

Testimony for Mental Hygiene Budget Hearings

Jim Karpe February 4, 2026

I'm here today to talk about love and freedom.
I will also ask you for money.

I love NYS's commitment to people with IDD.
We spend more money per capita than any other state.
We have the largest IDD Self-Direction program in the country. It will soon
be revealed to be over 40K people...

And I love what it has allowed my son to become. He lives a life marked by
choice and dignity. OPWDD's SD program has allowed him the freedom to
choose how to be supported.



And, what happens when we age? This year I mark my 66th birthday.



I have friends in their 70s and 80s who know that their child's individualized
life will fall apart when they die. There will no longer be some one to take
care of the administrative tasks, to fill in when a worker falls sick, and most of
all, nobody to be the champion of their child.

They fear that their child will be placed into a nursing home-- and thus off the
OPWDD rolls-- and die soon after that.

Family Advocates have allied with Fiscal Intermediaries, to pave a different
path. We are working to create a different alternative. It will cost slightly
more than SD, but much less than a nursing home. It will cause OPW's budget
to go up, and reduce the spend on nursing homes, which come out of a
different budget line. It will increase the lifetime costs, because it will increase
lifetimes.

We call this program PASS, Program for Accessible and Sustainable Services. We are seeking to launch
the pilot project this year, and then keep it running to create the evidence of effectiveness and the data
needed to design services and budgets. Attached you will find the draft proposal for the large-scale PASS
pilot. We are seeking private funding to launch this. A small amount of earmarked public funding would
help us to get this going.