families with a family member with a severe disability experience significant stress due to the relentless demands on their time (intensive daily caregiving, medical and therapeutic appointments, coordinating care and services, and advocating on behalf of their family member). Because of this, most families experience social isolation, marital difficulties, and strain on all family members, including siblings.

Many Montgomery County families noted difficulties in accessing services or information. Without clear access to information, they did not know their options and could not adequately prepare for

upcoming changes. They wasted precious time making dozens of calls and visits before getting the information they needed.

In the Workgroup's survey, only 24% of families reported using respite care services in the past year—a service that provides a much needed break from the ongoing demands of caregiving. When asked why they didn't use this service, 41% of respondents indicated an inability to find a caregiver or to afford the service. Only 32% of respondents indicated that they did not need the service. These responses were unrelated to the age of the family member. Families, including those on waiting lists, would benefit from the flexible support provided by respite services if the current barriers could be removed. Barriers include limited respite models; inadequately trained staff; difficulty finding staff for in-home and community support (in part due to inadequate compensation); and the physical inaccessibility of the County's respite house.

Having a family member with a severe developmental disability imposes economic hardships on the family, as highlighted in the previously mentioned December 2008 study published in *Pediatrics*. In the workgroup's survey, 61% of respondents reported that providing care to their family member has caused them either to leave their job (26%) or reduce their hours (35%). Of the 145 parents who responded to a question about their total out-of-pocket monthly expenditure for behavioral or therapeutic services, they collectively reported paying for over 400 services a month, totaling almost \$140,000 monthly. This may not include other direct support, medical and dental services, which are not covered by insurance or other funding sources. Many too have to travel to find doctors and dentists who have experience working with people with severe developmental disabilities.

Most adults with severe developmental disabilities are unemployed and, therefore, require support during the workday. This makes full-time employment impossible for many families. Also, many day programs operate only 5-6 hours per day, which also makes full-time employment difficult for families, given that people with severe developmental disabilities require ongoing support and supervision.

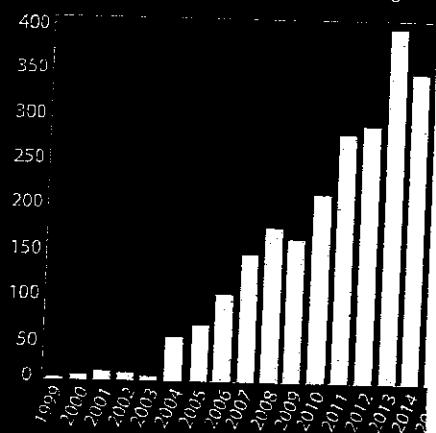
In a 2008 study by Easter Seals, 74% of parents of children with autism fear their children will not have sufficient financial support after they die, while only 18% of typical parents share this fear. The study also highlighted that parents are extremely or very concerned about their family member's future independence (79%), quality of life (77%), employment (77%), housing needs (69%) and education (73%)—all in stark contrast to the concerns expressed by parents of children without autism.

DID YOU KNOW...

The number of students with disabilities who exit school in Montgomery County annual has ranged from 83-101. Statewide, the number of students with autism who leave school continues to rise (see Figure 1).

This year, there were 16,485 students receiving special education services, of which 1,197 were preschoolers diagnosed with developmental delay and 2,117 were students categorized as having a severe developmental disability. This number also included 1,308 students diagnosed with autism.

Figure 1: Students with Autism Becoming Adults

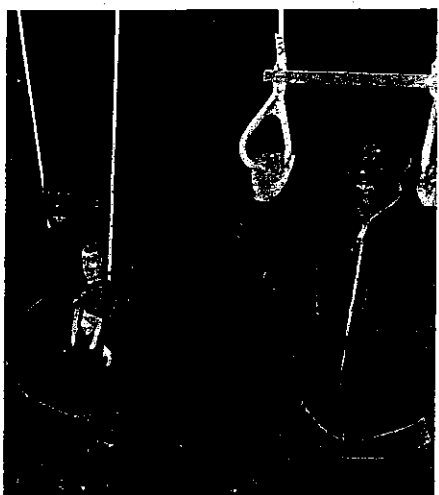




"We paid over \$40,000 out of pocket in 2007 for our child with PDD-NOS, a mild form of autism. It is crippling us financially."

PRIORITY 4. Increase the number of highly-skilled, responsive, and adequately paid people to provide direct support, medical, dental and therapeutic services.

There is an extremely high turnover rate among direct support staff who work with children and adults with severe developmental disabilities. This directly affects the quality of service people receive. Also, there is an insufficient number of providers of medical, dental and therapeutic services who have expertise working with children and adults with developmental disabilities and/or who accept Medicaid. Even providers who are experienced in working with people with severe disabilities often limit their services because of the substantial time commitment and inadequate reimbursement. Therefore, there is a need to create incentives for people to pursue and remain in careers in which they specialize in severe disability. In addition, because families often have to travel long distances to find services, it is critical that we support the development of local expertise.



"No one can fully understand the cost and work of raising a disabled child unless in that situation. Speech therapy costs \$185 per visit. Floor time costs \$295 per visit. Parents must do the therapy with the child between visits, and often it's a choice between therapy or going to work."

PRIORITY 5. Identify and utilize the full array of community services and supports available to all County residents.

People with developmental disabilities, especially severe disabilities, live fuller and more productive lives when they are engaged with all that their communities have to offer. It is unrealistic and undesirable to propose that the formal government-funded service system fully meet all of an individual's needs. People require broad and diverse support networks that will open doors to opportunities and keep them safe and healthy. Utilizing these community supports and services is cost-efficient, since the support that people receive from neighbors, community members, members of faith communities, and co-workers is freely given. The lifetime costs for a person with autism (including education, home and community-based services, and lost individual and family income) are estimated to be \$3.2 million (Ganz, 2007)—a number likely to be similar for people with other severe developmental disabilities. These extreme costs can be mitigated by both early intervention and the use of informal and/or typical community services.



*"I'm worried about
my son's future."*

For recommendations, see **A CALL TO ACTION: STRATEGIC STEPS FOR REAL CHANGE**, which details immediate steps that can be taken, most at little to no cost, as well as short and long-term activities to address the critical issues facing people with severe developmental disabilities and their families. This companion document is available at <http://www.montgomerycountymd.gov/hhstmpl.asp?url=/content/hhs/ads/disabilitysite.asp>.

For more information about these reports, please contact :
Montgomery County Department of Health and Human Services
Aging and Disability Services
Community Support Network
240.777.1216

Alternative formats of this document available upon request.
For Maryland Relay call 711

Definitions



Autism Spectrum Disorders (ASDs). This group of developmental disabilities is defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests. Many people with ASDs also have unusual ways of learning, paying attention, or reacting to different sensations. The thinking and learning abilities of people with ASDs can vary—from gifted to severely challenged. ASD begins before the age of three and lasts throughout a person's life. It occurs in all racial, ethnic, and socioeconomic groups and is four times more likely to occur in males than females. (Centers for Disease Control and Prevention (CDC): Autism Information Center, <http://www.cdc.gov/ncbddd/autism/index.htm>).

Developmental Disability. This term (as defined by the Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106-402) refers to a severe, chronic disability of an individual that:

1. Is attributable to a mental or physical impairment or combination thereof.
2. Is manifested before the individual attains the age of 22.
3. Is likely to continue indefinitely.
4. Results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency.
5. Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized support, or other forms of assistance that are of lifelong or of extended duration and are individually planned and coordinated.

Family Support. This term refers to resources, subsidies, services, and other assistance provided to families of persons with disabilities that are designed to support families in their efforts to maintain family members with disabilities at home, strengthen the role of the family as primary caregiver, prevent inappropriate and unwanted out-of-home placement, maintain family unity, and connect families with persons with disabilities who have been placed out of the home, whenever possible. The term includes service coordination, goods, services and financial assistance.

Intellectual Disability. This is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18 (American Association for Intellectual and Developmental Disabilities). Intellectual disability is characterized both by a significantly below-average score on a test of mental ability or intelligence and by limitations in the ability to function in areas of daily life, such as communication, self-care, and getting along in social situations and school activities. Intellectual disability has historically also been referred to as a cognitive disability or mental retardation (Centers for Disease Control and Prevention (CDC): National Center on Birth Defects and Developmental Disabilities, <http://www.cdc.gov/ncbddd/dd/ddmr.htm>, 2005).

Severe Developmental Disability. There is not a single definition for severe developmental disability, as definitions tend to be specific to what a person's unique disability may limit. For the purposes of this report, a severe developmental disability is one that creates significant barriers to one or more of an individual's abilities (such as mobility, learning, communication, self-care, self-direction, interpersonal skills, work tolerance, or work skills) so that the individual requires intensive and continuous long-term support.

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Workgroup Members



Lyda Astrove, Co-Chair
Dr. John J. Kenney, Co-Chair
Ronnie Biemans
David Cross
Claire Funkhauser
Paula Howland
Susan Ingram
Amy Kealiher
Joan Karasik
Lauren Newman
Ian Paregol
Neema Rosner
Rebecca Salon
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