

HB1176_TheArc. MDDC. MACS_Support JPR Committee.pd

Uploaded by: Ande Kolp

Position: FAV



Maryland Developmental
Disabilities Council

CREATING CHANGE • IMPROVING LIVES



Senate Judicial Proceedings Committee
HB 1176: Voluntary 9-1-1 Registry for Individuals Needing Special Assistance
March 30, 2023
Position: Support

The Arc Maryland, Maryland Developmental Disabilities Council (Council), and MACS are statewide organizations that work to protect and advance the rights and quality of life of people with disabilities. The Arc Maryland, MACS, and the Council were members of a workgroup that met several times over the summer to discuss ways to improve encounters between first responders and people with intellectual and developmental disabilities in Maryland. The group membership consisted of professional disability advocates, parents, people with disabilities, and first responders. The creation of a statewide voluntary 911 registry was one of the solutions the group explored in-depth.

This bill would establish a Voluntary 9–1–1 Registry Program to alert first responders of certain behaviors, diagnoses, or traits a person may present during encounters with first responders. Adults, parents or guardians of minor children, or legal guardians of adults (not including public guardians) can register for this program and provide information that helps first responders. This includes but is not limited to people with intellectual and developmental disabilities (IDD). **This registry is completely voluntary, and the information provided for the registry is safeguarded within the Computer Aided Dispatch (CAD) system.** Howard County currently has a Voluntary 9-1-1 registry program that has operated successfully for several years. The positive outcomes of this program cannot be understated. People who have wandered from their homes have been quickly located and identified. People who do not use words, or whose movements due to their disability may have otherwise been misunderstood, have been supported with compassion according to local parent reports.

One individual with IDD and diabetes, told us of how he put his health information into the Howard County registry. When first responders recently responded to a call for assistance, they saw his self-provided information in the CAD system. Upon arrival, the individual was unconscious from a diabetic emergency, and first responders were able to use the information they had to quickly determine what might be happening to him. It was a comfort to him and his family that he had the opportunity to provide first responders information about himself before the emergency occurred.

Important components of the 911 Registry Program:

- It is voluntary. People can choose to use it or choose not to use it.
- Only adults, including people with IDD, their parents (if they are minor children), or their legal guardians (not including public guardians) can enter information about the person into the voluntary registry.
- A person, their parents (if the person is a minor), or their legal guardians can REMOVE the person from the voluntary registry at any time.
- The bill includes a requirement for data collection so use of the program can be measured.
- A person's name and information gets removed from the registry if someone does not reregister annually. This is important so the registry information stays current.

- The registry does not replace the need for continued police training on interactions with people who have disabilities. The intent is only to be another tool for people with disabilities and others who need assistance, and first responders.

For more information, please contact:

Ande Kolp, Executive Director, The Arc Maryland akolp@thearcmd.org

Rachel London, Executive Director, Maryland Developmental Disabilities Council, rachel@md-council.org

Laura Howell, Executive Director, Maryland Association of Community Services, lhowell@macsonline.org

Hussman Foundation Testimony_HB1176_Benevides Lett

Uploaded by: Elizabeth Benevides

Position: FAV



Elizabeth Benevides
Associate Director, Hussman Foundation
Hussman Institute for Autism

House Bill No. 1176
Public Safety – Voluntary 9-1-1 Registry
March 29, 2023

Position: SUPPORT

More than 10 years ago, I requested the support of the Howard County Police Department (HCPD) in developing a Voluntary 9-1-1 Registry for residents with disabilities. HCPD responded to that request and since then, several hundred Howard County individuals have enrolled in the registry.

My son is autistic, limited in speaking, slow in processing, prone to anxiety, and at times may use negative behavior to communicate. In an emergency, he has no way to tell a first responder any of this. He also has no way to tell a first responder that he is unaware of danger, or that he does not understand why he must stay outside of a burning house or why he should not climb out his window. He has no way to describe the pain he feels when he is having a migraine; or why he is incredibly frightened by sirens or that flashing lights may cause a seizure.

The Voluntary 9-1-1 Registry for people with disabilities provides me with the peace of mind that a first responder will know all of this before arriving at my home, or at an emergency scene involving my son.

The registry is not only connected to a name, but to an address. It leads to an “address flag” so that not only is my son’s name pulled up, but should there be an emergency in the area, first responders will know my son is nearby. If my neighbor’s home is on fire, first responders will know that next door, there is a person who may need their protection as well. Similarly, if a tornado or storm blows through and takes down trees, it is important to know that there is a person with oxygen in a particular home or a person who relies on electricity to breathe. If there is a car accident, it is important to know that a child in the car has seizures and that may be more important to watch for, then exchanging insurance information.

For any one of us, the more we know, the better prepared we are to help. For people with disabilities, a first responder “in the know” can make all the difference.

The Voluntary 9-1-1 Registry does not benefit just one particular group of people. It is there for people with autism, such as my son, and also for people who are affected by dementia, a mental health issue, a physical disability, or any other condition that may heighten an emergency situation.

It is there for a blind person who wants a firefighter to know that they may require additional assistance to exit a building, or that they cannot be separated from their service animal. It is there for people with dementia who may go wandering and who may not be able to remember how to get back home. It is there for a child who runs to a nearby pond each time they elope from a guardian's home.

The registry saves first responders critical time. They know where to go, they know where to look first.

We know of situations in which first responders are aware of a person's favorite topic. In an emergency situation, talking about the Ravens, Jeopardy, Clifford the Big Red Dog, or the weather – whatever matters most to that individual person -- can de-escalate a situation, bring calm when everything else is in disarray.

We also know of situations in which first responders are told to speak slowly, allow more time for processing, to be aware of an OCD or particular behavior. Training is critical, but personal information that may not be able to be relayed in the middle of an emergency is crucial.

The registry allows us to put individual, person-specific information in the 911 system so it is there the minute a name or an address is given.

When my son experienced a migraine and the caregiver could not get through to me, she called 911. She did not understand why my son was kicking so hard he put his foot through the wall, why he was screaming in despair, or throwing things all to be "heard." When the dispatcher typed in his name and our address, *my voice* could be heard through my written words: "experiences migraines, needs Motrin; give him space, approach calmly, turn off sirens, no flashing lights. No demands. Usually lasts no more than 20 minutes."

When my friend's son had an emotional crisis at the community center swimming pool and the lifeguard called 911 for help, the officers knew in advance that this child's favorite topic was his family's boat. If they could redirect his attention, they could buy some time to calm him down, and guide him to a safe space to fully deescalate.

When a child wandered away from home and was found walking along a city street, she could be quickly identified by her picture in the 911 registry.

This bill protects people with disabilities. It is voluntary. A person's name and information cannot be entered without the person's permission or, for minors or adults with guardianship, without the parent or guardian's permission. We—as individuals and parents--decide what goes in the registry—how much or how little, and for how long. We can update or withdraw information at any time.

We know this program has worked in Howard County and has the potential to save lives. We know it has given families in Howard County peace of mind that first responders are more informed about their loved one. All individuals and families in every county and district in Maryland should be given this same peace of mind.

We know police officers and first responders benefit from this advance information. They feel better equipped to help. The costs are minimal. The data system is already in place in every

police jurisdiction. It is a matter of choosing a point person in the emergency dispatch system to enter the information, update the information, and send a notice to registrants once a year.

Many other states have these programs. Very few counties in Maryland have them. **Maryland is a leader in first responder training on intellectual and developmental disabilities. Adding this registry will enhance its effectiveness and responsiveness to people with disabilities.**

Respectfully submitted,

A handwritten signature in cursive script that reads "Elizabeth Benevides".

Elizabeth Benevides

HB1176 Testimony 3.29.23.pdf

Uploaded by: Jane Plapinger

Position: FAV

HB 1176: Public Safety- Voluntary 911 Registry
Senate Judicial Proceedings Committee
March 30, 2023

Position: FAVORABLE

As the mother of a 20-year-old son with autism, I feel compelled to share my story to help committee members understand the value of this bill to families like mine. When my son was younger, I could never imagine this sweet child having the types of serious behavioral challenges that I had heard can occur with autism. Yet as he moved into puberty, my son started having behaviors which became more serious over time. I did everything I could to address these behaviors. I brought in behavioral specialists to our home, I made sure he received behavioral supports at school, and I sought help at Kennedy Krieger's Neurobehavioral Clinic. Yet we nonetheless experienced frightening episodes at home where he became dysregulated and physically aggressive. He was 6 feet tall and I am 5 foot 3 inches. I had safety equipment that I was trained to use; however, that was not adequate to keep me safe, nor to keep him safe since sometimes he would engage in self-injurious behavior such as throwing his body against a second-floor window or throwing his head into the wall.

I was terrified for both of us during these episodes. Yet I was reluctant to call the police because of my fear that they might harm my son when they showed up and saw him out of control. After many dangerous episodes where I struggled on my own, feeling desperate, I called 911. The fact that Howard County – my county – had a 911 registry in which our family was listed made it easier for me to finally make that call. It gave me hope that the officers responding to my 911 call would have read the notes I had submitted with our family's registration. Before entering our home, they would know that they needed to be a calm and supportive presence, and that my son would not pose any danger to them. And as I hoped, they showed up prepared to follow my guidance, having read our info in the registry, and helped my son calm down.

We have all heard the horrific stories of people with mental health or developmental disabilities being harmed after a 911 call by well-intentioned responding officers. Families like mine relate to these incidents with fear that our family member could be harmed if we reach out to 911. We weigh this fear against the fear of injury to our disabled family member or other family members if we don't call 911 for help. This bill will hopefully better equip responders to safely respond to such emergencies, and thereby lower the barrier for families like mine to reach out when they desperately need help.

I see no downside to this bill, as it is voluntary.

Please note, this bill does not replace the need for continued police training on how to interact with disabled individuals. Nor does it address the larger issue of the lack of crisis programs for families like mine who have an individual with an intellectual

disability and behavioral challenges. Mental health crisis programs are not trained to support a family whose member is nonverbal or has limited speech. So currently 911 is the only option for families like mine. HB1176 will make that option a safer one for all involved.

Thank you for reading my story, and considering my perspective on this bill.

If you would like more information, please feel free to contact me.

Jane Plapinger
8612 Lawrence Mill Court
Ellicott City, MD 21043
jdplapinger@gmail.com
410-868-4057

FINAL HB1176.pdf

Uploaded by: Katherine Lopez

Position: FAV

Date: March 29, 2023

To: Delegates Atterbeary and Wilson, Wilson, Alston, Bagnall, Bhandari, Cullison, Guzzone, Hill, S. Johnson, Kaiser, Kerr, R. Lewis, Lopez, Martinez, Pena–Melnyk, Rosenberg, Taveras, White, and Woods

From: Katherine Lopez, Bilingual Program Administrator, The Arc Prince George’s County

Subject: SUPPORT HB 1176

Dear Committee,

I am writing to express my strong support for HB1176, the Public Safety – Voluntary 9-1-1 Registry for Individuals Needing Special Assistance Act. I believe that this legislation is a critical step towards ensuring the safety and well-being of individuals with disabilities during encounters with first responders.

If this bill were to move forward, individuals with special needs, their parents or guardians, would have the opportunity to register with local jurisdictions or 9-1-1 call centers in order to alert first responders of certain behaviors, diagnoses, or traits that the individual may present during an emergency. This information can be critical in ensuring that first responders can appropriately and safely respond to individuals with disabilities, including those who are deaf or hard of hearing, wheelchair users, or have intellectual or developmental disabilities.

As a disability service professional, I have heard stories of the challenges that people with disabilities and their families face when handling emergencies and interacting with first responders. Some individuals with disabilities qualify for services like DDA, which ensures that they have a designated aid that supports them during the day, while their familial caregivers may be at work. However, many people with a disability do not qualify for DDA. This can be an issue, as the individual with a disability may not be able to recognize and respond appropriately to an emergency, or may not be able to communicate with a first responder. This bill would mitigate the risks faced by people with disabilities during emergencies. First responders would be given the information they need to make sure they know how to effectively communicate and interact with an individual with disabilities.

Additionally, in high-stress situations, for example, individuals with autism may exhibit behaviors that could be misunderstood by first responders. Any bright lights and loud sounds coming from first responder vehicles and equipment could elicit a response from the individual with the disability. The individual could behave in other unexpected ways. If this behavior is unexpected by first responders, it could lead to dangerous or even tragic outcomes. This bill would help mitigate those risks by ensuring that first responders have access to important

information about these individuals. The risk is mitigated when a first responder is able to arrive at their house, recognize the behavior, and respond appropriately.

In summary, I believe that HB1176 is an important step forward in protecting the safety and well-being of people with disabilities in our communities in the state of Maryland. I urge you to support this bill and help ensure that it becomes law.

Thank you for your attention to this important matter.

FAVORABLE_TestimonyHB1176_ Public Safety _Voluntar

Uploaded by: Kim Tart

Position: FAV

HB1176 - Public Safety - Voluntary 9-1-1 Registry

Dear Members of the Health and Government Operations Committee:

My name is Kim Tart. I have resided in Prince Georges County for over 50 years. My husband and I are proud parents of Monty who is diagnosed with Down Syndrome.

Thank you for this opportunity to testify in support of HB1176. This bill provides our first responders with important information to protect and serve all of our neighbors.

We are Monty's "voice" and his connection to the community.... his connection to society. Our son has 3 strikes against him – he is male, his is black and his has a disability.

If I am able to connect with my county's 9-1-1 call center, I can share pertinent information about Monty's disability that can keep him safe.

Dialing 9-1-1 is the most familiar and effective way Americans have of finding help in an emergency. The Americans with Disabilities Act (ADA) requires all Public Safety Answering Points (PSAPs) to provide direct, equal access to their services for people with disabilities who use teletypewriters (TTYs), which are also known as "telecommunications devices for the deaf (TDDs)." Why not enhance 9-1-1 service to alert first responders of certain diagnoses or certain behaviors or traits that individuals may present during encounters with first responders?

This bill will benefit many more groups of people, but I see how critical it is for this bill to be enacted, because of the behavioral and mental health challenges some of the individuals with disabilities have. Interacting with strangers – especially those who may have limited experience or sensitivity with our population – can be disastrous.

This bill is a commonsense approach to ensure all of our residents receive the best support possible – even in dynamic times and periods of crisis. Sometimes split decisions and even life-changing decisions have to happen with first responders and it is clear that having key information about behaviors, abilities, disabilities, anxieties and special needs is a serious matter that needs our action.

With HB1176, the phrase "knowledge is power" is extremely true. I love that the bill gives people and guardians the ability to decide each year what information would be helpful for first responders to know before approaching someone's home.

I ask that you move HB1176 with a favorable report to make sure our first responders are equipped to serve and support all Maryland residents. Thank you for your support.

Kim J. Tart

Kim Tart
Proud Mom of Montgomery "Monty" Tart

SB1176.DD Council.Support - JPR.pdf

Uploaded by: Rachel London

Position: FAV



Maryland Developmental Disabilities Council

CREATING CHANGE • IMPROVING LIVES

Senate Judicial Proceedings Committee

March 30, 2023

HB 1176: Public Safety – Voluntary 9-1-1 Registry

Position: Support

The Maryland Developmental Disabilities Council (Council) is an independent, public policy organization that creates changes to make it possible for people with developmental disabilities to live the lives they want with the support they need. The Council was a member of a workgroup that met several times over the summer to discuss ways to improve encounters between first responders and people with intellectual and developmental disabilities. The group consisted of professional disability advocates, parents, people with disabilities, and first responders. The creation of a statewide voluntary 911 registry was one of the solutions the group explored in-depth because **it provides people who need assistance, including people with disabilities, AND first responders another tool to use.** It does not solve every problem, but it is a start.

WHAT does this legislation do? After further discussions with fellow advocates, the Maryland Association of Counties, and others, the Sponsor submitted amendments. As amended, HB 1176:

- Establishes a Voluntary 9–1–1 Registry Program to alert first responders of certain behaviors, diagnoses, or traits a person may present during encounters with first responders.
- Adults, parents or guardians of minor children, or guardians of adults can register for this program and provide information that helps first responders. This includes people with intellectual and developmental disabilities (IDD). **It is voluntary. People can choose to use it or choose not to use it.**
- Requires each person to register annually, and requires a person is removed if they do not update or validate the information.
- Clarifies that “noncompliance with information in the registry is not admission in any suit.”

WHY is this legislation important?

- **It creates consistency across counties.** Howard County currently has a Voluntary 9-1-1 registry program that has operated successfully for several years. The positive outcomes of this program cannot be understated. People who have wandered from their homes have been quickly located and identified. People who do not use words, or whose movements due to their disability may have otherwise seemed inappropriate, have been supported with compassion according to local parent reports.
- **It is low cost.** The fiscal note references a similar bill last year, and counties reported, “Such a system could be implemented with little or no additional cost.” In fact, the Howard County program started and continued with existing staff and resources.
- **It is an important tool for Marylanders who need assistance and first responders.** The Voluntary 9-1-1 Registry is designed to supplement existing resources. It does not replace the need for continued training for police and first responders. In fact, training about people with IDD is already required for police.

All Marylanders deserve options to increase their ability to live the lives they want with the support they need. This Voluntary 9-1-1 Registry is another strategy to make that a reality by giving people who need extra support and assistance and first responders a way to share that information and plan.

Contact: Rachel London, Executive Director, RLondon@md-council.org

217 E. Redwood Street, Suite 1300 • Baltimore, MD 21202 • 410.767.3670 • md-council.org

Dee Sapp, *Chairperson* • Rachel London, Esq., *Executive Director*

HB1176 - Voluntary 911 Registry - Malone Testimony

Uploaded by: Robert Malone

Position: FAV



Date: March 30, 2023

To: Senator William C. Smith Jr., Chair, Judicial Proceedings Committee
Senator Jeff Waldstreicher, Vice Chair

From: Rob Malone, Chief Executive Officer, The Arc Prince George's County

Re: Testimony In Favor of HB 1176

Dear Chair,

I am Rob Malone, Chief Executive Officer for The Arc Prince George's County. Thank you for this opportunity to testify in support of HB1176. This bill provides our first responders with important information to protect and serve all of our neighbors.

The Arc supports people with developmental disabilities and their families from birth throughout life. We are a go-to organization for resources and support. I know this bill will benefit many more groups of people, but I see how critical it is for this bill to be enacted, because of the behavioral and mental health challenges some of the people we support have. Interacting with strangers – especially those who may have limited experience or sensitivity with our population – can be disastrous.

This bill is a commonsense approach to ensure all of our residents receive the best support possible – even in dynamic times and periods of crisis. Sometimes split decisions and even life-changing decisions have to happen with first responders and it is clear that having key information about behaviors, abilities, disabilities, anxieties and special needs is a serious matter that needs our action.

With HB1176, the phrase “information is power” is extremely true. I love that the bill gives people and guardians the ability to decide each year what information would be helpful for first responders to know before approaching someone's home.

I ask that you move HB1176 with a favorable report to make sure our first responders are equipped to serve and support all Maryland residents. Thank you for your support.

DRM_HB 1176_FWA.pdf

Uploaded by: Samuela Ansah

Position: FWA

JUDICIAL PROCEEDINGS COMMITTEE**MARCH 29, 2023****HB 1176-Public Safety-Voluntary 9-1-1 Registry****POSITION: SUPPORT WITH AMENDMENTS**

Disability Rights Maryland (DRM) is Maryland's designated Protection & Advocacy organization, mandated to advance the civil rights of people with disabilities. DRM works to champion the rights of individuals with disabilities and eliminate the incarceration, institutionalization, and serious injury or death of people with disabilities due to the unnecessary involvement of law enforcement when responding to individuals with disabilities. We appreciate the opportunity to share our views on HB 1176, which would mandate that local jurisdictions and police departments create 9-1-1 registries for persons with disabilities. We understand this is modeled on a successful program in Howard County.

We do not believe that the creation of a 9-1-1 registry would be appropriate in every jurisdiction in Maryland, and recommend that HB 1176 authorize, but not require, the creation of such a registry in each jurisdiction. If local communities desire such a registry, the ability to create a registry would be there. It appears a similar program has been successful in Howard County because of the close collaboration between families, providers, and law enforcement and other responders, resulting in commitment to the registry's success. In other jurisdictions in Maryland, such an environment may not exist. For the past several years, DRM has advocated for changes to law enforcement and dispatch policies that would reduce police interactions with people with disabilities in Baltimore City. The creation of such a registry would be negatively viewed by some in the community. Further, the City of Baltimore is making significant efforts to DIVERT callers with non-life-threatening emergencies from law enforcement to other appropriate responders such as 9-8-8. Mandating the creation of a 9-1-1 registry by local law enforcement without robust community involvement contravenes the principles of community-oriented policing.

9-1-1 registries should never be a replacement for a strong relationship between a community and the police department and effective training. Investing time and resources into building strong community relations and partnerships will go further toward positive interactions between communities and law enforcement than 9-1-1 registries. In fact, there is no research or evidence to support that 9-1-1 registries improve interactions between law enforcement and people with disabilities. There may be the opposite effect, where 9-1-1 registries continue to perpetuate negative consequences for people with disabilities when interacting with law enforcement, especially when it is not paired with effective training for officers.¹

¹ The ARC, National Center on Criminal Justice and Disability, Policy Brief: Law Enforcement Registries for Individuals with Disabilities (2019), available at http://thearc.org/wp-content/uploads/2019/07/18-086-Law-Enforcement-Registries-Resource-Sheet_v3.pdf (last accessed March 29, 2023).

In Maryland, of the 109 people who died during police interactions from 2004 – 2014, 38 percent (41 people) were likely individuals with mental health conditions.² Similarly, in Baltimore, where the relationship between the police department and community members has been particularly fraught, the U.S. Department of Justice’s investigation into the Baltimore Police Department (BPD) revealed that officers often resorted too quickly to using force against individuals with mental health disabilities, particularly involving the use of tasers against non-violent individuals.³

DRM supports and advocates for the reduction of law enforcement as first responders to people in crisis. Such law enforcement response should be replaced with crisis response services and community supports. The result will be safer outcomes for people with disabilities. It is preferable that resources be invested in community supports for individuals with disabilities experiencing behavioral health crises. Rather than creating a mandate for jurisdictions to comply with, we encourage that the legislation simply *authorize* the creation of a registry. To that end, we propose the following amendments to accomplish that goal:

At pg. 2, line 2: ~~THERE IS A LOCAL JURISDICTIONS OR LOCAL 9-1-1 CALL CENTERS ARE AUTHORIZED TO ESTABLISH A 9-1-1 REGISTRY PROGRAM~~

At pg. 3, line 5: EACH LOCAL JURISDICTION OR LOCAL 9–1–1 CALL CENTER MAY

Pg. 4, line 28 (ADD): EACH LOCAL JURISDICTION OR LOCAL 9-1-1 CALL CENTER THAT HAS ELECTED TO CREATE A REGISTRY ...

The language on the disclaimer for the 9-1-1 registry should be transparent, clear and understandable for those who are placed on the registry to understand. Autonomy is an important principle for people with disabilities and with the undertone of a 9-1-1 registry, it is imperative that people understand the implications and rights of being placed on such a registry. To that extent, we recommend the following language be amended into the bill to appear on the disclaimer:

Page 2, Line 4-5, (C) THE PURPOSE OF THE PROGRAM IS TO AUTHORIZE INDIVIDUAL ADULTS, PARENTS OR GUARDIANS OF MINOR CHILDREN, OR GUARDIANS OF INDIVIDUALS WITH SPECIAL NEEDS TO REGISTER WITH A LOCAL JURISDICTION OR LOCAL 9-1-1 CALL CENTER THAT HAS CREATED 9-1-1 REGISTRY IN ORDER TO ALERT FIRST RESPONDERS ENCOUNTERING A REGISTERED INDIVIDUAL THAT THE INDIVIDUAL:

Page 4, Line 32, New Line (G)(2): EACH LOCAL JURISDICTION OR LOCAL 9-1-1 CALL CENTER THAT HAS CREATED 9-1-1 REGISTRY SHALL CONTACT THE INDIVIDUAL SUBJECT TO THE REGISTRY ONCE THEY HAVE REACHED 18 YEARS OF AGE TO NOTIFY THE INDIVIDUAL THAT THEY ARE ON THE REGISTRY AND INFORM THEM THAT THEIR INFORMATION MAY BE REMOVED UPON REQUEST.

² Joe Spielberger, *Chasing Justice: Addressing Police Violence and Corruption in Maryland*, American Civil Liberties Union of Maryland (January 2021), <https://www.aclu-md.org/en/press-releases/aclu-report-chasing-justice-exposes-racist-facts-about-police-violence-lack>

³ U.S. Department of Justice Civil Rights Division, *Investigation of the Baltimore City Police Dep’t 81-82* (2016).



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www.DisabilityRightsMD.org

(G)(3) AN INDIVIDUAL AGED 18 YEARS AND OLDER WHO IS UNDER GUARDIANSHIP AND IS PLACED ON THE REGISTRY SHALL RECEIVE NOTICE OF THE FACT THAT THEY HAVE BEEN PLACED ON THE REGISTRY, ALONG WITH A COPY OF THE INFORMATION PROVIDED TO 9-1-1 BY THE REGISTRANT.

(G)(4) AN INDIVIDUAL AGED 18 YEARS AND OLDER WHO IS UNDER GUARDIANSHIP MAY REMOVE THEMSELVES FROM THE REGISTRY UPON REQUEST.

(G)(5) IN THE NOTICES DESCRIBED IN (G)(2) AND (G)(3), EACH LOCAL JURISDICTION OR LOCAL 9-1-1 CALL CENTER SHALL PROVIDE THE PHONE NUMBER TO CALL OR EMAIL ADDRESS TO USE TO REQUEST REMOVAL FROM THE REGISTRY.

Thank you for your attention to this matter and we look forward to working with you. Please contact DavidP@DisabilityRightsMD.Org with any questions.

Testimony - Community Member.pdf

Uploaded by: Eryn Ainsley

Position: UNF

Hello. My name is Eryn Ainsley. I am a black person living with a mental health disability and I actually do not really support the proposed bill. I have been subject to nonconsensual actions by 911 responders and those whose unjustly called 911 on me based on false information. Just one example: Before 911 responders arrived, the person who called 911 on me did apologize to me for calling 911 but the 911 responders took nonconsensual actions against me. The person who called 911 on me was white and dialed after I said they were being racially insensitive. At any rate, I was silent for the entire duration of my confinement. I was let out the next day. And I stopped trusting community and 911/988 responders have my best interests in mind.

So yes. Typically, I don't trust 911 responders anymore for following false information and not the person in question without getting the facts. I don't even dial 911 or 988 for my mental health crisis anymore. The trust has been too far and too often broken. I just bare it all by myself and wait for therapy.

Furthermore, this is just another bill that I dread because of typically unreasonable and nonconsensual interventions by 911/988 callers and responders. Everyone is not a therapist, psych doctor or social worker who is privy to personal details of *every* person (from a mental health perspective).

Eryn Ainsley

HB1176_Voluntary911_KennedyKrieger_LOI_SENATE.pdf

Uploaded by: Emily Arneson

Position: INFO



Maryland Center for Developmental Disabilities
at Kennedy Krieger Institute
Building Partnerships. Changing Lives.

March 30, 2023

The Honorable Will Smith
Chairman, Senate Judicial Proceedings Committee
2 East Miller Senate Office Building
Annapolis, MD 21401

Re: Letter of Information on HB1176 - Voluntary 9-1-1 Registry

Dear Chairman Smith,

The Maryland Center for Developmental Disabilities (MCDD) at Kennedy Krieger Institute appreciates the introduction of the Voluntary 9-1-1 registry. This legislation will support individuals with disabilities in their encounters with law enforcement.

As you are aware, the MCDD is proud to be Maryland's University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) and a member of the national Association of University Centers on Disabilities (AUCD). MCDD links the community to vital services, research, and information to improve the lives of people with disabilities. Our mission is to provide leadership that advances the inclusion of people with intellectual, developmental, and other disabilities through preservice preparation and training; research and evaluation; community service and technical assistance; and information dissemination. This includes ensuring that individuals are living safely within their communities.

This legislation has tremendous potential in assisting law enforcement and emergency personnel to assist individuals with disabilities in emergency situations. We also appreciate that the registry is voluntary and has an annual communication commitment to reach out to participants to see if they are interested in remaining on the list.

We encourage the committee to meet with stakeholders in the disability community to discuss potential next steps of the legislation, including future training for police and first responders on de-escalation techniques, protecting the data, monitoring and data analysis of the list, advertisement of the program, and more.

We deeply appreciate the efforts of the Committee to create a voluntary 9-1-1 registry for individuals with disabilities.

Respectfully,

A handwritten signature in black ink that reads "Maureen van Stone".

Maureen van Stone, Esq., M.S.
Director of the Maryland Center for Developmental Disabilities

For more information, visit mcdk.kennedykrieger.org

911 registry testimony.docx finalWednesday, March

Uploaded by: Mat Rice

Position: INFO

Letter of Information

HB1176 – Voluntary 9-1-1 Registry for Individuals Needing Special Assistance

People on the Go of Maryland, Maryland's statewide self-advocacy organization ran for and by those with intellectual and/or developmental disabilities submits this letter of information to the Senate judicial proceedings committee for the consideration of HB1176 - Voluntary 9-1-1 Registry for Individuals Needing Special Assistance.

POG wants to start off by outlining the benefits of this legislation, which include:

- The 9-1-1 registry is voluntary.
- The information is not shared with outside entities only first responders.
- The information contained on an individual is deleted after two years if the individual, or family member fails to respond to attempts to renew their registration.
- Police would not have access to the registry during a traffic stop.

Although, there are pros to HB1176 here are the potential drawbacks of this legislation should it become law.

- No additional training is required in de-escalation for police and other first responders as part of this legislation. Individuals will be asked to disclose personal information about themselves, or their family members without demanding additional training. The mandatory in-service training is not currently adequate.
- More training is necessary to address issues of hidden bias and people with disabilities need to have a role in not only leading that training, but designing its curriculum.
- One concern with this legislation that POG foresees, but is not certain how to address. What happens if a person has a hidden disability, and they are in the situation, for example, like a traffic accident? Even though the police officer does not have access to the registry at that time, he or she could go back and access the registry in their jurisdiction, and if they find the individual involved is on the registry it could change their determination of who was or was not at fault for the accident.
- This legislation also makes no mention of how the individual's data will be protected. This is especially important if you are asking individuals to place not only their personal information like name, address, and characteristics but photographs potentially as well. We live in a time where hacking is rampant and entities like the Maryland Department of Health have been hacked before.

- At the suggestion of a POG self-advocate, POG recommends that language be added to enable an individual parent or guardian to remove themselves or their child from the registry at any time.
- How will the registry be monitored for overall effectiveness in increasing awareness about individuals with disabilities and their specific support needs? Currently, as far as POG is aware in the jurisdictions where these registries exist there is no mechanism for monitoring of their effectiveness. It POG's recommendation that entities like the Maryland Developmental Disabilities Council (DD Council), The Arc of Maryland, and whomever else The General Assembly may see fit to include be charged with the development of the survey. This survey could be conducted on an annual basis about the effectiveness of these registries in their applicable jurisdictions.
- POG recommends in lines 20 and 21 the phrase under penalty of perjury should be added when discussing the fact that an individual certifies they are the parent of a minor child or guardian of somebody with special needs. We see this as a necessary step towards protecting the rights of an individual with a disability otherwise a parent who does not in fact have guardianship may put an adult on a registry without the authority to do so.
- POG recommends that for anyone entering into residential services with a Developmental Disabilities Administration, or other applicable service provider disclose the fact that the 9-1-1 registry is voluntary and has to be discussed as part of their service agreement. This ensures that individuals and families are at the very least made aware that this is not something they have to participate in.
- The way this legislation is currently written it seems to be biased towards individuals with disabilities having a legal guardian. This may not always be the case, in the cases where this does not apply the individual with a disability should be required to legally attest in whatever way they are able. That they are making the choice to voluntarily place themselves on a 9-1-1 registry and that they understand the terms and conditions.
- This legislation does not take into account alternatives to guardianship. For example, a parent or guardian should utilize the principles of Supported Decision Making when discussing the registry with an individual. However, POG is not sure how to mandate this.

- Page 4, Line 32, New Line (G)(2) each local jurisdiction or local 9-1-1 call center shall contact the individual subject to the registry once they have reached 18 years of age to notify the individual that they are on the registry and may be removed upon request.
- (G)(3) An individual aged 18 years and older who is under guardianship and is placed on the registry shall receive notice of this fact, along with a copy of the information provided to 9-1-1 by the registrant.
- (G)(4) An individual aged 18 years and older who is under guardianship may remove themselves from the registry upon request.

In closing POG recognizes the steps that advocates have taken to make this legislation meet the needs that families have expressed while protecting the rights of the individual. However, we strongly advise that this language be added if not to this bill, then before any future expansion of this legislation is considered. Moreover, even though it is explicitly stated in this legislation as it currently exists POG wishes to make the point that one of the concerns that we hold is that by having legislation of this type in the state a future general assembly, or other entity may decide that something like this should be mandatory for individuals with disabilities. This should always be a choice and carefully monitored and it is with that understanding that POG feels that this legislation in its current form is the best for the goals outlined within. Thank you for your time and attention to this matter. Should you have any questions please contact Mat Rice.

Additions to the Letter of Information

People On the Go (POG) wishes to acknowledge the attempts by the House Health and Government Operations Committee to make House Bill 1176 (HB1176) better. Our members appreciate the removal of the term special needs throughout the legislation as many of our members consider such language, antiquated and offensive. We also appreciate the need for a mandatory report looking at the impact of registries of this type these programs should HB1176 become law. However, where we are concerned is that the reporting requirement is delayed until 2028, which means that 9-1-1 registries would be active for almost five years with no real monitoring. Additionally, we acknowledge the importance of the house decision to adapt language which would

prevent a public guardian of an individual that is appointed by the court from placing the person on the registry in their jurisdiction. However, language still needs to be added to the attestation requirement which requires an individual which would require someone not under guardianship to sign for themselves either by signature, name stamps, or other accommodation which says that they are the one choosing to be on a registry.

Returning to the topic of the individual under are required guardianship the house has not excepted POG's suggestions that language be adopted states under the penalty of perjury an individual must certify that they are the legal guardian of the individual with a disability. This is necessary because POG is aware that parents of people with disabilities who may not be under guardianship often say they are the guardian of the individual in question. This has also come up in discussion when discussing this bill with provider advocates.. Therefore, we would also suggest that some sort of proof of guardianship in the form of documentation be required.

Some advocates will say that the HIPAA law which protects an individual private health information is adequate. POG is not certain that this law could even be applied to HB1176, as the laws original intent was to protect the individual's healthcare information for themselves with their healthcare providers. Even if that is the case many individuals with disabilities are not aware of this law nor would they be aware that a parent or other supporter has put them on a registry without consulting unless these provisions we have requested are required. Even this may not prevent some individuals from having their rights violated if this legislation becomes law. Furthermore, we are providing a hyperlink <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7883355/>, this is to an article which outlines issues with HIPAA and we also recommend the Senate Adapt Language which would give jurisdictions the choice as to whether or not to enact programs of this type. This is because the relationship between police and the community will not look the same in each county within Maryland and in some cases has been more antagonistic. We would recommend that this be left up to the jurisdiction to decide and at minimum HB1176 could provide the standards that a jurisdiction is required to follow should they decide to undertake one of these programs.

We are attaching to our testimony a white paper developed by The Arc of the United States. We are not stating what their position is, that is up to the interpretation of the reader. However, this publicly available document makes some highly effective points that legislatures should consider before enacting laws of this type. In our initial letter of information POG agreed that the house adopt this language, and that we support the version as amended. However, at this time we strongly recommend that the Senate undertake the changes we have suggested. Regardless people on the go will work with the advocates should this bill become law..

POG had the opportunity to attend Kennedy Krieger Institutes Neurodiversity in the

Workplace Conference in Washington, D.C. Haben Girma, Human Rights Lawyer and Author was one of the keynote speakers at the conference and POG was able to ask her opinion of registries like this. Haben brought up the point that since she's not from Maryland, but if she wanted to visit and she needed to interact with first responders her fear was that she would be treated differently because she would not be able to access the registry since she is from out-of-state. This scenario brings up the point that if an individual chooses not to be on a registry they may be treated differently by first responders or even disrespected. Also, Haben is deaf and blind, and she has become a lawyer who graduated from Harvard Law, POG feels this is an important point to make because many of the advocates will say they need this bill to become law because some people can't communicate, but you have someone like Haben Girma who can communicate, it's all about the expectations set forth for people, we also must remember that when we enact laws that is not only for the present time, but for the future laws may not be perfect but must ensure we do all that we can to make sure that people get equal treatment.

Sincerely,

Mat Rice

Executive Director

People On the Go of Maryland mat@pogmd.org

Art US white paper on 911 registries Wednesday, Mar

Uploaded by: Mat Rice

Position: INFO

OVERVIEW:

Around the country, policing agencies are working to improve relationships with the disability community, whose members are more likely to be misunderstood, injured, or even killed during law enforcement interactions. One solution being proposed by law enforcement, disability advocates, and others that continues to grow in popularity is the creation of registries.



Registries are databases that contain personal information about individuals with disabilities, such as diagnoses or communication preferences. In some jurisdictions, this information is provided to law enforcement when they receive service calls or review identification cards with flagged addresses, such as those where individuals with disabilities live. Registries can be called a variety of names and can be created in a variety of ways, including by state legislation, by for-profit companies, or by policing agencies themselves.

The intended purpose of registries is to help law enforcement officers respond more effectively to situations involving individuals with disabilities.

DESPITE THEIR GROWING POPULARITY, THERE IS CURRENTLY NO RESEARCH OR EVIDENCE THAT REGISTRIES IMPROVE POLICE RESPONSES TO THOSE WITH DISABILITIES.

In fact, there are many unintended consequences that law enforcement agencies and others must keep in mind when considering starting a registry program in their own communities, including violations of privacy and increased stigma toward people with disabilities.

WHAT LAW ENFORCEMENT AGENCIES NEED TO KNOW:



Registries do not fulfill law enforcement's legal obligations toward the disability community.

When interacting with individuals with disabilities, law enforcement officers generally have two obligations:

1. Ensure effective communication.
2. Provide reasonable modifications to existing policies, practices, and procedures.



Effective communication means providing the same level of communication as officers would with someone without a disability (e.g., using an ASL interpreter with someone who is Deaf).



Providing **reasonable modifications** means ensuring that individuals with disabilities have the same access to policing services and activities as someone without a disability (e.g., modifying an agency's handcuffing policy when arresting someone with a physical disability).

In some jurisdictions, law enforcement agencies are required to provide continual training to officers on the topic of disability.



Registries will never be a substitute for effective training and strong, community partnerships.

In addition to law enforcement's legal obligations, many experts agree that relationship-building and partnerships at the community level go a long way in improving police-civilian interactions and building trust. In some communities, disability organizations are working directly with law enforcement agencies to establish mutually beneficial relationships, including training opportunities. Continual, comprehensive training is key to ensuring officers have the information and skills they need to interact effectively with those with disabilities.



Registries can contain outdated, misleading, or inaccurate information.

Like any other electronic or paper record, the information a registry contains must be updated regularly to be useful. In some cases, inaccurate information is being entered into registries by a variety of actors, including family members, or the information becomes less accurate over time. It is also not uncommon for people to have more than one disability, which means they can have multiple diagnoses. Long lists of clinical diagnoses in a registry can be confusing to responding officers, who often do not know how to use this information or what to do during an interaction.



Registries may inadvertently increase officer bias against people with disabilities, especially those with other marginalized identities.

If officers know a person has a disability when responding to a service call or flagged address, they may overreact in situations, or act in a way that is more biased than if they had not known the person had a disability. For example, officers may react with fear to certain diagnoses based on societal stereotypes and be more likely to use force. Biases can be both implicit (i.e., the person is unaware of their bias but still acts in a biased way) and explicit (i.e., the person is aware of their bias and acts accordingly). Registries may also reinforce broader stereotypes about the disability community (e.g., that persons with intellectual and developmental disabilities are “child-like” and in need of protection) and other marginalized communities, including people of color, members of indigenous communities, and those who identify as LGBTQIA+.



Registries may create a false sense of security for officers and community members alike.

Simply having information about someone's disability does not guarantee that an officer will act on that information or know what to do with the information during an encounter. In other words, registries are not foolproof. In many communities, only a handful of eligible people are listed on the registry, meaning the majority of people with disabilities officers encounter will not be, which diminishes registries' overall usefulness in the first place.

RESOURCES AND FURTHER INFORMATION:

If your agency is considering a registry for individuals with disabilities, please reach out to these disability resources in your community for further information:

[Chapters of The Arc](#)

The Arc has over 600 state and local chapters that may be able to assist your agency with training or information about people with intellectual and developmental disabilities. Chapters of The Arc also have connections to other state and local disability organizations, including groups led by individuals with disabilities.

[Protection and Advocacy Agencies \(P&As\)](#)

P&As are federally-funded organizations that provide advocacy to persons with all kinds of disabilities. There is a P&A in every state and territory. P&As can help your agency learn about your legal obligations toward the disability community and general information about various types of disabilities.

For further training and technical assistance, please contact [The Arc's National Center on Criminal Justice & Disability® \(NCCJD®\)](#) and learn more about [NCCJD's Pathways to Justice® Program](#).
Email us at nccjinfo@thearc.org.