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As demand on our system of care continues to build, solving the complex challenge of allocating scarce and limited resources while maintaining appropriate levels of care for New Yorker's with Intellectual and Developmental Disabilities (IDD) seems almost impossible. Without substantial additional funding on the horizon, the only viable pathway to achieving sustainability lies in developing and leveraging existing resources in an effort to control demand and improve the value of outcomes.

My name is Chris Palega, and I'm a parent who knows firsthand that being a family caregiver comes with profound and ongoing physical, psychological and financial stressors that are at times overwhelming. Just like so many family caregivers across the State, I deal with these challenges every day. Raising and keeping our developmentally disabled daughter safe and at living at home has been by far the most difficult challenge my wife and I have ever faced.

When friends tell me that 'I don't know how you pull it off', I think of families whose challenges are far greater than ours, and I'm humbled by the strength, fortitude, and resolve they demonstrate in caring for their developmentally disabled love ones at home.

Despite these challenges, many in our community believe that family caregivers who support their developmentally disabled loved ones at home are still the most powerful resource available to OPWDD as we work to solve our greatest challenges.

We, the family caregivers, are the largest sub-group of the direct care workforce. We number in the hundreds of thousands, and we're providing billions of dollars' worth of services without compensation. We have built, and we now maintain, the most utilized residential option for developmentally disabled New Yorkers by far, living at home with family. There is no doubt that family caregivers greatly reduce the demand on both the paid DSP workforce and much higher cost, much more restrictive Certified Residential Opportunities.

Today, I'm asking for your help as we work to support these families and the system of care we rely on every day.

Family Support Services (FSS) is OPWDD's only program intended to support families who are caring for their loved ones with IDD at home. FSS utilizes state-only dollars in order to provide a broad spectrum of flexible supports and services including crisis intervention, help for families with high and complex needs, recreation, respite, and reimbursement for the goods and services families need to help keep them intact and functioning. The program is tasked with meeting a number statutory goals including maintaining family unity and preventing premature or inappropriate out-of-home placement.

More than three decades ago, the State of New York clearly recognized the importance of this work through the adoption of Chapter 552 of the Laws of 1992, and its amendment of Mental Hygiene Law § 41.43. This important legislation clearly details the original legislative intent for FSS including that:

> *"Family support services should be family - driven, designed to meet the needs of the particular family requesting assistance as well as the needs of*

> *the individual with developmental disabilities, and flexible enough to meet the changing needs of such families."*
>
> *"the needs of the entire family should be considered in the development of family support services for individual families."*
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> *"…the legislature supports, to the extent allowable by existing state resources and legislative appropriations, the continued development and expansion of family support services, and the empowerment of families through the design of services which maximize the family's control over the nature of such services…"*

For many, Family Support Services are critical for keeping their family intact and functioning, as evidenced by the following experiences families have shared with me:

> *"Family Support Services has been a blessing that has helped us focus on our self-care and given us time to also support our other children."*
>
> *"FSS has been a God-send for our family…Without FSS we could not have kept him in the family due to many behavioral issues. He falls through the cracks in every available program."*
>
> *"The toll caring for two children with autism can never truly be measured…The breaks we do get from care are vital to keeping our marriage and family secure and manageable. In a system so in flux, one consistent support has been FSS."*

Unfortunately, years of policy driven disinvestment in the Family Support Services program has made it abundently clear that we must pause to become recquainted with the original legislative intent for FSS, and we must be guided by it to redefine how we value the work of family caregivers.

You may not be aware that despite a longstanding $97 million annual budget allocation for the provision of Family Support Services, there is currently only about $55 million in FSS under annual contract, with an additional $3.5 million annual investment slated to come back into the system in 2026. This comes after more than six years during which no FSS contracts were expanded or created to replace those that closed or were reduced. This includes providers across the State who choose to walk away from their FSS Family Reimbursement contracts due to the additional and unnecessary burdens placed on them by Administrative Directive Memorandum (ADM #2022-02R), the so-called Family Reimbursement ADM.

Despite clear legislative intent, under ADM #2022-02R OPWDD has compiled and implemented a restrictive "non-allowable" list of FSS goods and services without families playing a determinative role as described in MHY § 41.43 (c).

This has had a negative impact on families who struggle to keep their loved ones with developmental disbilities safe and living at home. As one family shared with me:

> *"My son Daniel has tried to use the Medicaid brand (three to be exact) of diapers as they requested. However, the diapers are so poorly made, that when he goes to the bathroom, it leaks all over his clothing. You can only imagine how embarrassing this is for a 10 year old boy who wants nothing*

> *more than to be just like his peers. I purchase diapers that work for my son and they cost me about $3,000 a year. There is no reason family reimbursement shouldn't cover this cost. We've tried Medicaid brand diapers. They don't work. Now let us use what does work and offer my son the dignity he deserves."*

This and other exclusions enacted via ADM #2022-02R, such as deeming some of our community's most challenged families as "paid caregivers" add to years of disinvestment in FSS while stifling the program's ability to serve families in a way that is family driven, flexible, effective, and accountable. As one family caregiver shared with me:

> *"…it floors me that those that are in the most severe crisis, get little to no help or funding. I'm not trying to sound overly dramatic; it is just true. I would love to know the statistics of families like ours that are on medication for anxiety, high blood pressure, panic attacks, post-traumatic stress, fear of loss of income and property destruction that we cannot get any type of reimbursement for. This encompass the whole family as a unit, not just the parents but also the siblings that live within the home. To take away ANY reimbursement from families that are paid caregivers, it is just another act of cruelty."*

There is a simple, cost effective legislative solution that will provide much needed and well deserved relief for families like these. I ask that you amend MHY § 41.43 (c) in a manner aligned with the programs original legislative intent, to unequivocally establish families' right to make determinations regarding what constitutes an appropriate good, service, or subsidy under FSS. And I ask that you you amend MHY § 41.43 (c) to insure that all qualified families in need have access to Family Support Services' full menu of supports.

There is a profound lack of available data on the FSS program. This deficit greatly hinders our ability to best support the hundreds of thousands of family caregivers who are critical to OPWDD's success. Unfortunately, at a time when OPWDD is making notable progress in the aggregration and dissemination of data, data on Family Support Services remains excluded from this effort by design.

We must engage in a data driven development of our understanding of the true, long term value of the system sustaining work of family caregivers, and we must develop a data driven understanding of how we can invest in these families to leverage one of the most expereinced, most committed, and most effective workforces in New York State, our family caregivers.

There is a simple, cost effective legislative solution that will ignite this effort. I ask that you amend MHY § 41.43 (e) by reactivating and further developing the sunsetted data collection and reporting requirements therein. This effort should include OPWDD, professionals from our community, family advocates and self-advocates, all working in partnership as we strive to understand the true value that unpaid family caregivers bring to a system of care in crisis, and how supporting these heroes can make the entire system of care more resilient, and even sustainable. I ask that you include legislative oversight of this critically important work.

A statewide FSS needs analysis survey that returned over 4,000 responses from family caregivers, self-advocates, professionals, and others demonstrated high levels of unmet need in all FSS service categories. Unfortunately, the severe and unnecessary underspending I've discussed has helped to create a service system where effective, high value FSS programs are by no means consistently available across the state. Of course, the negative impacts of this is felt disproportionately by rural communities and by communities who are traditionally marginalized and underserved.

At a time when the proposed 2027 Executive Budget seeks to reduce by one third the historical yet uninvested $97 million allocation, there is a simple and cost effictive legislative solution that will put us on a pathway toward what everyone is seeking, a sustainable system of care. I ask that you amend the family support services appropriation language during this cycle in order to ensure that OPWDD is investing the amount approved by the Legislature and Administration of the State of New York for FSS.

As influencers, policy makers, and leading government officials across the State work to redesign our current, unsustainable system of care, I urge you to keep in mind that regardless of how our monumental challenges are resolved, the people in the community that I've come to know have long been convinced that the success of any solution will be wholly dependent on the work of family caregivers who support their ones with intellectual and developmental disabilities at home.

Properly targeted investment in family caregivers, with or without Federal Financial Participation, is not only the right thing to do, but it is also among the most responsible and effective investments that can be made as we work to ensure the success of our system of care and the people who rely on it every day, because our community knows that making families stronger will make the entire system of care much, much stronger.

Thank you for the opportunity to share this important testimony on Family Support Services with you, and for your unwavering support for intellectually and developmentally disabled New Yorkers.

The image above is a word cloud generated by comments to an FSS Family Reimbursement ADM Survey that looked at the impact of ADM #2022-02R on OPWDD's ability to meet eleven stated and statutory goals for FSS. Survey participants were FSS Program Coordinators, FSS Agency Contacts, and their FSS Reimbursement Committee members. Data was collected after six months of ADM #2022-02R's implementation.

Overall, the research revealed that front line sentiment that felt the ADM reduced or greatly reduced OPWDD's ability to meet the goals queried (66.4% N=949) outweighed that which found that the policy enhanced or greatly enhanced the same (13.1% N=187).