

HB1953 FAV
**Developmental Disabilities Administration - Self-Directed Services Manual -
Public Comment**

Martha Gabler, District 20
10125 Markham St., Silver Spring, MD, 20901
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Dear Respected Members of the House Health Committee:

Our family is FAVORABLE in regard to HB1953, and we respectfully request your support for this bill.

Our family would benefit greatly from a 90-day public comment period to review and comment on the very complex documents involved in managing a Self-Directed program for an individual with Intellectual and Development disabilities. My name is Martha Gabler. I am the Mother and Legal Guardian of Douglas Gabler, a profoundly nonverbal 29-year-old man with severe autism. Douglas has participated in Self-Directed Services under the DDA Community Pathways Waiver since 2017.

We appreciate Douglas's opportunity to participate in Self-Direction because he is thriving with this personalized approach. He has an excellent daytime Direct Support Professional who has been working with him for almost 6 years. Because of the trust and mutual understanding that has developed between them, Douglas has the opportunity to participate safely in community activities and volunteer work that bring joy and accomplishment to his life and to others.

Self-Direction is an extremely complex program for Participants and families to navigate. Many of the rules are excellent, because they set out the rights and responsibilities of the various parties involved in each Participant's plan. We welcome rules and procedures that verify program integrity and financial accountability, and we take pains to comply with them.

However, we do not welcome sudden, unexplained policy changes that are imposed with no notice, no explanation, no opportunity to collaborate, and shockingly short comment periods, despite the length and complexity of these documents. The constant changes in the past two years have not only made the system feel arbitrary and capricious; they result in continual chaos as we jump through hoop after hoop trying to comply with bewildering new requirements.

Sadly, abrupt changes with little notice and no collaboration have become the pattern for the last two years. You may recall the first time this happened in late 2024.

On Thursday, October 24, 2024, the Self-Directed community was stunned to learn that the DDA had issued a new 23 page Self-Directed Services Comprehensive Policy and a new 115 page Self-Directed Services Manual. The DDA announced that this manual would take effect on Thursday, November 7, 2024, just **13** days later! To make matters worse, the comment period exactly straddled the Presidential election on Nov. 5, 2024, thus creating a massive distraction just when the entire country was intensely focused on national issues of great concern.

The Maryland General Assembly suddenly found itself inundated with calls and emails from constituents for days, and finally a conference call was organized for November 4, 2024, just one day before the election! I remember feeling sorry for the Delegates and Senators because, as elected representatives, they would probably have liked to follow the electoral process minute-by-minute, but they sacrificed and made time for us.

This pattern of dropping lengthy documents for comment with no notice and short time frames constantly upends the lives of Participants and families as they scramble to react. The Self-Direction community faces the following struggles:

- There is no advance notice to Participants and families that a massive change may be under consideration.
- There is no opportunity for Participants and families to review proposed changes in advance and provide feedback.
- There is no opportunity for dialog with the DDA.
- It is unreasonable to expect Participants, family members, and the many other parties involved in Self-Direction to review documents that are 100 to 500 pages long, that contain dense regulatory and policy language, and to submit meaningful comments within a 30-day timeframe
- It is unreasonable to expect Participants, family members, and interested parties to re-arrange their work and activity schedules to set aside the immense amount of time needed to participate effectively in this process within 30 days.

Further changes should not be attempted until the 90-day comment period has been implemented.

However, the abrupt announcements and short 30-day comment period are not the only things that should be changed. I would like to request that more steps be required of the DDA prior to creating any more changes to the Self-Directed Services Manual, or other important documents.

The DDA needs to explain WHY a change is necessary.

The DDA should provide information about whatever “problem” it has uncovered and why their “change” is the “solution” to the “problem”. This would include:

- A specific description of the “problem”
- A detailed description of a consultation process to include all stakeholders in addressing the “problem”
- Serious collaboration with all stakeholders should continue until all **facts** relating to the “problem” are available, including:
 - **Data** describing the extent and frequency of the “problem”
 - A description and explanation of the “solution” the DDA wishes to implement
 - Consideration of “solutions” developed by other parties
 - Data describing whether this “problem” has occurred in other states, to what extent, and how well this “solution” addressed the “problem” in other states
 - A **cost-benefit analysis** of the costs, in both time and money, for all stakeholders to implement this “solution”
 - Description of a trial period to see if the “solution” actually solves the “problem”
- Full and complete consideration of all these points should be completed and published before any proposed documents are released for the 90-day comment period.
- The ensuing implementation process should be carefully designed and monitored to ensure that the “solution” actually does solve the “problem.”

Governments and interested stakeholders write regulations and policies to create a reliable operating environment, so that everybody knows the rules and knows what they are expected to do. Once created, these regulations and policies should not be changed, constantly, on the fly, for no clear reason.

The current Community Pathways Waiver Amendment #3–2025 is **438** pages long. The current Self-Directed Services Manual is **160** pages long (up from **115** pages in the first Services Manual). This should be enough documentation for almost anything. For comparison, the U.S. Constitution is **20** pages long (in Word format).

There should be no more arbitrary and capricious changes. Participants need the rules to be consistent because Participants and families are not only trying very hard to keep current service plans in place, we are also trying to figure out long term care options.

When changes to regulations and policies are arbitrary and capricious, we cannot make decisions, and we cannot take action. If we risk taking an action based on one set of policies, we might find our innocent Participants in big trouble after yet another surprise policy change that revokes the previous policy. This is untenable and cruel.

In conclusion, please support this bill. Please support the goal of Participants and their families to have stability and transparency for their programs in the short term, and the ability to plan for the long term. Please approve the 90-day comment period.

Thank you for your consideration.

Sincerely,

Martha Gabler

Martha Gabler, District 20
Mother and Legal Guardian of Douglas Gabler
10125 Markham St.
Silver Spring, MD 20901
Home: 301-681-2716
Cell: 301-641-1943
Email: martha.gabler@gmail.com

Link to Community Pathways Waiver Amendment #3 – 2025, 438 pages long:

https://health.maryland.gov/dda/Pages/Community_Pathways_Federally_Approved_Application_Amendments.aspx

Link to Self-Directed Services Manual, 160 pages long:

<https://health.maryland.gov/dda/Pages/sdforms.aspx>