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Health and Government
Operations Committee

Subcommittees

Government Operations
and Estates and Trusts
Insurance and Pharmaceuticals



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Testimony in Support of HB 1171

Public Health – Demonstration Program – Developmental Disabilities

Madam Chair, Madam Vice Chair and esteemed members of the Health and Government Operation Committee,

HB 1171 establishes a State Advisory Council on Self-Directed Services for persons living with development disabilities. The Bill specifies the composition of the Council's 25 members, defines their terms of services, and outlines the research and reporting responsibilities of the Council. The State Advisory Council on Developmental Disabilities is being formed to guarantee that the elements of Self-directed services remain intact for individuals living with developmental disabilities.

In 2005, Maryland created the Independence Plus program to provide individuals living with developmental disabilities with supports to select their own service providers and direct their own care. The Independence Plus program made it viable for family members to be part of that care.

In 2013, the State of Maryland merged the Independence Plus program with Community Pathways creating one waiver for persons living with development disabilities. Since then significant changes to self-direction options have taken place through amendments to the "Community Pathways Waiver"; changes that have strayed from the intentions of the original model for Self-directed services. This waiver program has constricted freedom of choice, diminished access to needed services, and limited control for people living with intellectual disabilities.

HB 1171 protects and restores the intent of Self-directed waiver services introduced in the Independence Plus program. With oversight and support from the State Advisory Council participants are allowed to hire families to provide extraordinary care and compensate them for 40 hours/week. The bill supports Brokerage services, chosen by participants, to assist participants and families with day-to-day management and training. The broker becomes an integral part of the participant's Person Centered Plan. Finally, the Council monitors Self-directed Care in communities around the state and makes recommendations to assure the health and welfare of participants.

Research and anecdotal feedback from professionals suggest that self-directed care is the most respectful form of program support for individuals living with intellectual or developmental disabilities. Participants are free to live the life they choose, taking risks, learning new skills, developing talents, and experiencing a measure of independence—supported by family members and professionals.

Self-directed care is individualized care that is flexible and adaptable to the changing needs of the participants. It is care that builds on the strengths of each participant and addresses individual needs. In the final analysis, self-directed care encourages individuals to remain in their communities and precludes the need for institutionalization. The State Advisory Council on Developmental Disabilities ensures that the best practices within Self-directed care remain in place for individual and families.

For these reasons, I urge you to support **HB 1171**, and I request a favorable report.

Thank you.

Delegate Karen Lewis Young