

Testimony to the New York State Legislature
Joint Hearing of the Senate Finance and Assembly Ways and Means Committees
THE 2019-2020 EXECUTIVE BUDGET
TOPIC: MENTAL HYGIENE
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Submitted by
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Dear Senators and Assembly Members,

My name is Amber Decker I am a Family Peer Advocate, Parent and a Caretaker. My son has a Developmental Disability. I am a caretaker for my elderly parent who has a serious mental illness who has struggled throughout her adult life. I grew up homeless with my single parent in NYC, who was always in and out of Hospitals. We never had access to supportive housing and other community services, they did not exist during the 1980s. With a long history of voluntary and involuntary hospitalizations since 1987 for both medical and psychiatric illnesses my parent was never able to hold down a job and receives social security for her mental health impairment. Currently I live in Brooklyn New York but work with many families across the state of New York many of which are dealing with loved ones whose lives are seriously impacted by their disabilities.

I want to bring your attention to the millions of dollars that we as parents and caretakers for the severely disabled save the state of New York and tax-payers everyday by utilizing self direction.

Parents and caretakers are often left out of budget considerations, no one factors the cost of our lives. I can tell you we pay with our lives to keep our loved ones out of the most restricted settings like nursing homes, hospitals and prisons. We pay with our lives advocating day and night for services that we know they are entitled to, that we know that they need in order to be afforded the same rights as those without disabilities. We pay with blood sweat and tears everyday. Many of us have no choice and cannot work full time jobs with benefits due to the demands of advocating for our loved ones. Clearly the nursing home operators and union lobbyists are very unhappy with Olmstead, Money Follows Person, the ADA, and the HCBS Settings Final Rule because the deinstitutionalization trend takes money away from nursing homes. How many of those living in an institution would prefer an opportunity at a meaningful life? Parents and caretakers make that happen everyday for our loved ones until we are broken. The Governor's Medicaid Redesign Team has steamrolled managed care for the severely disabled with little to no thought on how it will affect the voiceless, vulnerable, disabled New Yorkers who look to the State as their only source of services, supports, and protection. Managed

care is a code-word for privatization, plain and simple. The Governor is attempting to get the State out of the business of caring for society weakest members and turning that moral duty over to for-profit investors who only care about share prices. MRT is the great sell out.

Health And Recovery Medicaid Managed Care Plans (HARPS) Gross Under Utilization of Behavioral Health Home and Community Based Services:

When my seriously mentally ill parent with Bipolar Disorder now age 63 was forced into mandatory managed care in 2005 almost 14 years ago, she lost so many services including day treatment services. Was psychiatrically hospitalized at least six times from 2005 -2010. The Medicaid managed care plan said she could not see a therapist and psychiatrist on the same day. The Medicaid managed care plan that she was auto enrolled in bit by bit besieged my mentally ill parent with many restrictions on mental health treatment and life became again a revolving door in and out of the hospitals, no one ever explaining or helping her assert her rights under the Mental Health Parity Act, we can never get that time back. Clearly this population's mandatory enrollment into a Medicaid managed care plan did not go as the MRT expected, because in 2015 there was the creation of a new Medicaid Managed Care Plan called Health and Recovery Plans (HARP)¹ into which almost 100,000 individuals were auto-assigned. My parent was again without notice or education auto-assigned by the New York State Department of Health into one of these plans with the hope of accessing BH HCBS (Behavioral Health Home and Community Based Services) which have been described as the following²:

Behavioral health HCBS benefits for the member:

1. Psychosocial Rehabilitation
2. Community Support and Treatment
3. Habilitation Service
4. Family Support and Training
5. Short-Term Crisis Respite
6. Intensive Crisis Respite
7. Education Support Services
8. Peer Support Services
9. Non-Medical Transportation
10. Pre-vocational Services
11. Transitional Employment
12. Intensive Supported Employment
13. On-going Supported Employment

¹ https://www.health.ny.gov/health_care/medicaid/program/update/2015/jul15_mu_speced.pdf

² https://www.health.ny.gov/health_care/managed_care/plans/docs/hiv_care_management/2016/hiv_cm_report.pdf

14. Self-directed Care

I spent over one year trying to get answers and access for my loved one to receive these new BH HCBS services of which she was entitled. No one knew how or what BH HCBS were or how they actually worked, not even the HARP Medicaid managed care plans and yet managed care plans were now receiving even more Medicaid monthly capitated payment funds. Not even Medicaid Choice run by Maximus, paid with taxpayer dollars in “ *Helping you make smart decisions about your future health care*”, when I called them to ask for their help, they knew nothing about BH HCBS and HARP plans all they could do was assign a plan to her.

The New York City Regional Planning Consortium’s lack of Consumer and Stakeholder Engagement of Families and Parents:

I attended countless meetings at the (RPC) New York City Regional Planning Consortium <http://www.clmhd.org/rpc/> filled with hope that I has finally found the contacts that could help my loved one to access BH HCBS. At these meetings I asked numerous times where the funds for BH HCBS were being diverted to for NYC residents? No one there could ever answers any questions.

It’s important that you know that the NYC DOHMH (New York City Department of Mental Health and Hygiene) never solicited parents or families in these discussions. It is unclear who has oversight of the DOHMH. They were never able to give answers as to how the New York City’s Health and Mental Hygiene Department was utilizing state Medicaid dollars or any other funds for the STC (Special Terms and Conditions) populations. Furthermore The OPWDD never once came to the NYC Regional Planning Consortium (RPC) meetings despite claiming to work together on the CLMD website: <http://www.clmhd.org/rpc/>

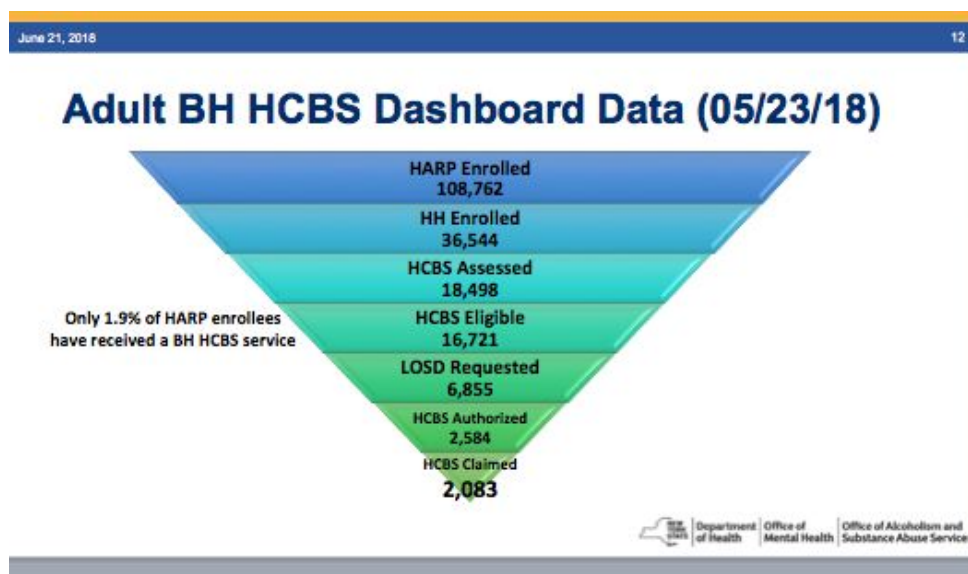
State Run Government Entities like the OMH and the OPWDD all have a piece of the pie but cannot answer simple questions about medicaid managed care plans who are now responsible for delivering services, nor can they troubleshoot access for vulnerable populations in any meaningful capacity. I contacted OMH (Office of Mental Health) who has a dedicated website just for managed care issues and complaints:

<https://www.omh.ny.gov/omhweb/bho/complaints.html>

with zero response to questions about access and oversight of Health Homes, HARP plans and BH HCBS services. The Seriously Mentally ill who need mental health services are placed on long waiting lists for services like ACT (Assertive Community Treatment). No one helps these individuals assert mental health parity laws and most of the medicaid managed care plans do not offer single case agreement or out of network options.

Health Home Care Managers Have No Idea or Ability To Connect The Vulnerable To Services For Which They Are Entitled:

The Health Home Care Manager³ did not even know my parent was auto-assigned to a HARP plan and no assessment for BH HCBS was done until 2017 almost two years later, and during that time the hospitalizations did not stop, the mental illness was not treated and my loved one continued to be a danger to herself and others. After I took every free webinar and read every single thing I could about the HARP plans and BH HCBS⁴ for the Serious Mental Illness (SMI) population, I was able to assert her rights to at the very least the HCBS assessment. Which was all for nothing because even after being approved for Tier II BH HCBS we were unable to access them, networks new nothing, many of these BH HCBS providers told me they were not being paid or that they canceled their program. The utilization numbers of BH HCBS services for this population reveal this, and even after four years is extremely low only 1.9% of HARP enrollees have received any BH HCBS services.



For this reason it has become my full time unpaid job navigating layers of bureaucracy. That includes hours of dealing with impersonal Medicaid managed care plans customer service agents. The learning curve for accessing benefits and services is so steep many people simply give up or never even get started. Enrollment in a HARP plan did allow for one positive thing and only very recently, and after years of emails, research and phone calls; I was able help my SMI loved one to be apart of a pilot program that allows access to “Self-Directed Care”, she is

³ https://www.health.ny.gov/publications/1123/hh_brochure.pdf

⁴ https://www.health.ny.gov/health_care/medicaid/program/medicaid_health_homes/docs/hcbs_poc_workflow.pdf

one out of a handful of individuals enrolled in this most-enlightened and person-centered of options. The Medicaid Managed Care plan did not help with securing this service, the Health Home care manager did not help to secure this service either. I on my own with an unyielding effort found and helped to ensure that she received approval for this service. In spite of the state's promising "self directed care" in its 1115 Waiver Amendments⁵, sadly this still just a pilot program in New York State and is only in two regions with just a handful of participants. Mandatory Medicaid managed care enrollment imposed in 2005 for the seriously mentally ill has been completely flawed in New York State, if not a total failure. Behavioral health provider claims have been denied repeatedly. Ask yourself how this affects those that need these services? The misappropriation of Medicaid dollars and capitated payments to Medicaid managed care plans for services not delivered for the SMI population and the clinical providers that serve them can only be described as fraud and abuse. New York is at high risk of being audited for clawbacks by the federal government.

Therefore the Legislature should do everything in its power to strengthen access to "self directed care" for those who are passively enrolled into HARP plans and ensure that Behavioral Health providers are paid timely and appropriately for services rendered to this population. And that HARP plans have true network adequacy when it comes to BH HCBS services.

The Transition to Mandatory Medicaid Managed Care for the Intellectually and Developmentally Disabled Under the Office for People With Developmental Disabilities (OPWDD) and The New York State Department of Health:

My son who is now 13 was diagnosed with Autism at age 3. He has been enrolled in the Office of People With Developmental Disability Waiver since he was 8 years old. He has been in receipt of Home and Community Based Services, specifically self-direction services which has allowed him to remain in the least restrictive environment where he interacts with typically developing peers. With OPWDD's self direction program my son is able to participate in meaningful classes in the community with the support of his self hired community habilitation life coach and has access to transportation to and from these programs, has physical health and fitness opportunities, community engagement experiences and socialization opportunities that he would not have without the OPWDD Medicaid waiver. My personal experience with watching my parent lose services under Mandatory Medicaid Managed Care, the poor roll out and under utilization of HCBS services for the SMI population makes me fear the same fate for the Intellectually and Developmentally Disabled population. Will my son too to be denied access and services that he needs under managed care? What about all 100,000 OPWDD participants?

⁵ https://www.health.ny.gov/health_care/medicaid/redesign/2016/2015-10-01_1115_waiver_stcs.htm

Will the providers that have been working with them to deliver HCBS services vanish and be forced to close due to denied payment from Medicaid managed care plans in the future?

The steady and fast changes that have been underway will jeopardize access to OPWDD waiver services for this population including my son. The OPWDD describes three Phases of its Transformation Agenda. Of these, Phase One was abruptly launched on July 1, 2018, with shockingly inadequate and misleading claims of readiness. Not that you would know anything is amiss from what the OPWDD itself says in public. I advise the Legislature not to trust one word out of the OPWDD mouth regarding managed care. I urge the Legislature to make its own inquiries and to listen to the stories of its own constituents, how they are being neglected, are losing services, are getting months of run-arounds, and how their care managers are quitting in droves. I collected over 40 testimonies and circulated a CCO/HH survey⁶ of which 170 participants revealed that the roll out of care managers for the I/DD OPWDD population has been a complete and total failure for many families. In spite of high rates the lack of service coordination and support before the Phase One rollout, the service gap has grown under managed care. The survey results have been shared with OPWDD and New York State Department Office Health with little to no response. The survey revealed very serious concerns and issues with the CCO/HH roll out on July 1 2018 including issues around access, privacy, competence and fair treatment.

Many states are precipitously forcing their intellectually and developmentally disabled populations into ill-conceived and deeply flawed private managed care plans, and the same horror stories are repeated in every state: services cuts, service denials, bankruptcy of service providers, disabled people left high and dry. After a few years of the nightmare, the respective legislatures must step in and stop and/or reverse the managed care runaway train. People die preventable deaths. New York State's OPWDD is falling down the same rabbit hole.

The Governor's Medicaid Redesign Team is a flagrant give-away to large institutions and unions who will reap billions in profits while destroying what was once the country's best social safety net for people with intellectual and developmental disabilities:

The Legislature cannot sit idly by and be a rubber stamp for the Governor's reckless and heartless assault on people with disabilities. The Legislature must open its eyes, reach out to its constituents, and learn the ropes in order to properly regulate the new private bosses of Medicaid managed care for disabled New Yorkers. The Executive branch is pulling a very fast one on everybody, and it is the duty of the Legislative branch to serve as a check and balance on the imperial Governor.

⁶ CCO/HH Participant Survey <https://goo.gl/forms/Bc7SDXVgHfaqf3ws2>

The DOH and OPWDD are now a major propaganda operation, selling glittering lies about managed care and covering up any hint of trouble. The DOH and OPWDD are shaking in their boots lest the federal HHS OIG get wind of the systemic government-sanctioned Medicaid fraud occurring as we speak at the OPWDD and its Seven Care Coordination Organizations/Health Homes. Participant families are completely stonewalled by the OPWDD. Sadly, the federal Center for Medicare and Medicaid Services simply signs off on the Governor's MRT agenda, even though Uncle Sam is paying 90% of the first two years of CCO/HHs. Nobody represents the voiceless disabled people who are directly affected.

The Legislature must do its duty to represent The People in Albany. I ask the Legislature to ignore the bureaucrats and the lobbyists, because they are selling out people with disabilities this very minute. The OPWDD managed care timeline indicates the rollout of Phase Two of OPWDD managed care this year. Ignoring the disinformation propaganda campaign, each phase of the OPWDD managed care rollout is nothing less than right-wing privatization and market consolidation. But the joke will be on the State, because it is a hard-and-fast rule of the basic economics of supply and demand that a monopoly provider can name his price, and the payer will be over the barrel and have to pay it. The Governor's MRT scheme will consolidate disability service providers into a single private plan, and the costs to the State will skyrocket. The State is needlessly giving up all of its negotiating strength and leverage - why? Was it for campaign contributions? The OPWDD is an \$8 billion dollar budget item, and lots of private operators would like to get the fingers into that money. The State must not simply give away the farm.

The logical outcome of monopoly private Medicaid managed care plans is service cuts, which will fall hardest on Home and Community Based Services across the board for the Special Needs populations. This will drive disabled people out of their homes and into institutions. It does not take a genius to perceive that the operators and unions of those institutions bought access to the reins of power and control of the MRT. The 100,000 OPWDD Intellectually/Developmentally Disabled participants are pawns and sacrificial lambs in a massive power and money grab. This was the Great Sellout. Unless New York's HCBS sector is prioritized over institutions, New York's intellectually and developmentally disabled population may be a future subject of a US Department of Justice Olmstead enforcement lawsuit, similar to the one recently concluded for the seriously mental illness population with a deinstitutionalization consent decree.

The OPWDD Phase Two on managed care has not yet been fully authorized. Phase One is currently a disaster. Phase One must be repaired completely before there is any talk of moving to Phase Two. The Legislature CAN and MUST stop any talk of Phase Two immediately. The

Legislature must hold hearings on Phase One to discover the full extent of the OPWDD deception and mismanagement going on across the state right now.

The OPWDD's Transformation Agenda did not do anything beneficial for the real problems: inadequate housing for people with intellectual and developmental disabilities and a desperate shortage of direct service providers due to inadequate wages. To the contrary, Phase One has made each of these problems worse. Make no mistake, the changes proposed in Phase Two will multiply those core problems, not fix them.

Conflicts Of Interests Are Rampant At The OPWDD For the last four years OPWDD has had an "Acting" Commissioner only, named Kerry Delaney. If anyone is wondering where she went you can now find her sharing insider information to a for profit managed care plan called Partners Health Plan (PHP). Soon PHP will be the largest Medicaid Managed Care Plan for the OPWDD population. We hope that Kerry Delaney will not forget those that have waited and gone without services under her authority for the last four years.

The OPWDD at this time has no way of knowing how many individuals are in receipt of HCBS services. Many of those with eligibility are simply waiting for services for years. The OPWDD loops all of its enrollment and service authorization protocols through a non-functioning information technology system called MediSked. The Legislature must create a rational procurement pathway for healthcare information technology, because MediSked is killing the OPWDD. Despite numerous attempts at FOIA requests and emails, the public has no idea how MediSked was chosen to run all of OPWDD service functions. There is reason to suspect insider profiteering. The OPWDD and DOH have failed to justify the current rates that it pays for Group Homes, Certified Residences, Intermediate Care Facilities, including Day hab services. Nor have they published utilization numbers, on the delivery of Home and Community Based Services, Some of these Include the following:

- Camp
- Counseling
- Crisis Intervention
- Day Services/ Day Habilitation
- Environmental Modifications (E-Mods)/ Adaptive Equipment
- Employment Services
- Evaluation, Intake and Referral
- Family Care
- Family Support Services
- Financial Assistance
- Forensic Services
- Health Care

Housing/ Individual Support Services
In-home Services
Parent Advocacy and Training
Recreation
Respite Services
Residential Services
Service Coordination
Transportation
Waiver Services

The successful delivery of these services is a vital in order to establish and understand what access looks like currently. This needs to be done prior to any further discussion of Phase Two of Managed Care. The absence of this information opens the door to a huge mismanagement and further exploitation of Medicaid dollars.

The OPWDD Fails To Adhere To Open Meetings Law & Fails to Respond to Stakeholders, Self-Advocates and Families Questions:

To be clear the once Interim Acting Commissioner of the OPWDD Kerry Delaney for the last four years has failed to produce any “Status Reports” or feedback from families in spite of New York State Laws, Rules and Regulations that require the OPWDD’s Commissioner to do so. Delaney failed to engage stakeholders meaningfully even worst denied access to those who ask for meaningful participation. Parents and Families spend countless unpaid hours navigating services from an unresponsive system. Money did not following the person under Commissioner Delaney’s watch. And now there is another interim Acting Commissioner. OPWDD cares so little about keeping it’s families informed and did not even publish the name of their newly appointed Commissioner anywhere. Families were told the name of Kerry Delaney’s replacement from the news media, but we have no official introduction from the OPWDD or any public statements from him.

The Developmental Disabilities Advisory Council and the Family Support Service Committees are both councils that are established under New York State MHL § 41.43 and MHL 13.05. Both are subject to Open Meetings Laws. None of the members have been provided any training nor is it clear that they understand their own roles as stakeholders and advocates. It would be great to ask the OPWDD for clarification on how families and self-advocates are selected to participate on these public advisory bodies. There are members remaining on these councils for decades who are either being stonewalled, manipulated or profiteering. For example,

one appointee happens to also be the CEO for Life Plan <http://lifeplancony.com/about/> which is one of the new Care Coordination Organization/Health Homes; while also sitting on the JAC⁷ (Joint Advisory Council for Managed Care) and the DDAC. This CEO has not recused himself from the position of Chair to date.

These advisory bodies are established in what appears to be an un-democratic, vague process. There is very little movement or progress on them, vacancies are not announced and the population is not represented. A great deal of profit being made under the disguise of “stakeholders” from the OPWDD and it’s various advisory bodies. Those that do speak up are excluded or railroaded. It is unclear why there is so little opportunity for meaningful engagement of parents and self advocates. The New York State Department Of Education has School Boards, PTAs (Parent Teacher Associations) and these appointments are decided through a vote, but the OPWDD allows for no such process. In fact it is the complete opposite.

Phase One Of Managed Care for the OPWDD Population and Care Coordination Organizations Health Homes (CCO/HH):

The OPWDD and the DOH have failed to give authorization numbers for many of it’s services and now because of MediSked⁸, a new IT System that been imposed and adopted by all Seven New Care Coordination Organizations, Health Homes has proven to be a useless waste of taxpayer money. Currently Medisked is the only IT system in use by all seven CCO/HH. While Medisked has existed for some time, the CCO/HH are new and yet all of them use this system which was not a requirement listed in the original applications see:

https://www.health.ny.gov/health_care/medicaid/program/medicaid_health_homes/idd/docs/hhid_d_application_part_2.pdf

The word Medisked is not listed anywhere in the application and yet each and every CCO/HH uses Medisked. This gross monopoly and misuse of taxpayers money remains unchecked. Medisked is not regulated by the OPWDD or the DOH and is undermining LTSS data, falsifying information crashing, is not fully operational. It went through zero readiness reviews and has caused a number of problems for the OPWDD population and providers. Yet they have no choice but to rely on this cheap and useless platform. Rather than invest in a true Electronic Health Record (EHR) the OPWDD has imposed that all CCO/HH use an unchecked EHR, which is Medisked. In order become a CCO/HH all of them had to use this system. The OPWDD has yet to respond FOIA requests concerning their 2017 EHR RFP:

https://opwdd.ny.gov/opwdd_resources/procurement_opportunities/OPWDDDEHRRFP

The Legislature should ask who is regulating Medisked?

⁷ https://opwdd.ny.gov/opwdd_services_supports/people_first_waiver/opwdd-joint-advisory-council-managed-care

⁸ <http://www.medisked.com/products/medisked-coordinate/>

Many questions remain unanswered from the OPWDD. The Legislature should ask the OPWDD one question about Phase One of managed care for the OPWDD, the aim of which is to create over 100,000 “Life Plans” between 7/1/18 and 6/30/19: **“How many Life Plans have been completed since 7/1/18?”**

The OPWDD brazenly refuses to give any information on the Life Plan agenda. Is this because the OPWDD simply does not know? Is this because the number, which should be nearly 60,000 by now, is embarrassingly low? While there are many unanswered questions the answer to this one would reveal the current disaster. If the number is too low, then the federal government will have every reason to claw back hundreds of millions of dollars already paid to CCO/HHs: money was paid but services were not provided, which is the definition of fraud. The OPWDD is skating on very thin ice with Phase One of its deeply corrupt managed care agenda. Phase Two will only compound the instability and risk of fraud. The legislature and the public need to know who is in charge of the CCO/HH? Who is accountable for the ongoing care mismanagement disaster that is now costing more money to taxpayers?

Housing Issues Are Overlooked For Individuals With Developmental Disabilities Specifically The OPWDD Population:

Recently The New York City Human Resources Administration/Department of Social Services (HRA/DSS) was the subject of discrimination in the news media. What you do not hear about is what it is like for someone who cannot move, speak or understand, to access Services at these places. The truth is because this work is done by families and parents which is why the number one concern from us is: What will happen when we die? Who will advocate and navigate services for my adult child when I am gone?

CCO/HH Care Managers do not have the training and capacity to navigate housing issues for the Individuals with Developmental Disabilities population. CCO/HH Care Managers do not know how to advocate with of the Local Department of Social Services. Many individuals with I/DD and their families simply have no one to assist in navigating the Office of Temporary And Disability Assistance (OTDA) services. If parents and families of those caring for an I/DD adults died, there are very few who would assist them with accessing supports and services to meet their basic needs in order to remain in the community. Parents of this population are breaking ground and working countless hours to create programs for those with I/DD and are never compensated. Even worst are ignored and left out of the conversation. Many parents of those using Self Direction under the OPWDD say they are the real care managers.

All that we want is to ensure that our loved ones needs are met, that our children (including adult children) are not subject to repeated abuse, neglect and exploitation.

Group homes across the state have closed in favor of an integrated model and yet subsidy amounts have not been increased in over a decade and in some counties (like Manhattan) the rent subsidy is too low as compared to actual housing costs. The Live In Caregiver function is almost impossible to use the way it is currently designed. Most of the OPWDD Financial Intermediaries will not even accept a case that has the Live In Caregiver in the budget

Ideas that are innovative and cheaper for the taxpayers are usually developed by parents and caretakers. They do the everyday groundbreaking work and problem solving for their loved ones and at great cost.

Thank you for the opportunity to submit this testimony.

Please feel free to contact me with any questions.

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