



July 31, 2017

Dear SKIP Families:

I am writing to you with a heavy heart to explain the impending changes New York State is mandating to providing care for individuals (adults and children alike) with intellectual and developmental disabilities (I/DD). We believe wholeheartedly that these changes will be detrimental, and we are committed to safeguarding the interests of those we care about most – you, our SKIP families. We are making every effort to mobilize against the proposed transformation of the critical support system you have come to rely upon, and **we invite you to join us in raising our collective voices against these disruptive changes. Your voices can make a difference.**

The New York State's Office for People with Developmental Disabilities (OPWDD) is in the process of transitioning the care of individuals with I/DD to a new model called Coordinated Care Organizations (CCOs) which includes enrollment in Managed Care by July 2018. This model mandates that the coordination of Medicaid Services be shifted from voluntary provider agencies, such as SKIP, to State-selected large Care Coordination Organizations (CCOs). This new model would eliminate the role currently served by Medicaid Service Coordinators.

For the past 35 years, SKIP has provided transformative advocacy, guidance and care management for more than 5,000 I/DD children and their families each year, based in part on the simple understanding that family life enhances the healing process. Now, with these impending sweeping changes by the OPWDD to transition to their Managed Care model, it is clear that the very core of what has made SKIP programs so successful in helping families will be jeopardized, as will our families.

While every family is different, and may have varying medical, financial and emotional needs, the desire to keep the family intact is largely the same. Allowing I/DD children to stay in their own homes and communities rather than removing them to institutionalized/hospitalized care is the very foundation upon which SKIP was created.

The information below is intended to crystallize the complicated and bureaucratic issues for you based on our research and to the best of our understanding.

THE PROBLEM WITH THE NY STATE OPWDD TRANSITION TO MCO MODEL

The OPWDD plan to expand and tailor the Health Home care management program for people with I/DD is presumably intended to provide "person-centered, integrated 'conflict free' care management," with "more choice and flexibility." However, in implementation, it will have the opposite effect. The OPWDD has produced some very slick and verbose websites and communications tools regarding the proposed care delivery model and CCOs. However, the realities leave many shortcomings for the families they are intended to serve:

601 West 26th Street, Suite 522 ❤️ New York, NY 10001 ❤️ 212-268-5999 ❤️ Fax 212-268-7667
50 Vantage Point Drive, Suite 4 ❤️ Rochester, NY 14624 ❤️ 585-352-7775 ❤️ Fax 585-352-7879
338 Harris Hill Road, Suite 101 ❤️ Williamsville, NY 14221 ❤️ 716-626-2222 ❤️ Fax 716-626-2220
145 Village Square, Suite 102 ❤️ Painted Post, NY 14870 ❤️ 607-973-2262 ❤️ Fax 607-973-2347

- There is virtually no proof of concept to this proposed new model; no analytics, no review or results assessment from the state(s) (i.e., California) that have adopted a similar model. Considering that this MCO model is upending the I/DD community, *the lack of testing and review is astounding.*
- The new model's focus on children presents as more of an afterthought than a priority. There is no requirement to have any expertise with the 0-21 aged population and no compliance for EPSDT (Early Periodic Screening, Diagnostic and Treatment) that is the core of the child health component of Medicaid.
- That medically fragile children can simply be rolled into a new home health model does not recognize the nuances of a community-based model for children. Case in point: the State's OPWDD Valued Outcomes requirement, designed to be "person-centered," does not directly address children or their families.
- The new OPWDD plan will create even more layers of bureaucracy and shifting processes. Rather than bringing more choice and flexibility, the formation of large overseeing entities will force the closure of smaller community agencies and will jeopardize the relationships with families, many of whom have been long-term members. The new plan would require that all CCOs have a minimum of 5,000 members, and are therefore likely to create large and cumbersome agencies with limited personalization for the families.
- Third-party insurance (which more than half of SKIP families hold) and HIPPA regulations (which may prevent an easy sharing of information, electronic and otherwise, with newly formed CCOs) will likely render a seamless transition to the new model ineffective and/or unachievable.
- To date, there is a lack of substance to this plan, which has a timeline extending into 2018 for implementation. A new network of OPWDD-approved CCOs and providers must be established, approved, and on-boarded. It is naïve to assume that these new organizations will be able to fill the same role in improving the lives of children with disabilities and in navigating the myriad of issues, large and small, that their parents/guardians/caregivers face and must contend with on a daily basis.

THE IMPACT ON OUR FAMILIES

Above all, at this point in time, with the Affordable Care Act, Medicaid and the healthcare system as a whole being rocked to its core more so than at any other time in history, it is untenable that such sweeping and unsubstantiated changes be made to a system that, for the purposes of many I/DD families, has worked well.

While under Federal law, state Medicaid programs must cover certain populations, including disabled children, it is the optional and most expensive programs that may be targeted for cost reductions. Programs that defray costs of home aides and medical equipment that help severely disabled children (and adults) to stay in their homes in their communities may be at risk, and the lifeline that SKIP provides in care coordination and advocacy would be threatened.

Quite simply, at a time when so much in the healthcare world is evolving, and vital programs may be altered, it is even more important that I/DD families get not only the medical/financial assistance you may need, but help in understanding the unfolding labyrinth toward achieving quality care for their child, the very care SKIP provides.

By living at home with their families, medically fragile and disabled children are able to participate in family life, and at a lower total healthcare cost. In New York State, the average

cost of hospitalization per child exceeds \$337,000, while at-home care costs an average of about \$69,000, a savings of more than 80 percent.

Specifically, the planned changes will include:

- A proposed transition to CCOs, comprised of networks of existing OPWDD providers that will provide integrated care coordination as Medicaid Service Coordinators (MSCs) are transitioned out of care manager roles into new roles with big agencies.
- A transition that is largely being dictated by the Federal government, the Centers for Medicare & Medicaid Services (CMS), in an attempt to dissuade conflicts of interest in care management and services.

Here's what it means for SKIP families:

- Families will undoubtedly be uprooted. Approximately 50-60 MSCs would be reassigned or eliminated out of SKIP's team of more than 150 dedicated MSCs. This means that nearly 2,000 I/DD children, and their families, currently served by SKIP would lose the close relationships and history they have built with our committed staff.
- These families will virtually be on their own to navigate the new bureaucracies. Children may lose the routines and services they have come to know and understand. While a transition period of a year or so is par for the course within the government, for a family dealing with a child with I/DD, that time is critical to their well-being and hope for moving their child forward.
- By its very nature, the transition will result in losing the convenience and close collaboration of working with SKIP as a comprehensive resource. SKIP case managers have worked with countless families to guide them on everything from ensuring fair hearings to understanding school IEPs to arranging for nurses and home care so that family members may continue to work, or even just go to the grocery or attend an event -- everyday matters that many of us take for granted.
- Referrals, interviews and caregivers will be more so assigned than selected. Presently, most of our referrals are from SKIP families recommending us to other I/DD families in need. That sense of family will be lost. We currently have about 300 families on our wait list, and due to the impending changes, SKIP has had to curtail new enrollments.
- While the goal of the new CCO plan is to integrate primary, behavioral and specialty healthcare under one umbrella, because it is not designed for the pediatric community, some pediatric sub-specialties will see limited support. Wait times for those in need of treatment by a psychiatrist, for example, may exceed six months in certain regions.
- The required appeal system and assurance that rights are protected are not clearly enforced under this new OPWDD plan.
- Overall, the new Managed Care model is unsustainable and the ratio of family to staff will likely increase, making it harder and more complicated to secure the support that is greatly needed.

WHAT YOU CAN DO

SKIP is making every effort to push back on this new model in its currently proposed form and, quite frankly, to stop it in its tracks.

We need your help as a powerful opposition voice. We understand that you are oftentimes overwhelmed with just the daily tasks of family life with an I/DD child. So, please, let your voice

be heard in any way you can about these planned changes which are sure to directly impact your family. **Here are some ways you can participate and make a difference.**

- We will provide templates for letters, as well as phone numbers, for you to contact your state and local representatives in the NYS State Senate, NYS State Assembly, the US Congress and US Senate, as well as for outreach to the Governor, the Commissioner of Health and the Acting Commissioner of the OPWDD. If you are comfortable with sharing an overview on your circumstances and how your family life, health and livelihood depend on the services you receive from MSCs at SKIP, we encourage you to provide background when communicating with officials, but remember to keep your family's privacy in mind.
- In addition, we are in the planning stages for a forum to be held in late summer at the SKIP New York offices so together we can address these issues. Please email me directly at mmikol@skipofny.org to let us know if you are interested in attending. If it is too difficult for you to join us in person, let us know if you would be available to participate remotely via call-in or Skype.
- Please let us know if you have workable relationships with legislative leaders in New York State or with members of the media. We do have such relationships, but more is better for such advocacy campaigns.
- Please let us know if you are willing and able to be interviewed by media who may be interested in this issue and/or whether you would be willing to provide us with a quote we can use in our communications with media, legislators and/or other key influencers.
- At some point we may sojourn to Albany to make our case in person to legislators. Please let us know if, schedules permitting, you would be willing to join us in that endeavor.

It is our honor to serve our SKIP families and we take our responsibilities in case management very seriously. We hope you will join us in making every attempt to thwart this new and inadequate model of Managed Care for your children and all I/DD children.

Please contact me directly with your response and about any questions you may have.

Thank you.



Margaret Mikol
Executive Director
mmikol@skipofny.org
212-268-5999