



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

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