Testimony Before the Senate Budget and Taxation Committee SB0362 – Unfavorable February 29, 2024 Presented by Beth Gude

Good afternoon and thank you for the opportunity to speak to you about an issue of great importance to me and my daughter, Caroline. I am a member of the Self Directed Advocacy Network Board (SDAN) but am here today to speak to you as Caroline's mother. I am here to ask that you remove any reference to ARTICLE-HEALTH-GENERAL SECTION 7-101 & SECTION 7-409 from the BRFA which repeals important provisions of the 2022 Self-Direction Act thus restricting access to her DDA budget, which is developed based on her support needs after an intensive person-centered planning process.



Caroline lives in an apartment in Rockville, using a Housing Choice Voucher. She is an active, funny, engaging person who is dependent upon others for everything – everything that you do in life, from getting up until going to bed at night – must be done for Caroline to ensure her health, safety, community inclusion and happiness. She does not recognize danger and would not be able to call for help if she did. She must be re-positioned every 2 hours to avoid skin break-down and infection. She does, however, have her own business, and is definite in her life choices - communicating with accessibility switches, communication apps and body language.

Caroline has been self-directing her DDA services for about 8 years. She uses the same person-centered planning process as her peers, whether they use traditional or self-directed services. Services, such as Personal Support hours, are comprised of a "brick" which includes costs for direct care staff, employment related expenses, training, transportation, program support and administrative expense.

One category of services is IFDGS – Individual and Family Directed Goods and Services. This is self-direction's blanket term for Program and Administrative costs - I have attached a DDA document which explains how IFDGS may or may not be used. Please note the section titled **Day to Day Administrator.** And also note that DDA states "Funding must come from cost savings in the budget". This service was added as part of the 2022 SD Act. It became available to participants at the start of this Fiscal year on July 1,2023. Because DDA chose to include this service in the IFDGS category, a return to the proposed \$5000. spending cap (already somewhat artificial) is completely unrealistic.

Currently, I, like many other family members, provide this support to Caroline and her team as "natural support". Inclusion of the Day-to-Day Administrator in the SD Act was tremendously exciting as it provides an opportunity to educate and train others to assume the many roles family members take on. It means that self-direction may be sustainable for Caroline even when I am no longer able to manage what is, in essence, a small business with seven employees. The

need and urgency is especially relevant as Caroline has never been accepted by traditional providers into their programs.

This section of the BRFA was added without notification, consultation or any form of transparency to those most directly affected. I would offer that a work group of all stakeholders study the issue prior to any changes to the SD Act.

Thank you for your time and consideration of this issue which will have a great impact on persons using self-directed services.

Beth Gude 1003 Brice Rd Rockville, MD 20852

Individual and Family Directed Goods and Services Self-Directed Services 7/1/2023

Below is a tool for people who are self-directing their services and their teams to use to understand what Individual and Family Directed Goods and Services (IFDGS) may and may not be requested. This tool is meant to complement DDA's Self Directed Services Individual and Family Directed Goods and Services policy/guidance.

What are IFDGS?

- Services, equipment, activities, or supplies that support people who self-direct
- Help meet listed needs in the PCP
- Help maintain or increase independence
- Cannot be provided through the waiver program or a state plan There are three

categories of IFDGS:

- Recruitment and Advertising
- Day to Day Administrator
- Other Goods and Services

Recruitment and Advertising

- Helps to fund activities that support staff recruitment for jobs Can include:
 - Making print or electronic flyers for sharing job advertisements
 - Software to create flyers (Adobe, Canva, Vista)
 - Printing physical flyers
 - Staff registries (Indeed.com, Care.com)
- Dedicated funding comes from the detailed service authorization in the Person-Centered Plan (PCP)
- Must request in an Initial, Annual, or Revised PCP

Day to Day Administrator

- Direct and non-direct support to the person self-directing
- People can hire an employee or vendor to be the Day to Day Administrator, including relatives, guardians, or legally responsible individuals

• Can include:

- Household management and scheduling
- Employee scheduling
- Scheduling appointments o

Personal money management •

Exclusions:

- The Day to Day Administrator cannot provide any other service at the same time
- O A person's Support Broker cannot be their Day to Day Administrator
- The Day to Day Administrator cannot work more than 40 hours per week unless authorized by the DDA
- Funding must come from cost savings in the budget
- Must request in an Initial, Annual, or Revised PCP

Other Goods and Services

Included	Not Included
Activities that promote health	Goods and services that compromise health and safety
Fees for programs/activities that promote socialization and independence	Experimental goods or treatments
Small kitchen appliances for independent meal planning	Co-payments for medical devices
Laundry appliances to promote independence and self-care	Over the counter medications or homeopathic services

Sensory and safety items related to disability	Items used solely for entertainment or recreation
Personal electronic devices	Monthly cable television fees or services
Toothbrushes and dental services not covered by insurance	Monthly telephone fees
Weight Loss programs and services	Room and board

Nutritional consultation and supplements	Food
Internet services	Utility charges
Other goods and services that meet standards	Tobacco, alcohol, Marijuana or, illegal drugs
	Vacation expenses
	Vehicle insurance, maintenance, or other transportation-related events
	Clothing, shoes, or other personal items
	Haircuts, nail services, and spa treatments
	Tuition
	Staff bonuses
	Subscriptions
	Training
	Services in hospitals
	Cost of travel, meals, and overnight lodging for staff/family/support
	Service animals
	Exercise rooms, swimming pools, and hottubs
	Fines, debts, legal fees, advocacy fees
	Contribution to savings accounts (including ABLE)
	Country club membership/dues
	Leased/purchased vehicles

Other IFDGS must be requested using the IFDGS Request Form