



**Montgomery County Commission on People with Disabilities
Developmental Disabilities Advisory Committee
Meeting Summary – February 13th, 2017**

Sue Hartung, Co-Chair • Larry Bram, Co-Chair

Present:

Parents: Lyda Astrove; Susan Hartung (Co-Chair); Larry Bram (Co-Chair), Easter Seals; Reda Sheinberg; Camelia Fawzy; Betty Bahadori; Annette Jolles; Wendy Parker

Organizations: Shawn Lattanzio – DHHS, Behavioral Health; Kim Mayo – Community Support Network Administrator; Seth Morgan – Commission on People with Disabilities, Chair; Karen Morgret – Treatment & Learning Center; Sara O’Neil - MMARS; Judith Pattik- DDA; Daniel Hammond – Autism Waiver Coordinator, MCPS; Eldora Taylor – Community Support Network; Melissa Shaffer-Reyes - MMARS; Kim Khan; Rosemary DiPietro – Community Support Network; Jenn Lynn, UpCounty Community Resources; Margie Parrott – MCPS; Jay Kenney, HHS

Welcome and Introductions

Susan Hartung, Co-Chair, convened the meeting and introductions were made.

Jake Edwards, Montgomery County Police Chief Autism Ambassador

Handout: www.montgomerycountymd.gov/HHS-Program/Resources/Files/A%26D%20Docs/DDAC/JakeEdwardsAutismSafety.pdf

Jake Edwards Presentation:

I am 14 years old and excited to be able to help you learn about Autism safety. Please be patient if I need to use my chew stick or do jumping jacks. My body can get into overdrive and bust out laughing. I was named a White House Champion of Change in 2015 and was just awarded a citation from Governor Hogan for my contributions to Maryland.

For me, having Autism means my brain works really, really fast and I can easily get distracted. Sometimes I can’t make the best choices because controlling my impulses and knowing the consequences of my actions is hard. Many people think that people with Autism don’t know what is happening around them. But that is not true. In fact, sometimes it is the opposite. My Autism allows me to feel what you are feeling and I have very strong senses and very deep emotions. I need everyone around me to be happy and I can feel it if they are not happy. That means if those around me are angry or tense I feel those emotions too and it can make me feel confused. Sometimes if my mom and dad are mad at me I can tell by looking at their body language or facial expressions.

When the Montgomery County Police came to my house recently I felt very scared. My legs were shaking and my heart was beating really fast. It was hard to talk to them because one face was happy and another was mad. My body wanted to hide, run to my bedroom, but mom and dad made me stay and help me keep calm and listen. The police were polite, but they were not happy to have to speed with their lights and sirens on only to find out I was acting silly. Sometimes my autism makes my body feel out of control. I want to jump around, bite my finger and scream. That can be scary. I can get out of control when I feel confused, hear a consequence, or don’t know what will happen next. I may even start laughing when I am scared or anxious. My emotions can be misplaced. I am working very hard on that at school and with my team of doctors.

Another challenge I struggle with are my super power Autism eyes. My brain works like a camera. If I see a scary face or someone mad at me my brain snaps that picture and I cannot take anything else. I shortly get stuck on that visual. If you ask me a question and I don’t react to it the way you expect me to you may think I am blatantly not following directions or am being disrespectful, but I am really just stuck on what I am seeing in my head and the fear of what is about to happen

next. Some friends are calmed by holding favorite objects that they have to carry in their pockets all the time. One of the things I struggle with is my chew stick in my pocket. When I feel nervous I have to reach into my pockets to find my chew stick. Police may get nervous when I put my hands into my pockets.

When I feel nervous or anxious I may struggle with some things. 1 - I can easily get hyper. 2 - Jump around and easily get distracted. 3 - Bite my finger. 4 - Injure myself. In the past I threw my school desk, a science table, classroom chairs, I even broke the school windows. I still sometimes when I don't get my way. I am overwhelmed with emotions. Controlling my body impulses makes me very tired. I need 12 hours of sleep. I go to bed at 6:00 pm. I get at 6:00 am. The other day I slept 15 hours. My body is changing quickly.

At my Kennedy Krieger school, they taught me to control my impulses by taking breaks, going on walks with the hall pass, using the light room or outside. I'm working very hard with that with Nicole, my OT therapist. I like how they're helping me. Chewing gum or on my chewing stick makes me feel calm. Sometimes it helps me focus. Wrapping up in a blanket helps me slow down, too. The blanket on my bed weighs 30 lbs to keep me calm. Every day at school my teachers brush my arms and hands with lotion to help me relax and focus on my studies. I used to do that, but may start doing that in high school. Some friends with Autism may repeat what you say or the last words they hear. That can be called Echolalia. And they cannot help it. Sometimes it gets worse when we are nervous or scared. Be careful not to cuss because we will repeat those dirty words, too.

If you come to help us when someone who is upset, you may not know what to do. The most important thing to do is let us calm down. If you talk when we're upset and we don't hear you, or if you try to touch us, that could make things worse. Please be patient to understand if we don't respond to your questions right away. Just sit with us until we are calm and then we will be ready to talk.

The police are here to help us and police are our friends. It is important for police officers to understand that people with Autism are amazing, gifted, and kind. Sometimes if someone doesn't look at you, it may be painful. People with Autism are smart and we all need to be respected. We can change the world some day. Thank you for listening to my speech.

The floor was opened to questions:

It was asked if Jake had ever been separated from his Mom, Dad or teachers? At summer camp he would always leave school. He would become worried, scared or nervous, and run away. That was at his old school and he does not do that at his current school.

Montgomery County Police Department Dementia/ID/Autism Outreach Program (formerly Project Lifesaver) – Officer Laurie Reyes, Special Operation Division Command, Montgomery County Police Department,

Website: www.montgomerycountymd.gov/pol/resource/lifesaver.html

Brochure: www.montgomerycountymd.gov/POL/Resources/Files/PDF/Lifesaver/AutismAlzheimerBrochure2016.pdf

Officer Laurie Reyes discussed how the Autism/Intellectual and Developmental Disabilities (IDD)/Alzheimer's Outreach Unit (formerly Project Lifesaver) began in 2005 in response to the tremendous amount of wanderings and elopements that occur in the Autism/IDD communities. On average, the Montgomery County Police Department (MCPD) investigates two to five wandering/elopement Autistic/IDD cases per week, although that number sometimes increases during the summer.

In 2004, Project Lifesaver gave tracking bracelets to chronic elopers. There was a very high demand from the residents for tracking bracelets, but they are only effective if all other measures are in place and if you have an educated community including police officers, caregivers, and individuals. MCPD quickly learned that tracking has to be the last step in prevention of wandering/eloping. Since then, the Autism/IDD Outreach Unit has created a layered approach to Autism/IDD awareness, through education, outreach, follow up, empowerment, and response. Officer Reyes runs the program, but officers in different districts assist her. A group of officers are highly trained to respond to calls where an individual with Autism or IDD has eloped. These officers understand the dynamics of keeping loved ones safe.

The annual Autism/IDD Night Out Event provides valuable safety information to loved ones while also providing an opportunity for officers to receive additional information from caregivers about these medical conditions. Typically, 40 to 50 officers participate and 400 people attend the event. The fifth annual event date has not been scheduled yet.

The Outreach Unit also works with Montgomery County Public Schools to talk to students that will soon be graduating and will be out in the community. It is a good opportunity for the students to interact with the police. They also teach local hospitals and next month will provide a training at Children's National Hospital.

The ICD-9-CM code for wandering, that went into effect October 1, 2011, is designed to promote better data collection for and understanding of wandering and to prompt important discussions about safety among healthcare providers, caregivers, and the person with a disability to the fullest extent possible.

They are working with the MVA and DOT to get more awareness through driver programs and to educate the likelihood of difficult interactions between drivers who have Autism and law enforcement. They offer a wandering safety kit that includes a brochure with safety information, their website, and Officer Reyes cell number and e-mail address. They are sometimes able to offer Autism safety tee-shirts, which are designed for those who cannot speak for themselves and are in immediate danger. Individuals who wear ID bracelets are encouraged to show them to officers in the community to build that bond.

There was a question if officers know to speak to the caregiver and if officers understand that caregivers can be different race than the companion like the shooting incident in Miami of a caretaker with an adult male with autism.

<http://time.com/4421072/autistic-man-caretaker-shot-florida/>

Officer Reyes said the dynamic is becoming more common and they show in training a picture of John Bucknam with his African American caregiver. If the caregiver is in control of the situation and is able to articulate to the officer, then the officer will respond and listen to that caregiver. If the caregiver is not in control, then the officer will step in.

It was asked if the Outreach Unit works with the City Police Departments. All City Police Officers go through their training academy and also receive training through continuous education from the Department's Crisis Intervention Team (CIT). Officer Reyes noted that if someone has had an unsatisfactory encounter with an officer in the general Montgomery County area, please contact her so she can reach out to that officer. They are often very receptive.

Parents are often afraid to call the police because they don't know what will happen. Officer Reyes encouraged parents and caregivers to create a 9-1-1 script such as saying that your son or daughter is having a meltdown, that you need us there for support, and that you are the child's advocate. Officers are taught to respond to the caregiver. A sample script is included in the Outreach Unit brochure.

It was asked if they follow-up with the provider, caregiver or parent. Officer Reyes explained that officers do follow-up and they are also taught to think about why the individual may be eloping or acting out and to identify. In potential abusive situations, the case will go the Special Victims Unit.

It was asked about transport for psychiatric evaluations if the provider or caregiver asks for the individual to be transported. Officer Reyes said that there has been an issue with officers not wanting to be a 'mentally unstable' label on a person who has Autism or IDD. In certain circumstances, case-by-case, officers have performed the emergency evaluation and the individual is transported no different than any other individual going for care. The MCPD has a great partnership with the hospitals. Again, if anyone has been in a situation that did not follow protocol, please contact Officer Reyes.

Officer Reyes encouraged Committee members and attendees to read the following article that referenced medicaid changes based on community inclusion. She has concerns about service providers choosing who to take on as a client, especially those that may not want to take on a client with wandering tendencies. Article:

<https://www.disabilitycoop.com/2017/01/10/wandering-poses-medicaid-waiver/23160/>

Future Status of the Developmental Disability Advisory Committee (DDAC) – Susan Hartung

DDAC was originally formed as a committee as a recommendation from Chuck Short, Special Assistant to County Executive Leggett, and the Developmental Disabilities Transition Advisory Workgroup, which included representatives

from MCPS, DORS, Behavioral Health, and Health and Human Services. The committee was tasked with addressing the issue of Montgomery County deciding to no longer providing resource coordination due to the funding formula and reimbursement by the State. The State then entered into having Total Care and MMARS do the resource coordination. At the request of the Commission on People with Disabilities the County then agreed to provide Resource Coordination to 500 residents. The DD Advisory group then became a subcommittee of the Commission. A discussion was held regarding whether the focus of the Committee is broader than Montgomery County and if so if the Committee should be separated from the Commission on People with Disabilities as an advocacy group. CPWD's role is to primarily advise the County Executive and the County Council. Due to new legislation that was passed by County Council and became effective August 11th, 2016, CPWD can now advocate at the State level with prior approval by the Office of Intergovernmental Relations. Judy Pattik, noted that while she is from the State, she primarily focuses on Montgomery County issues when attending these meetings. The Committee decided to continue meeting as a committee of the Commission in order to stay current with changes that occur as these programs are primarily State-funded. It is important to stay informed on issues and their impact on County citizens in order to be proactive rather than reactive.

Susan reminded Committee members and attendees that they may advocate as an individual but they cannot identify themselves as speaking for or on behalf of the Committee/Commission.

Update - Developmental Disabilities Administration (DDA) – Judy Pattik, Regional Director, Southern Maryland Regional Office (SMRO)

Since the last meeting, 1 TY16 has been placed. There are 26 TY16s that have still not been placed. Three have declined services and the rest are being worked on. Some individuals are on the waiver and do not have a provider, and others are not yet on the waiver.

Update – Autism Waiver (TY) – Montgomery County Public Schools (MCPS)

Daniel Hammond, Autism Waiver, reported that Governor Hogan's FY18 budget released in January includes an additional 100 slots for the Autism Waiver, with about 20 to 30 of those slots slated for Montgomery County. Daniel also reported that Medicaid has approved Applied Behavior Analysis (ABA) for children under 10. Children must be on Medicaid in order to receive it.

Update - Coordination of Community Services (CCS): Updates were tabled due to time constraints.

Chair and Vice-Chair Update: None.

New Business: None.

Announcements: Larry Bram announced that Easter Seals has free tickets to people with disabilities, low-income individuals, and their families to attend the first night of the Ringling Bros. and Barnum & Bailey Circus on Thursday, March 30th. Please contact Larry for a form.

Next Meeting: Monday, March 13th, 2017 from 4:00 p.m. to 5:30 p.m. The Committee will be meeting at the Rockville Memorial Library until May 2017. Address: 21 Maryland Avenue, 2nd Floor, Rockville, MD 20850.

Respectfully Submitted,

Carly Clem, Administrative Assistant
Betsy Luecking, Community Outreach Manager
Commission on People with Disabilities