

Two parts

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Mitchell Shear, M.D.
2 Hayloft Lane
Roslyn Heights, NY 11577

February 11, 2014

Senator John A. DeFrancisco
Chair, Senate Finance Committee
416 Capitol
Albany, NY 12247

Assemblyman Herman D. Farrell, Jr.
Chair, Assembly Ways and Means Committee
LOB Room 923
Albany, NY 12248

RE: Testimony Before the Senate Finance Committee and the Assembly Ways and Means Committee Concerning the Governor's Proposed Budget

Dear Senator DeFrancisco and Assemblyman Farrell:

I am here today with my wife to express my deep concern regarding budget and policy changes that could potentially result in the removal of my daughter, Samantha, from her life-saving residential placement at the Judge Rotenberg Educational Center, Inc. ("JRC") in Canton, Massachusetts. The Governor's budget claims a "savings" of almost \$8 million, a savings that is a result of returning to the state about 100 transitional care adults who were placed in programs outside New York as school age children. If the Legislature accepts a budget that requires the return to New York State of disabled persons placed outside of the state, without exception or any right of appeal, would be the equivalent of signing a death warrant for my daughter.

I am a physician by training. I am licensed in the State of New York and I am Board certified in the fields of Internal Medicine and Geriatrics. I currently have my own private practice serving adult patients. But today I appear before you not as a doctor but as a father.

I would like to tell you about my daughter and how JRC has saved her life. My wife, Marcia, and I first discovered our daughter was different when she was about two years old. She would not relate well to others, had very little speech, and would stare at her hands or small objects for hours at a time. She also had frequent tantrums and cried often. She began with early

intervention, and over the next ten years, she attended four specialized schools for autistic children, all in New York State. Numerous therapists and teachers also came to our house to work with our daughter after hours, most of which we paid for out of our own funds. All of these schools worked closely with her in small groups, and on a one-on-one basis, using learning trials, and positive reinforcement. In addition, she was under the care of a psychiatrist, and given heavy dosages of several different psychotropic medications. Despite the best efforts of many talented and dedicated professionals, she required the use of a helmet with a faceguard, weighted and padded gloves, and physical restraint to protect her head and face.

No matter what we tried, our daughter continued to progressively deteriorate. Over the years, she became more violent. She would attack us, other children, and her teachers. She would bite, scratch, kick, hit, pinch, and head-butt. She became increasingly self-abusive. She would throw herself on the floor, hit herself, and throw herself against hard objects. She constantly had marks and bruises on her body from her own self-abuse. We were also prisoners in our own home; we could not take her anywhere, due to her behaviors. This had an impact on our other children as well. The final straw came when she hit herself in her head with such force that she detached both retinas of her eyes and was virtually blind. The Anderson School, where she was at the time she detached her retinas, told us they could not handle her, and asked us to find another school. This is when we learned about JRC.

Samantha has been at JRC since 2005. Shortly after her admission, and with judicial approval and our consent, aversive therapy began. This treatment uses a graduated electronic decelerator (“GED”) device, which administers a two second shock to the surface of the arm or leg, and it was incorporated into her program at JRC. Within several weeks of getting treated with the GED device, a miracle happened—our daughter stopped hitting herself, and stopped her violent behavior. She appeared much happier. She was able to be weaned off all of her psychotropic medications which caused her side effects including tremors, anxiety, insomnia, sedation, increased agitation, hyperactivity and loss of appetite. As a physician, I was amazed that a few weeks of skin shock accomplished what years of other protocols, treatments, and drugs could not. As a father, I was overjoyed.

There was, however, a period of deterioration. In June 2006, aversive treatment became a big issue in New York State. The Board of Regents passed a regulation that prohibited the use of the GED for the antecedent behaviors that lead up to more aggressive and self-abusive behaviors. Our daughter became more aggressive and angry. Some of her old harmful behaviors returned. Parents of JRC students, including my wife and I, went to Federal District Court and obtained an injunction, stopping the State Education Department from enforcing this regulation with respect to persons for whom aversive therapy was part of their IEP. After the judge's decision, the GED was once again able to be applied as indicated in Samantha's treatment program at JRC. Our daughter improved, was happier, and was no longer dangerous to herself or others. This was proof that she needs an ongoing program that offers intensive 24 hour per day behavioral treatment delivered by highly trained staff which includes, when necessary, aversive therapy and the GED. Such a program is simply not available to her in New York.

Because of her treatment at JRC, Samantha has been able to undergo medical treatment to help address the damage she did to her vision by detaching her own retinas. While her vision is still far from normal, she has required six eye surgeries to repair the damage she inflicted on herself. None of these surgeries would have been possible, prior to her treatment at JRC. More recently, our daughter had another challenge. Due to a congenital condition, she had to undergo complex orthopedic surgery on both legs to correct a balance problem, and prevent future arthritis. JRC staff were absolutely wonderful at providing her the needed care to successfully accomplish this surgery. They accompanied her to all of her appointments at the Boston Children's Hospital. She remained in the hospital for 6 days after her surgery. JRC had staff members in her room 24 hours a day during her entire stay in the hospital. In her post-operative period, the staff was with her in her residence at all times, and met her every need. She could not bear weight for six weeks post-operation, and the staff helped her and transported her to school and to all of her post operative doctor's appointments. One of the most remarkable things about her surgical experience is, through all her pain and all her frustration of not being able to walk, she remained calm, and pleasant. This proves the durability of Samantha's treatment program at JRC. If she were anywhere else, we are certain her old behaviors would have returned, and would have affected her post-operative outcome. She could not have had this medically necessary surgery prior to receiving treatment at JRC.

Our daughter has now been at JRC for almost nine years, and we have seen nothing but love and affection for her on the part of the entire staff. The bottom line is that this program has helped, and continues to help, our daughter. In contrast, all other programs, including all of the programs we have tried in New York, have failed. Our daughter is a different person than she was nine years ago. She is happy, able to concentrate and learn, and fun to be with. She is not on psychotropic medications. She no longer requires physical restraint or a medically necessary helmet to keep her safe. She has made significant academic and social progress and has been able to go on field trips and to enjoy visits with her mother, two brothers, and me. Samantha's placement at JRC has done more for my daughter and for our entire family than we could possibly express in words. There is no program in New York that could provide this quality of life for our daughter or keep her safe from her own dangerous behaviors.

But Samantha is now almost 21 years old, and in anticipation of her transition to adult services, we have been contacted by the Office for Persons with Developmental Disabilities (OPWDD) and informed they will identify a placement in New York for Samantha. No such placement has been identified, and I seriously doubt that there is no in-state program that can safely treat my daughter's severe disabilities.

My wife and I believe that our daughter would be dead, or in an institution isolated and heavily restrained and sedated, if it were not for her treatment at this wonderful school in Massachusetts, and its caring staff. I know that there are many other parents from New York who feel the same way. Along with other parents of New York students at JRC, my wife and I have asked OPWDD to consider the severity of our children's disabilities, to not act recklessly with regard to our children's health and safety and to provide us with answers regarding what services OPWDD plans to provide to our children in New York. The response from OPWDD has been disappointing and our questions have remained unanswered. I have attached the most recent correspondence here.

In summary, I ask you to please consider the severe effect this proposed budget could have on these disabled individuals and their families if they are forced to leave JRC and return to

New York without ensuring that they can receive the care and treatment they need to survive. I strongly urge you to reject any proposal that could have such disastrous effects. Alternatively, if you must allow OPWDD to bring these disabled individuals back to New York, at the very least give us as parents the same due process rights to challenge a change in placement or services as currently exist for disabled adults in New York. Without the right to have an OPWDD decision reviewed by an impartial hearing officer, and ultimately a court, a decision to move our daughter could literally be a death sentence.

Sincerely,



Mitchell Shear, M.D.

July 10, 2013

Jill Gentile
Associate Commissioner
New York State
Office For People With Developmental Disabilities
44 Holland Avenue
Albany, NY 12229-0001

Re: OPWDD Clients Living at JRC

Dear Associate Commissioner Gentile:

We are the parents of severely disabled adults from New York residing at the Judge Rotenberg Educational Center, Inc. ("JRC"). Most of our children are funded by the New York State Office For People with Developmental Disabilities ("OPWDD") and the remainder are in the final year(s) of New York special education funding and will be eligible for OPWDD funding within the next two years. Our children suffer with severe behavior disorders that cause them to engage in self-mutilation, violent aggression or other behaviors that have caused them serious harm, and in some cases have threatened their very lives. Our children were not effectively treated or cared for in New York placements, including in New York hospitals, and they were experiencing intense pain and physical deterioration until their New York school districts placed them at JRC. Most of our children have been residing at JRC for many years. They have all received effective behavioral treatment at JRC, which has kept them safe, happy and very healthy. They have made more behavioral, medical, educational, vocational and social progress at JRC than we ever thought possible. Our children at JRC range in age from 19 to 42 and some have lived at JRC for 20 to 30 years.

At JRC our children have found a safe place to live and thrive. To our knowledge, JRC is the only program equipped to effectively treat our children and keep them safe with its 24-hour intensive behavioral supports, trained staff, expert medical services and proven capability to address the toughest behavior disorders. We visit our children often, as we did when they were suffering at ineffective New York programs and hospitals, and we have seen for ourselves JRC's ability to keep our children safe and healthy, as compared to the dire conditions when they were previously placed in New York. As a group, we have seen countless programs in New York that have attempted to treat our children, and none of them have had any success; they often resorted to sedating, restraining and/or isolating our children, which caused them great pain and suffering and allowed for no quality of life. Through its effective behavioral therapy, JRC has been able to stop our children's dangerous behaviors without heavy dosages of sedating drugs or restraints, which has given our children their first chance in life to safely spend quality time with their families, get an education, learn a job skill and become integrated into the community.

In February, 2011, over two years ago, OPWDD sent each of us who had adult children residing at JRC a notice that OPWDD was partnering with unidentified New York "providers" to develop services in New York that would meet our children's needs. The same notice was sent to those of us who have children residing at JRC who will be aging out of New York special education

funding within the next two years. However, OPWDD has yet to identify New York providers that have developed an effective behavioral program that addresses the unique behavioral needs of our children and could manage their dangerous behaviors without resorting to heavy dosages of psychotropic medication, restraint and isolation. While a few parents have been contacted by a New York provider, in each case the provider was not knowledgeable about the needs of their child and did not have a viable plan for providing effective services. Since February, 2011, we have been asking OPWDD for information about the types of qualified placements that will be available for our children in New York, and for a description of the behavioral therapy and other services that will be used to treat our children as effectively and safely as JRC is so successfully doing. The only concrete information that OPWDD has given to us is that Governor Andrew Cuomo has ordered the agency's leadership to return all of our children to New York by June, 2014, at which time all OPWDD funding of our children at JRC will stop. If we do not accept the New York placements to be offered to us by OPWDD, then OPWDD will immediately end funding at JRC. OPWDD has also told us that our children may again be subjected to heavy dosages of dangerous, sedating medications if our children's dangerous behaviors return after they leave JRC.

It seems to us that OPWDD's only priority is that it comply with the arbitrary order of Governor Cuomo, that all of our children must return to New York by June, 2014, regardless of their needs and regardless of the risk of irreparable harm that such a move may cause to our extremely vulnerable children. This merciless mandate is, of course, counter to and directly violates OPWDD's responsibilities; as often quoted by OPWDD: "The Office for People with Developmental Disabilities is responsible for identifying and providing appropriate service in the least restrictive setting possible to New York residents with developmental disabilities who have aged out of educational and child care programs." OPWDD also said in a 2011 letter to many of us:

OPWDD's vision for your adult child, as well as all individuals we serve is to enjoy meaningful relationships with family, friends and others in our lives, experience personal health and growth and live in a home of their choice and fully participate in their communities. Our mission is to help people with developmental disabilities live richer lives.

If OPWDD moves our children back to New York by June, 2014, it will deprive them of JRC's appropriate services and least restrictive community setting, where they are thriving for the first time in their lives. JRC's program has given our children the opportunity to enjoy meaningful relationships with family, friends and others, to experience personal health and growth, to live in a home of their choice (i.e., JRC) and to participate in their communities at JRC. Our children's lives are richer now at JRC, particularly when compared to the pain, injury and sorrow they previously experienced while admitted to ineffective programs in New York and were drugged into submission.

In multiple letters sent to each of us in the past 18 months, including on February 18, 2011, October 24, 2012 and February 25, 2013, OPWDD stated its "commitment to develop quality adult services in New York" and expressed its intent to "transition" our children away from JRC.

Yet, OPWDD has not provided us with one reason to support this “transition,” or even to make sense of it, other than “the Governor has ordered it, and so we have to do it.” We have expressed to numerous OPWDD officials, and to JRC officials, our outrage over this arbitrary and reckless government decision. Many of us have spoken with OPWDD, asking for information about how OPWDD plans to move our severely disabled children back to New York without causing them severe emotional and physical injury, and potentially death, including the questions described below. OPWDD has not been able to answer any of our questions. Apparently in response to our many questions and intense fear, OPWDD scheduled a family information session to occur at two locations: March 18, 2013 in Hauppauge, N.Y.; and March 19, 2013 in Manhattan. We attended those meetings and participated from beginning to end, but again OPWDD was unable to answer our critical questions. OPWDD’s slide presentation and talk did not contain information that was new or responsive to our concerns. The lack of information from OPWDD about a “Governor mandated” move of such a large, intensely disabled and fragile population has us all frightened and very concerned for the health and safety of our children.

The dire concerns we have, and the questions we have been asking OPWDD with a lack of response, are as follows:

1. Where will OPWDD send our children? In the past, we have been forced to perform exhaustive searches for appropriate New York placements for our children, and found none. One of our children was rejected from seventeen placements in New York before he enrolled at JRC. Most of us have had a similar experience. Now, OPWDD seeks to force us to once again engage in a futile search for an appropriate placement in New York that simply does not exist. The New York placements where OPWDD hopes to send our children have told each of us, time and again, that they simply do not have the staffing, training or skill required to effectively treat, protect and care for our children.
2. How will OPWDD and its “providers” treat our children? OPWDD has not identified any new treatments that have not already been tried and failed with our children at previous placements in New York. One of our children, who suffered two detached retinas as a result of her uncontrolled head-banging while in the care of a New York placement, was unsuccessfully treated with positive behavior supports at four different placements in New York before enrolling at JRC. Most of our children have had similar experiences with failed treatments. We are concerned that without any new treatments, and without any data confirming OPWDD’s transition success rate, that any New York placement will be ill-equipped to manage our children’s treatment and care. There is simply no program in New York with the 24-hour intensive behavioral supports and the trained staff that is provided at JRC. By returning our children to New York, OPWDD unnecessarily risks injury to our children. Our children’s health and safety should not be sacrificed so that OPWDD may experiment with the same treatment approaches that have failed our children in the past.
3. Will OPWDD and its “providers” sedate our children with drugs against their, and our, wishes? OPWDD has acknowledged that any New York programs to which our children are transferred would have the right to heavily drug our children if they cannot control our children and there is a risk of harm to our children or the staff. Our children were

heavily drugged when they were placed in New York prior to JRC. When our children were previously placed in New York, those placements would threaten to go to court or take custody of our children away if we did not consent to their use of heavy dosages of medication. The use of drugs with our children is dangerous and, as demonstrated by JRC, unnecessary. Any New York placement that depends upon the prescription of medication for the treatment and care of our children is not an acceptable or appropriate placement.

We have received OPWDD's most recent letter, dated May 23, 2013, thanking us for attending OPWDD's March family "information" session. This letter, again, does not give us any answers to the questions that we have been asking. The letter does repeat what appears to be OPWDD's only priority: funding at JRC will end once OPWDD offers any services in New York to our children. These New York "services" remain unidentified. The letter repeats OPWDD's acknowledgment that psychotropic medication may be used with our children if they return to New York. The letter claims that a "majority" of the individuals who have returned from JRC are "doing well." We have been hearing from New York parents of former adult JRC residents that their children have gravely deteriorated and are restrained, isolated and suffering severe pain and injury because their new New York placements do not have effective behavioral treatment and/or staff qualified to treat severe behavior disorders. They are being sedated with heavy dosages of psychotropic medications. They have been admitted to psychiatric hospitals for so-called "stabilization." Rather than effectively treat their behavior disorders, their New York providers have reported their children to the police. It appears that these individuals are part of the "minority" who have returned to New York from JRC and are not "doing well." Our children continue to need JRC's intensive behavioral program and they will become part of the suffering minority if OPWDD attempts to continue on this reckless path of returning our children to New York, regardless of their needs. Finally, OPWDD's letter offers to involve us in developing and shaping the services to be provided to our children in New York, but this is impossible given that OPWDD cannot describe these services or answer any of our questions about these services.

OPWDD's stated "plan" to pull our children out of the only proven, successful program where our children have made progress, without any evidence indicating a likelihood of our children's success with the same New York placements and treatments that have failed them in the past, is insufficient and inappropriate for our children's needs. We urge OPWDD to reconsider this unnecessary and reckless position, and to continue to support our children at JRC.

Sincerely,

Myron Staff
Myron Staff
Shabekia Lewis
Elizabeth Rivera
~~Staff~~
SURAIYA NASSER

Juan Staff
Lorraine Staff
Carlo Casoria
CARLO A. CASORIA
Amar Miller
ANAMAR MILLER
4
PAMELA BYERS

Cornie Watson
CORNIE WATSON
Cheryl Lawler
Cheryl Hawler

horraine Biggs
horraine Biggs
Alma Garcia
Patricia Crawford
Patricia Crawford

Mari Rogus
MARIE ROGERS
marcia Shear
Marcia Shear
Mitchell Shear
Mitchell Shear

B. J. Saff
Bartii Sangare
Barbara MUKOMANA
BARBARA MUKOMANA
Phyllis Coughman
Phyllis Coughman

ALMA GARCIA
jeanette ALLEYNE
Jeanette ALLEYNE

ONE-CLINTON BROWER
ONE-CLINTON BROWER
Kosaly (Coughman)

Cheryl B. Lloyd / Cheryl B. Lloyd
Stonia ALVARO - Anthony

Kelly Swanson
[Signature]

Elsa Nardi
Edgardo SANDY
Edgardo SANCHEZ

Daisy Ramo
Melys [Signature]
Melys SANCHEZ

cc: Senator David Carlucci
Assemblywoman Eileen M. Gunther
Assemblywoman Donna A. Lupardo
Senator Simcha Felder

Courtney Burke, Commissioner NYS OPWDD
Glenda P. Crookes, Executive Director JRC

Luigi Montilla
Luigi Montilla
Kapustina
Larisa Kapustina
A. Kapustin
Alex Kapustin

Marie Washington
MARIE WASHINGTON
Jan Washington
SENKID WASHINGTON

cc: Senator David Carlucci
Assemblywoman Eileen M. Gunther
Assemblywoman Donna A. Lupardo
Senator Simcha Felder
Courtney Burke, Commissioner NYS OPWDD
Glenda P. Crookes, Executive Director JRC



September 26, 2013

Dear JRC Families:

Thank you for the July 10th letter where you expressed your shared concerns about your family members leaving JRC and receiving adult services in New York State. I am very sympathetic to your concerns and I understand that many of you have had difficulties in the past getting the needed care for your family members. I want to assure you that OPWDD only wants the best for your family members, only wants to help them live rich full lives in the community.

Currently, your family members are at a school. The school is intended to serve students until they are 21 years old. OPWDD doesn't have the long term authority to fund individuals in school settings. Your children, as all children, should be afforded the opportunity to receive age appropriate services and move on to their adult lives. The services offered by New York State providers are far more varied than those offered in school settings and are individually developed based on the choices and interests of the individuals and their families. Each service plan is tailored to the individual and is revised as the individual's interests and needs change.

I would like to take this opportunity to discuss some of the concerns shared in your letter and to assure you that OPWDD clinical staff will be reviewing each adult services plan developed by a provider to ensure the provider can meet your family member's needs.

A concern mentioned in the letter is that families will be responsible for searching out services on their own. This is not the case. OPWDD has identified providers and will continue to identify providers that can serve your family members; OPWDD will do its best to provide families with a choice of providers. Another important concern mentioned in your letter is that many of you didn't have success with providers in New York State in the past and that New York State providers are ill equipped to serve individuals with severe behavior disorders. Many OPWDD funded agencies serve individuals with challenging behaviors that are very similar to those of your family members and serve them successfully. These agencies have behavior intervention specialists (many of whom are nationally certified behavior analysts), licensed psychologists, psychiatrists, medical doctors, and nurses on their staff. They have staff with the skill and experience to work with individuals with challenging behaviors. In addition, OPWDD will not approve an agency to provide services unless our clinicians believe that the agency can provide the appropriate services. Prior to OPWDD making an official adult services offer, OPWDD clinical staff review a preliminary service plan for each individual to ensure the agency has the appropriate staffing in place, that the agency has a behavior support plan in place, and

Executive Office

44 Holland Avenue, Albany, NY 12229-0001, TEL: 518-473-1997 FAX: 518-473-1271
75 Morton Street, New York, NY 10014, TEL: 212-229-3231 FAX: 212-229-3234
101 West Liberty Street, Rome, NY 13440, TEL: 315-336-2300x246 FAX: 315-571-7115
500-A Balltown Road, Schenectady, NY 12304, TEL: 518-381-2110 FAX: 518-381-2150
TTY: 866-933-4889, www.opwdd.ny.gov

We help people with developmental disabilities live richer lives

that the services described will meet the individual's needs and interests. This plan is sent to the family with the formal adult services offer so that the family can review it before giving consent to the service offer.

I understand that many of you remain concerned about the use of psychotropic medication with your loved ones. OPWDD has a rigorous process for approving the use of such medications, and absent an emergency, such medications cannot be used without your consent or a court order. A number of our provider agencies that have been serving former JRC individuals for more than a year have not used psychotropic medications for these individuals. Although OPWDD cannot guarantee that psychotropic medication will never be used for a particular individual, we can assure you that you will be consulted if it is being considered, and that the provider will discuss with you the reasons why it is believed the medication is necessary. In addition, medication when used effectively does not impair a person's ability to function but instead, increases the individual's ability to integrate into the community and to fully participate in his/her own life.

I know many of you hear rumors about individuals returning from JRC with ill consequences but contrary to these rumors, these individuals are living full lives in the community.

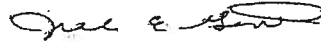
Once again, I encourage you to participate in the planning process. OPWDD has many opportunities available for your family members and you can play an integral role in developing the services that will best meet your family members' needs.

- You can choose to have your family member come home and receive the services needed to support him/her at home.
- You and your family member can self-direct the services and hire your own staff to provide them.
- Your family member can live in a small community residence, in a shared apartment or in his/her own apartment with supports. In some cases, you can help determine the location of the residence.
- You can work with a provider agency to help identify the supports your family member will need.

So, I ask for your cooperation; please work with OPWDD and our provider partners to develop services for your family members. It is important that you make and keep appointments to see the types of services these agencies provide. You may also ask to talk with other parents/grandparents of individuals served by these agencies. You are encouraged to share any concerns you may have as the services are developed for your family members. OPWDD would like both you and your family member to be satisfied with the services provided.

OPWDD cannot continue to provide funding for individuals after they complete their schooling. Please work with OPWDD to help shape the services your family members will receive and to help shape your family members' future. If you have any questions, please contact your DDRO representative. Attached is a list of coordinators for each county. Thank you.

Sincerely,



Jill E. Gentile
Associate Deputy Commissioner

cc: Senator David Carlucci
Assemblywoman Eileen M. Gunther
Assemblywoman Donna A. Lupardo
Senator Simcha Felder
Ms. Laurie Kelley, Commissioner
Ms. Glenda Crookes, Executive Director JRC
DDRO Directors
DDRO Coordinators

November 8, 2013

Jill Gentile
Associate Commissioner
New York State
Office For People With Developmental Disabilities
44 Holland Avenue
Albany, NY 12229-0001

Re: OPWDD Clients Living at JRC

Dear Associate Commissioner Gentile:

As you know, we are the parents of severely disabled adults from New York State ("NYS") residing at the Judge Rotenberg Educational Center, Inc. ("JRC"). All of our children are either funded by your agency now, or will be eligible for funding within the next two years as they age-out of NYS special education funding. When we read your letter of September 26, 2013 (the "September 26 letter"), after waiting two and a half months for a response to our July 10, 2013 letter, we were very disappointed. Your comments reflect a continued lack of knowledge about our children's severe disabilities, their treatment needs, and the type of program at JRC that is currently meeting all of their needs and keeping them safe.

A. *JRC Has A Fully Licensed Adult Residential Program That Provides Our Children with A Wide Array of Individualized Adult Services.*

In the September 26 letter, you incorrectly state that our children "are at a school." This is untrue. JRC also operates a fully licensed adult residential program. Our children live with other adults in the JRC group homes that are each individually licensed and regulated as an "Adult Group Home" by the Massachusetts Department of Developmental Services ("DDS"), the Massachusetts agency responsible for licensing private facilities which offer adults residential services and provide treatment of persons with an intellectual disability. Our children also attend JRC's adult day program; it too is licensed and regulated by DDS. DDS licenses JRC to provide adult residential and individual home supports (residential services) as well as employment and day supports (community-based day services and employment support services). JRC has been operating a fully licensed adult residential program for over thirty years. It is difficult for us to imagine that the New York State Office for People with Developmental Disabilities ("OPWDD") was unaware that JRC is a state-licensed adult program and that you would put such inaccurate information in a letter you copied to New York Senators and Assemblywomen.

You also state that "[t]he services offered by New York State providers are far more varied than those offered in school settings and are individually developed based on the choices and interests of the individuals and their families." In truth, OPWDD has not provided us with any information about the services that are currently available in NYS that could effectively treat our children's severe behavior disorders and keep them safe from harm. OPWDD continues to promise to find or create those services in NYS but has yet to make that a reality. In contrast, our children have been receiving a wide array of very effective adult services at JRC which have

met all of their needs and given them the opportunity for good health, happiness and integration with their families and the community. The services that JRC offers adult clients are "individually developed" by a team of treatment professionals, based on the clients' needs and input from the clients' family. JRC provides our children with extremely effective and critical adult services, including: behavioral treatment; medical treatment; post-secondary education; vocational training both at JRC and in the community; employment and supported employment in the community; volunteer work in the community at food banks, pet day care centers, churches, etc.; and constant access to the community and all of the leisure, social and educational activities available in the community. The JRC staff is experienced and highly trained to treat and care for disabled adults with severe behavior disorders. JRC's high staff-to-client ratio and state of the art equipment and technology designed for adult clients provide age-appropriate services and help integrate them into the community to the greatest extent possible while at the same time keeping them safe from physical and emotional harm.

B. OPWDD Has Not Identified Agencies in NYS That Can Meet Our Children's Needs.

You state in your September 26 letter that OPWDD has "identified providers" that can serve our children. Yet OPWDD has not identified to us providers that claim to have the resources and qualifications to care for our children. Unfortunately, our children engage in dangerous behaviors that can result in grave physical injury and emotional harm. The providers on the list you sent to us in May, 2013 are programs that you assert "will be working to develop services in New York State," but to date, only a few of the families have received any indication that these providers claim to have in fact developed effective and safe programs that could meet our children's needs.

You state that "[m]any OPWDD funded agencies serve individuals with challenging behaviors that are very similar to your family members and serve them successfully." We have asked OPWDD to send us, but we have not received, information on these agencies. Please provide us with the names of these agencies and the credentials of their clinical staff and allow us to: visit the agencies; review their policies; meet their staff, including the behavior intervention specialists, licensed psychologists, psychiatrists and medical doctors who are charged with developing service plans for adults with severe behavior disorders; observe their clients; and speak with the clients' families.

C. OPWDD's Proposed Process for Approving A NYS Provider for Our Children Denies Due Process Rights And Puts Our Children at Risk of Severe Harm.

At the information sessions held in March, 2013, you informed us that we would have the opportunity to evaluate a NYS agency and the service plan it proposes to provide our child before OPWDD offers us admission to the NYS agency. This would give us the opportunity, if needed, to explain to OPWDD the reasons why the agency, and/or the services offered, would not meet our child's needs and place them at risk of physical harm and severe regression. In the September 26 letter, however, you now state that OPWDD will send us the preliminary service plan "with the formal adult services offer so that the family can review it before giving consent to the service offer." This process is completely unfair, dangerous, and devoid of due process rights, if OPWDD plans to terminate funding at JRC once the formal adult services offer is

made. Family consent to the NYS placement is not legitimate if OPWDD plans to terminate funding at JRC if the family declines consent based on the placement not being equipped to meet the needs of our children, thereby putting them at risk of severe harm.

It is alarming that a service plan for our children can be reviewed and approved by OPWDD without input from us. You previously stated to us in your October 24, 2012 letter that: "OPWDD needs your assistance to ensure that the services developed will meet ... [your child's] needs here in New York State. You know ... [your child] best and can help shape the services that are developed for him by being part of the planning process." You have maintained that OPWDD needs our assistance in developing a service plan for our children as we know our children "best"; in practice, however, OPWDD apparently plans to approve and offer the placement before giving us the chance to review it. Our children's survival depends on us having the opportunity to review potential placements and decline them if we can demonstrate that the proposed placement will not meet their needs, all without suffering a precipitous loss of funding.

D. Our Children Are Thriving at JRC without Any Medication And Any NYS Provider That Requires Our Children to Be Medicated Will Be Doing So Because Their Program Does Not Have The Behavioral Treatment And Other Services That Our Children Need.

We have repeatedly expressed concern about our children returning to NYS to receive ineffective behavioral treatment, which will result in the reemergence of their dangerous behaviors and then NYS providers taking the position that they have to medicate to the point of sedation and against our wishes. We are informed that for the NYS providers mentioned in your May 23, 2013 letter, treating clients with medication is the rule, not the exception, as upwards of 95% of the providers' client population receive medication treatment. Our children are doing exceptionally well in JRC's behavioral treatment program. JRC does not treat our children with medication because they do not need medication if they have a twenty-four hour properly equipped behavioral treatment program operated by a highly trained and experienced staff. You have unsuccessfully attempted to alleviate our concerns by first emphasizing the so-called rigorous process for approving psychotropic medication to treat our children, and claiming that we will be "consulted" if medication is considered. In accordance with OPWDD's regulations, if a NYS provider recommends administering medication to our children as a "restrictive/intrusive intervention" and if we do not consent to the NYS provider's recommendation, the NYS provider can simply disregard our wishes and obtain the necessary consent from a court in order to begin medication treatment. This is not a "rigorous process" and it certainly does not guarantee that we will be properly consulted.

You have also stated to us that "medication when used effectively does not impair a person's ability to function." The reality is that there are no medications in existence that effectively treat our children's self-injurious, aggressive and other harmful behaviors. The medications that are prescribed for individuals with severe behavioral problems are typically in the form of cocktails at high dosages and are used to sedate and thereby "impair a person's ability to function." These medications do not, as you state, increase our children's ability to "integrate into the community" and "fully participate" in their own lives. It is an intensive behavioral modification treatment program like JRC, which is free from the debilitating effects of psychotropic medication, that

allows our children to have as full a life as possible, including allowing our children to: be free from life threatening self-injury and aggressive behavior; learn; work; and access the community and their family safely and productively. If our children require medication at a NYS provider, whether on an emergency basis or as a "restrictive/intrusive intervention", it is because OPWDD has needlessly taken them out of an effective behavioral treatment program and placed them with a NYS provider that cannot meet their behavioral needs. Our children will suffer the consequences of OPWDD's ill-advised decision to remove them from JRC, where they will again suffer the harmful side-effects of these ineffective medications.

E. We Have Always Been Ready, Willing, And Able to Participate in A Planning Process And Will Do So As Soon As OPWDD Starts One.

In the September 26 letter, you "encourage" us to "participate in the planning process" and you inform us that OPWDD has "many opportunities available." We are ready, willing and able to participate in OPWDD's planning process but OPWDD has not yet notified us that an actual planning process is under way for our children other than a few families that have heard something from OPWDD. If and when OPWDD starts a planning process for our children, then please let us know and every family will be glad to participate.

We must also point out that the four service opportunities you list on page two of your September 26 letter are completely unrealistic. Our children cannot "come home" and receive services at home. Our children engage in dangerous, life-threatening behavior and bringing them home puts them, family members and our neighbors in danger of serious physical harm. Also, we cannot "self-direct the services" and hire our own staff to provide them. We do not have the requisite expertise to interview, hire and train staff to provide our children with intensive behavioral and medical services in our home. Our attempt to self-direct services would also put our children, family and community in danger. For the same reasons, our children cannot live in a shared apartment or an individual apartment. In the few occasions that families have met with representatives of programs that OPWDD has approved for our children, we were offered residential, but no day, programming. When we questioned these representatives about our children's day programming we were told that only after we start at the residential program will we receive assistance in applying to day programs. Our children require a structured residential program that provides them with intensive treatment and high levels of staffing on a twenty-four hours per day/seven days per week basis from the moment they are discharged from JRC.

You ask for our "cooperation" and that we "work with OPWDD and other provider partners to develop services for your family members." We have fully cooperated with OPWDD. We have attended and participated in all OPWDD meetings where you requested our attendance. On the other hand, OPWDD has not developed any services for our children and has been unable to answer any of our many questions about where OPWDD plans to place our children and what specific treatment service will be provided that will keep our children safe and off of dangerous psychotropic medications. Your answer to our questions about drug treatment has us even more concerned that OPWDD will use court orders to put our children on ineffective and damaging drugs without our consent after our children have regressed in a New York program ill-equipped to care for an adult with a dangerous behavior disorder.

F. There Are Former JRC Clients Who Are Currently Suffering in NYS Programs That Cannot Meet Their Needs.

You invited us to "ask to talk with other parents/grandparents of individuals served by these agencies." Please arrange for us to speak with as many parent/grandparents that OPWDD can identify whose children have similar behavioral problems to ours and are served by NYS providers. We will talk with each and every one of them. We have repeatedly asked private service providers to allow us to speak with parents of their current clients, but these providers have not honored our requests.

In fact, we have already spoken to many parents who told us their stories of their children "returning from JRC with ill consequences." The experiences of these former JRC families are not "rumors", as you have suggested. The parents of these children have shared with some of us their frustrations and anguish over the mistreatment of their adult children in NYS facilities, some of the same programs on OPWDD's list of providers attached to your May 23, 2013 letter. One such individual, T.M., is at a NYS residential program where her severe and dangerous behaviors, including head banging and attacking others, have escalated since her discharge from JRC, necessitating hospitalizations, intensive 1:1 staffing and the use of medications which have not helped her and have led to major weight gain. None of these interventions have suppressed her dangerous and disruptive behaviors. She continues to engage in behavior which prevents the NYS program from providing her with opportunities for productive and enjoyable activities and she is now isolated and withdrawn.

Another individual, C.S., is at psychiatric hospital whose staffing is not adequate enough to safely and effectively manage his severe behaviors so the hospital has relied on sedating medication, in lieu of behavioral treatment, causing him to become dangerously overweight. Despite treatment with medications, C.S. continues to engage in dangerous and destructive behaviors, including head banging that is so intense that C.S. split his head open. C.S.'s parents desperately want him to be transferred to a private, community-based provider, rather than be hospitalized, but to date OPWDD has not been able to provide it. Yet another individual, S.D., is at a third NYS adult residential program where his behaviors have spiked since his admission, putting him and others at risk of severe physical harm. In the last year, he has been hospitalized for assaultive and out of control behavior and he is on psychotropic medications because the NYS program is otherwise unable to control his behavior (and despite the NYS program's promise to his mother that it would not prescribe medications). Countless other former JRC clients have not received from OPWDD and its "network of NYS providers" effective treatment for their behavior disorder, and continue to engage in assaultive, self-injurious and destructive behavior, resulting in the prescription of sedating medications, frequent restraint, psychiatric hospitalizations, placement in locked facilities, and incarceration. All of these people had formerly thrived at JRC and were safe, healthy, and free from these harmful medications.

In sum, we have attended OPWDD's meetings, where we asked OPWDD critical questions about our children's care and we received no concrete answers. Thereafter, we wrote to you asking the same questions and it took you over two months to respond, once again without

providing us with answers to our questions. OPWDD's stated "plan" to pull our children out of the only proven, successful program they have ever had, in order to meet an arbitrary and needless deadline of June 30, 2014 will put our children at grave risk of serious bodily harm and potentially even death. We once again urge OPWDD to reconsider this unnecessary and reckless position, and to continue to support our children at JRC.

Sincerely,

Zada Gaines ~~file~~ - Matthew Gaines 917-~~542~~-5321-212-662-3553

Michele Puzo 845-849-2307

~~Arthur~~
Cheyl Lloyd Cheyl Lloyd -

Marcia Shear + Mitchell Shear 516-626-8312

Patricia Crawford

Lorraine Staff 718 882 0701

Maria Coronado 718-464-3161

Jeely Guzman 646-796-8124

Maur Washington 718 584-8179

 Maria Green 718 809 1585

cc: Senator David Carlucci
Assemblywoman Eileen M. Gunther
Assemblywoman Donna A. Lupardo
Senator Simcha Felder
Ms. Laura Kelley, Acting Commissioner of OPWDD
Ms. Glenda P. Crookes, Executive Director of JRC

Connie Watson

Jeanette Alleyne

Cheryl Lavelle

Phyllis Coughman

~~Delia~~

Alexandra

A. Kemp

Sharon Halsey

Jessie Brown

~~Frances~~

~~Frances~~

B. Sayre

Nicholas Malinowski

Carlo A Casoria

Lorraine Biggs

Marie Rogers

Marie Emmanuelle

Phyllis Coughman

Suzanne Walcott

darisa Kapustina

Alexander Kapustin

S. Hervet Hersey

TERESA BROWN

SURAIYA NASSER

Pamela Biggs

Bartji Sangare

Nicholas Malinowski

CARLO A. CASORIA

Lorraine V. Biggs

MARIE ROGERS

MARIE EMMANUELLE

VANESSA Trahan

①

Sheela Francis

Daisy RAMOS EDWARD L. 646-249-
Elizabeth Kivira @ 46-467-476
6640

~~Kelly and Lynn Walker 858-247-1177~~

NEKON'S SONIA BERNARDO - 718-482-1530

Burua G. Forbes 631-473-7745

Roger P. Falso 631-473-7745

Linda Doherty - LINDA Doherty 631-669-0073

~~FRUIT. S. S. RICHARD DOHERTY~~ 631-667-0073

Eileen Williams Thomas Williams 917-868-4454

Michelle Francis Jessica Grant 347-217-3994

Marlene Forrest Jessica Grant - 1917-880-9719

Dawn Johnson Bruna Swettenham (973) 925-2242

SYLVIA BIGGS 718-589-5849

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~~XXXXXXXXXXXXXXXXXXXX~~

IVONNE Barreto Genesis Ruiz

→ 347-817-852/6

Rita Gaines

(917) 267-4528 Matthew Gaines

Joseph Pain Matthew Gaines (646) 674-6704