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June 9, 2020

The Honorable Andrew M. Cuomo  
Governor of New York State  
NYS State Capitol Building  
Albany, NY 12224

Dear Governor Cuomo:

We are writing to ask that you coordinate with OPWDD Commissioner Dr. Kastner and DOH Commissioner Dr. Zucker with regards to the Developmentally Disabled population and the Group Home visitation policies and the Day Habilitation Programs re-opening. As you know, all visitation to group homes stopped in March due to the Corona virus and all Day Habilitation programs stopped at the same time. At that time, we were in the midst of the pandemic and the outbreaks were on the rise. Everyone was in complete agreement that those decisions were the appropriate decisions in order to protect our vulnerable population. Since that time, many of the families have been waiting for and searching for continued guidance about visiting their loved one and about when day hab programs could re-open. Many have reached out to OPWDD and/or DOH and have been told it is up to the Governor. With the pandemic on the decline and more and more of the state beginning it's UNPAUSE, the families are desperate to get their loved one's quality of life back. Here are some of the FACTS directly from the families:

**Mindy K. Rosengarten** FACT: we have not seen our son since March 8th. He is non verbal and it's not enough to see him over FaceTime. It is time to allow socially distant visits at group homes.

**Debbie Kniesser Knapp** FACT: My 15 yr old son is in residential. I have not seen him smile once in any picture, any FaceTime, or at either of the two short visits I've had with him. He is sad, frustrated, having increased behaviors due to lack of routine and services, being able to see his family, go into the outside world at all!

**Kevin Cooney** FACT: My daughter is non verbal, she is now melting down over the quarantine. She needs to return to day hab. The parents of children in group homes have not seen their children in months. The special needs community has been ignored.

**Patricia Hanna- Graff** FACT: Group homes are not like nursing homes and should not be treated as such. My son lives with 5 other individuals, not a large facility. If staff come and go daily, why can't families follow the same safety protocols and visit?

**Wendy Kanis** FACT: People with special needs are being separated from their families and their rights are ignored.

**Amy Johnson** **FACT:** We can accompany our loved ones to dr visits but cannot have them visit our homes.

**Annie Noel** **FACT:** My son is 19 years old and in residential. Visiting on the grounds once a week for 30 minutes is not enough. He wants to come home and misses going for car rides, and basically just to see the outside world. He was always a very happy kid,, but as time goes on I am seeing him looking sad, depressed, and lost the sparkle in his big beautiful eyes. The simple things that he always loved does not make him happy anymore. He cannot benefit from distance learning, he keeps saying he wants to go back to school, and he is slowly starting to regress. He just wants to come home and spend time with his family. Our kids should not be in phase 4 grouped with nursing homes. Please listen to all these desperate families begging for a change.

**Marilyn Dagostino** **FACT:** Why can't I visit a group home when the staff is in and out all day. They have as many germs as me. I wash, water a mask and will get my temp taken. Strangers are allowed in, and not me. This is a home not a nursing facility, Very different.

**Pat Reagan Webster** **FACT:** My son, who lives in a group home, routinely asks staff about visiting family. **FACT:** My son and his housemates are young men and are not at the same risk from COVID as elderly Nursing home residents. **FACT:** My son and his housemates are exposed to several staff daily all of whom go out into the community. He is not in a sterile environment so what does keeping him from his family accomplish.

**Susan Iovino Brunjes** **FACT:** My son is 24 in group home. After 1 month of lock in he couldn't handle it. It was height of the pandemic and I was afraid he'd hurt himself and god forbid need medical attention. I took him home. Now fast forward 7 weeks later and he still home and it's rough but I can't bring him back till restrictions change. They have done nothing at all with plans and provisions to unpaue safety.

**Jennifer Blazar Schutzer** **FACT:** My son feels abandoned. He cannot understand why he can't come home to visit. He is very sensory seeking and has gone 11 weeks without a hug.

**Amanda Palumbo** **FACT:** My brother will not answer our phone calls or FaceTime for over two weeks because it's too much for him to hear us and not be able to see us.

**Jan Hurtado** **FACT:** My daughters are in same group home..been in lockdown mode for 3 months ..their mental health is being effected..confused, depression, elopement...they are at a developmental level of 2yr old. Autistic, Non- verbal..Don't understand why my husband and I are not present in their lives..no home visits us visiting them at residence, feeling abandoned...Only 5 young women ages (23-30) in household..No covid cases ever..its not a nursing home...it cannot go on...it'll destroy who they are..they will become angry later in life.

**Catherine Volgende Snaith** **FACT:** Our 24 yo nonverbal son's sIB aggressive Behaviors have gotten worse since his day hab program stopped. One incident required him to seek medical attention at CityMD during the height of the pandemic! ( putting him at higher risk to contract the virus) We have brought him home from residence since March ( for the 2 week 'pause') and have had some very very difficult days since-as in crisis mode -almost 911 calls-agitated,OCD-wants no part of online sessions-we agreed with his doctor to increase his medication on such occasions but by doing so we put him at risk for seizures. He needs his schedule back-Home visits from residence and day hab open.

**Stacey Schultz Wohl** **FACT:** my non verbal son is at an autism boarding school and we have not seen him since February. I have a daughter with autism who was abused and mistreated at A long island boarding school and it was extremely hard for us to place my son. We went every week or two to see him or bring him home for a visit.

**Linda Zukoski Brady** **FACT:** My 29 year old Autistic-Non Verbal son with epilepsy has been regressing since having no program. He doesn't have any understanding of a story to tell him about COVID. A lot of crying and meltdowns.

**Russell Snaith** **FACT:** It has been over 75 days of lockdown and there has been one communication from OPWDD with no new information, evidence of progress in re-open plans or actions to provide protocols and guidance to service providers. **FACT:** Service Providers are waiting on OPWDD for direction. **FACT:** We have had to adjust meds to address behaviors brought on by the lack of routine, outings and Day Habs. This in turn, causes other issues with unwanted side effects and exacerbates their conditions.

**Rosetta Atteritano Malvese** **FACT:** I can't believe I have to justify having a relationship and seeing my daughter in her group home .... this is insane !!!!

**Lisa Krebs Borgen** **FACT:** Those in group homes have not seen their family in months and can't get answers on when they can see their children. And in all this dysfunction, cuts/changes to the HCBS waiver and Medicaid are still being discussed to cause even more horror and less services. Those with special needs should not be the forgotten and overlooked!

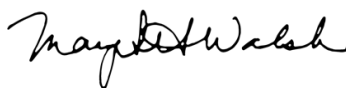
**Caroline Frers Breuers** **FACT:** My 23 year old son who lives in a group home has shown evidence of mourning us by either having behaviors (he hit the wall so hard the blind dislodged and hit him) while looking out the window to the parking lot where he expects to see us coming or by becoming very quiet, sad & non responsive when looking out the same windows expecting a visit that can't happen!

Please consider the lives of these individuals and their families. We fully respect that this needs to be done in a safe manner with safety protocols in place, but it is time to figure it out.  
Thank you very much!

Sincerely,



Missy Miller 20<sup>th</sup> AD



Mary Beth Walsh 112<sup>th</sup> AD.



Ed Ra 19<sup>th</sup> AD