

Written Testimony on HB1053, DDA-SDS-Parent Providers

Jeneva Stone

Family Caregiver

FAVORABLE

My disabled son Rob, an SDS participant, gains a great deal of security from having family-as-staff. My husband and I are available to sub at short notice when other DSPs are absent. We are also able to care for Rob during the evenings.

Rob has wanted us to be part of his staff, even as he has been hiring non-family DSPs. My husband and I are supportive of Rob becoming more independent (and, frankly, we have other things we need to do with our time), yet we all acknowledge that until such time as medically complex individuals can remain in their communities under Maryland's Medicaid programs independent of their parents, we still have a role to play in Rob's care.

Given the turmoil at the DDA and MDH, and the relative hostility of both to allowing family-as-staff, we need to ensure codification of this participant right. Given the uncertainty about the SDS Act of 2022, we need to ensure that this piece of it is codified.

I urge you to vote favorably on this bill.