

## People on the Go of Maryland



### Letter of Information

#### **HB 1176 – 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 Health and Government Operations Committee for the consideration of HB 1176 - 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 the registry.
- 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 the registry 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 and 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.

Sincerely,

*Mat Rice*

Executive Director

People On the Go of Maryland

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