Jeneva Stone: 4415 Highland Ave., Bethesda MD 20814 (D-16)
Testimony on HB1020, Health & Government Operations Committee **(favorable)**

I am urging you to pass HB1020 out of committee with a favorable rating. I am the parent of Robert Stone, a self-directed participant in Montgomery County. **Rob has complex medical needs, so self-direction was the only program that truly allowed him the full community access he deserves**.

Rob transitioned from high school wanting to be an advocate, an artist, and a writer. I am proud to say he has achieved all three of those goals! He has his own website, has testified multiple times in Annapolis on disability rights issues, and has been active with health care issues at the federal level through his work with Little Lobbyists, a family-led organization advocating for the health care of children with complex medical needs & disabilities.

I am 57 years old, and Rob's dad (my husband) is 60. Rob depends on self-direction's flexibility and commitment to choice. **However, self-direction is still subject to the DDA's internal rulemaking authority**. I have worked with the DDA on Rob's services since 2005 (when Rob had an ISS grant), and **my family has surfed through over 16 years of rules and services changed by the DDA with little or no notice**.

These rule changes have affected Rob's ability to purchase equipment, hire certain types of staff, and have access to his community. **The DDA makes internal rule changes with little input from the community it serves. We then have to go through the onerous process of speaking through our children's case manager intermediaries (CCS)**, providing more documentation (often previously provided), and making yet another argument for our child's right to certain services. In many cases, these requests are denied.

As I said, I'm 57 now, and I can, for the time being, continue to fight these **basic service battles** with Rob, but at some point, I will not.

If you pass HB1020, and it becomes law this session, Rob will be able to count on basic parameters in self-direction without my having to intervene. The DDA will have no choice because these will become law, no longer subject to their internal processes.

Our community needs certainty and predictability in self-direction. We need better training for the CCS.

Furthermore, the number of people choosing self-direction is increasing exponentially with every passing year. I advocate with 4 different disability organizations, and have a seat on 2 commissions that deal with disability-related issues. As I have become more visible, friends and friends of friends are contacting me regularly—either wanting to know more about how to do self-direction or to check with me to see if what their child's case managers (CCS) are telling them is accurate. **So, clearly, better training on self-direction for CCS is important!** And that is in this bill.

All of these new self-directed participants need certainty and predictability as well. In a recent public meeting, I heard an MCPS official say that about 1/3 of transitioning youth are those with complex medical needs—and that group has been choosing self-direction more and more because many traditional providers are not open to them. **Recent estimates of self-directed participants in Montgomery County show that the program has increased by up to 20% or more over the last few years**.

As I speak to parents of those who choose self-direction, I am hearing that this is related to the family's wishes to ensure that their children remain members of their communities, pursuing their own passions. Self-direction is what opens doors for many of those with I/DD.

You can look at it this way: **The success of the federal IDEA has raised expectations about what those with I/DD can do after school ends. Maryland's services for those with I/DD need to keep apace of what our community wants. The DDA has to balance too many competing factors to ever guarantee certainty and predictability in self-direction. It's time for the legislature to ensure that our families have that going forward**.

Thank you.