# Testimony by Linda Blumkin at the Olmstead Public Forum 9/28/2012

My particular focus is on the needs of people like my daughter Jessica, who is almost 23 years old and has a rare genetic disorder, Cornelia de Lange Syndrome, that resulted in mild mental retardation, autism, and (with the onset of adolescence) challenging behaviors including physical aggression. She attended an out-of-state residential school from 2004 through her "aging out" date of June 2011 – one of the 650 NYS students sent away to such schools at an annual cost of $140 million.

Clarence Sundram, the Governor's Special Advisor on Vulnerable Persons, told the Governor last fall that despite this large expenditure we know virtually nothing about what is going on with these kids. They include some of our State's hardest to place students. And a good number of them then become our hardest to place adults. Like Jessica, who remains on an interim basis in an out-of-state residential placement while awaiting an appropriate setting in New York to which she can return.

As the Supreme Court said in the Olmstead case: "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings." Justice Kennedy's concurrence in Olmstead cautioned: "States may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the services and attention necessary for their condition." Olmstead recognizes that we need a spectrum of services to meet the diverse needs of the developmentally disabled, not restricted to the polar opposites of a large institution versus an IRA [Individual Residential Alternative] with limited supports. And now, with the closure of most of the large OPWDD [Office of Persons with Developmental Disabilities] facilities and an OPWDD policy of no new admissions to the few remaining ones, that leaves the isolated group home in the community as the sole option.

For New Yorkers, who – decades after the closure of Willowbrook -- vividly recall the reports of its horrors, the thought of placing developmentally disabled individuals in an "institutional" setting is anathema. Anything but a group home model is unthinkable.

But let's think about the unthinkable.

Lauren Axelrod is a young woman who suffered brain damage as a result of epilepsy. She is one of 600 residents at a largely campus-based program in Chicago licensed as an ICF-DD (Intermediate Care Facilities-Developmental Disabilities) – a big institution.

Before today's audience of disability rights advocates stands up and heads to Chicago to rescue Lauren, what if anything more do we need to know? What about the fact that she is the much loved daughter of David Axelrod, President Obama's senior advisor and strategist, and Susan Axelrod, a founder of Citizens United for Research in Epilepsy ("CURE").

And shouldn't we ask who is running this dreadful institution? Sister Rosemary Connelly, its Executive Director, who recently wrote: "Misericordia Heart of Mercy Center stands in contradiction to the national trend that all persons, no matter how disabled they are, should be living in isolated houses in the neighborhood. We believe in these isolated houses in the neighborhoods for a segment of our population who are more abled and do enjoy this environment. We will be opening our 8th house in the fall and our 9th home in the neighborhoods in the New Year. But the reason our residents living in the neighborhoods have great lives is because our campus complements their daily lives beautifully. I still hold that if they did not have access to our campus, their lives would be more restricted than those living on campus."

Would I place my daughter Jessica at Misericordia or a New York version of Misericordia? In a heartbeat. But Misericordia doesn't have room for all of the Illinois residents who need its help, and there is no Misericordia equivalent in New York. Nor is New York developing smaller campus-based programs for people whose needs are greater than an isolated group home in the community can accommodate, perhaps with a few cottages on a common property, sharing facilities on the property like a day program (for people who realistically cannot handle daily trips from their residence to day hab or a job), nursing support, behavior management specialists and other services.

Instead, the isolated group home in the community becomes OPWDD's take-it-or-leave it alternative. And for people like Jessica, this means that if the group home staff cannot manage their challenging behaviors, they call 911 and the police come, handcuff the unmanageable person (even the ones like Jessica who are 4’7” tall) and take them to a psychiatric emergency room to be “stabilized” before they are returned to the environment incapable of managing them. After a few of these roundtrips, the person then moves from OPWDD’s budget to that of the Office of Mental Health as they are shipped off to long term psychiatric hospitalization in a facility ill-equipped to address the behavioral issues of someone with autism or other developmental disabilities. Some University of Pennsylvania professors have asked whether there truly is an autism epidemic or if there are older people with autism hidden somewhere. They looked and they found at least some of them in Pennsylvania’s psychiatric hospitals. And there is no reason to think that more would not be found in psych hospitals in New York and other states. If anybody cared to look.

A few months ago I directed a Freedom of Information Law request to OPWDD, asking for data on the number of 911 calls from group homes that resulted in taking behaviorally challenged residents to psych ERs. The response? OPWDD does not track this data. A high-ranking OPWDD official gave a talk a few weeks ago to the Metro DDSO family support group about behavior management and I asked her about these 911 calls. She said that she had heard that someone had made a FOIL request about this – I admitted that I was the requester – and she committed to follow up. I have emailed her several times since to ask the results of her followup, but she does not answer. Since OPWDD does not track this data, we cannot quantify how big a problem it is. Anecdotally, it appears to be significant. But apparently not significant enough to elicit action – or even a response -- by OPWDD.

The needs of intellectually disabled women with autism and/or behavioral challenges are a particularly pressing overlooked area. Many providers will say that if an autistic young woman with challenging behaviors were a man, they would have an appropriate program but – regretfully – they have nothing for women in this situation. Although autism disproportionately affects boys and men, it does not spare girls and women. Many are undiagnosed and even when diagnosed their needs frequently are not met.

Applied Behavior Analysis techniques are applicable to developmentally delayed adults, particularly those with challenging behaviors, but are insufficiently used. ABA is the only evidence-based methodology for individuals with autism but there are few programs that continue into the adult years the ABA techniques shown to help these same individuals when they are younger. Consistency for people with autism is recognized to be essential in helping them order their world and control their behaviors – how does it make sense to use ABA while they are in school and then cold turkey drop this essential support as soon as they age out? This is devastating to the individuals and costly to NYS as people dependent on this support in childhood and adolescence fall apart without it as adults and require more expensive care in more restrictive settings, or languish in a community setting that cannot effectively manage them.

The current system of requiring that individuals be placed only in their county of origin results in unfairness and irrationality when needed placements are allocated on the basis of who is at the top of the list (or otherwise favored) in a particular locality instead of who in NYS most needs or would most benefit from a particular placement. The discrimination against NYC residents, especially those from Manhattan, is particularly acute with little or no new development in this borough. If their disability means that it is difficult or impossible for them to tolerate living in crowded, congested surroundings – as is true for many with autism – they are still kept within NYC even though what they require is a suburban or rural setting. While staying close to family is one value, it is not the sole value, and families who would prefer to see their autistic loved one in a calmer quieter setting than NYC should have the ability to ask that they be considered for placement outside the city. And from a fiscal and public policy perspective, costs are less – both of the physical setting and labor – outside NYC and the ready availability of land and buildings at reasonable prices allows consideration of development of new models – e.g., clusters of homes sharing common on-site support facilities.

**As I said in May 2011, we can and must do more with less.**

**But will we?**