



**HOUSE HEALTH AND GOVERNMENT OPERATIONS COMMITTEE**  
**HB 1148: Behavioral Health Care – Treatment and Access (Behavioral Health Model for Maryland)**  
**February 28, 2023**  
**Position: Support with Amendments**

The Maryland Down Syndrome Advocacy Coalition (MDAC) is a coalition of the five Down syndrome organizations in Maryland as well as individuals with Down syndrome and their family members who have come together to advocate for improved quality of life for all individuals with Down syndrome throughout the state of Maryland. MDAC works in coalition with other disability and advocacy organizations across the state and supports many legislative and policy efforts.

MDAC recognizes that the entire behavioral health care system in Maryland is broken and needs to be restructured, and we were glad to see the introduction of HB 1148, a bill designed to result in the development of a multi-year blueprint for behavioral health reform in Maryland. Unfortunately, the current bill does not adequately address needs of the Down syndrome and broader intellectual/developmental disabilities (IDD) community, so MDAC, along with the Howard County Autism Society, Pathfinders for Autism, the Hussman Institute for Autism, and the entire DD Coalition have requested amendments to this bill which have been provided directly to the lead sponsors. MDAC supports the bill with these amendments.

A common misconception is that people with Down syndrome are always happy. This is completely untrue – they experience a wide range of emotions just like everyone else, both good and bad. They also experience mental/behavioral health disorders at a higher rate than the general population – more than half of all children and adults with Down syndrome will face a major mental health concern during their lifetime. The most common mental health concerns in people with Down syndrome include anxiety, attention deficit disorder, depression, obsessive-compulsive disorders, oppositional behaviors, and tic disorder. Unfortunately, both preventative care and crisis care for people with Down syndrome who also have behavioral health conditions are severely limited. In trying to access preventative care to address behavioral health concerns before they turn into crises, people with Down syndrome are routinely turned away from clinical therapy and psychiatric practices. There is a shortage of mental health providers throughout the state in general, and there are even less providers who will admit a patient with IDD to their practice, with excuses that “we don’t know how to treat ‘those people’” or “our malpractice insurance doesn’t cover it,” routinely being given. If a family is lucky enough to find a practitioner who will admit their loved one with IDD to their practice, that practitioner

often will not have received any specialized training to effectively compensate for the unique characteristics of some people with IDD such as expressive language and processing difficulties. And barely any of these preventative or crisis mental health services are available to support families in their own homes, in which they would much prefer their loved ones stay than having to go to a hospital or in-patient facility.

When a mental health crisis strikes which compels families to bring their loved ones to an emergency room, children and adults with Down syndrome – like people with autism -- languish for days, weeks, and sometimes months in an ER while awaiting a bed at a residential treatment center because they are required to come directly from an ER. While stuck in the ER, these patients are not receiving any therapies, education, social opportunities, nor even the ability to walk outside and get sunlight. For many families, a bed never becomes available, and they wind up having to go home, even worse off than when they came in.

As the blueprint bill is currently written, it does not explicitly include the IDD community. Therefore, we are requesting amendments to:

- Add an individual self-advocate with IDD and a family member of an individual with IDD who have been consumers of the mental health system to the Commission;
- Add recommendations that specifically address the ER overstays, community treatment options, specialized training to effectively treat patients with IDD, and oversight of private hospitals;
- Add a fifth workgroup that would focus on specific barriers to behavioral health care for people with IDD and make recommendations for wrap around supports, crisis prevention, and community-based treatment options (or, alternatively, explicitly add this focus to one of the existing workgroups);
- Add language specifically including people with IDD in the definition of “mental disorders”; and
- Expand the proposed pilot program to teenagers in addition to adults.

MDAC, as well as our partners in the IDD community, greatly appreciates the sponsors’ willingness to amend the blueprint bill to address our concerns. Massive reform of the behavioral health care system in the state is much needed and long overdue, but it needs to address the needs of ALL communities, including the IDD community. Therefore, we are supporting this bill with amendment.

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