

Testimony for the Task Force on the Closure of State Developmental Centers

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**New Jersey Department of Human Services
Capital Place One
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Members of the Task Force, I'm Geoff Dubrowsky. I represent VOR, a national advocacy organization for persons with intellectual and developmental disabilities. I am speaking in support of the written testimony submitted by VOR's New York Coordinators, Cristy and Hugh Dwyer. Their extensive written testimony was submitted last week and I understand you were each provided a copy that I expect you will read and review in detail.

My son Dan, is 16 years-old, 6ft tall and over 220 lbs. He lives at home and has severe autism. On several occasions he has attacked my wife, ripping her hair from her head and using his teeth to harm us. On recent occasions the Brick police had to be called because he was getting the best of me. They needed two officers to get him into handcuffs and took him via squad car to the local hospital ER, where they had no idea what to do. Someday soon, these attacks will leave one of us in bad shape and then and only then will the State of New Jersey realize

we need out-of-home placement for him. I feel it is his right to have an array of residential options. We want these options to include developmental centers so if he is unable to manage these outbursts, he does not harm someone in what you claim to be the community or wind up in prison, which is a current practice here in New Jersey.

My nephew, Benny is 25, has fragile X syndrome, he lives at home with his 70 year old father. Currently he is well and involved in many programs, but cannot live alone because he is physically unable to properly toilet himself. Someday, soon however, he too will need out-of-home residential care.

My niece, Heather, has profound autism with severe behaviors. In her teens, she put her family at serious risk of injury and destroyed their home. Benny lived in fear, slowing his own development in the process. Since the age of 13 Heather, soon to be 29, receives exceptional care at Hunterdon Developmental Center where skilled professionals have managed her behaviors very well, with minimal medication. She is still prone to behavioral outbursts when faced with change, but she enjoys significant independence thanks to the structured services that Hunterdon provides in her community.

You see Hunterdon is where she lives, works, has friends, and has access to medical and dental professionals prepared to deal with the severity of her disability.

My family and their diverse needs are why I am here today. I am also here because Heather and Benny lost their mother, my sister on June 23, 2011 while battling to stop the actions that 3 of you are taking as a given! Yes my sister the late Robin Sims is not resting in piece and it breaks my heart to have to be standing here in her place at all! I am sure, my mom, Sally Dubrowsky who is here today, despite also losing her husband 3 months ago shares my feelings for her grandchildren and wishes you protect her rights to protect them as her daughter would have liked.

The Task Force, however, is embarking on a decision that I fear will fundamentally affect their futures for the worse. It's quite clear, that you are predisposed to decide in favor of developmental center closures. The name says it all: Task Force on the Closure of State Developmental Centers.

It doesn't have to be that way.

As Cristy and Hugh Dwyer detail in their written testimony, the law which establishes this Task Force is stunningly biased. Its criteria, however, provide this Task Force with some discretion to vote against any closures. I have spoken about the law that created this task force with several legislators including US Congressman Chris Smith. During our 3 hour meeting he tried to reach out to the Governor with no response. Funny because Congressman Smith is the third most effective member of Congress and always had his calls returned during the elections.

Specifically, as I read the Task Force’s statutory charge, the Task Force is required to “perform a comprehensive evaluation of all the State developmental centers and provide recommendations” with regard to the closing of developmental centers. Five criteria, listed in order of importance, are provided. All relate to choice, which is given the greatest weight, and to cost.

A thoughtful, thorough consideration of these criteria should lead the conclusion that preserves developmental centers for people who require that level of care – for families that want that piece of mind- for people like Heather who have been in their communities for decades – while also expanding community-based supports for people whose needs are not as severe and who do not want or yet need to be served in developmental centers.

We can have it both ways if you embrace what the letter of the law allows. The ramifications for a political decision –rubber stamping the obvious intent to close one or more center(s) – are significant and exactly counter to what those in support of closure hope to accomplish. Specifically –

- **Choice will be denied** if developmental centers close, contrary to state guardianship law, Olmstead, and Medicaid law.
- **Costs will increase if necessary services are provided.**

Think about it: The vast majority – more than 80% - of developmental centers residents are eligible for these services because they have

severe or profound intellectual disabilities, multiple physical disabilities and complex medical needs. They require the life-sustaining supports only available at developmental centers.

Does you really believe that scattering these people into smaller homes will save money, if they are provided the services they need? Why do we have hospitals? Why do we have ICUs? We might fancy the notion of having a team of doctors on our beckon call in our own homes if we find ourselves in need of complex medical care, but that's not realistic because it's not cost effective. We cannot even care for our elderly properly, nursing homes are filled with people with Downs Syndrome who have fallen off your radar completely as have the autistic adults in our Juvenile Prison System. I have seen and I have help provide educational opportunities to this population. Perhaps talking to the LT Governor Kim Giordano will clear this up for you, as she knows first hand and worked to make a difference.

And, what about the Heathers of our world? Does this Task Force really believe that a community provider who pays its staff not much more than minimum wage will be able to manage her behaviors safely? Does this task force really believe like a Jet Blue executive that we can pay less for the same quality of individual.

- **People WILL die, be injured, be abused, and be isolated – the true cost of saving money.**

Of course, the worry by VOR is that costs will be saved because people will not get the services they need. **This will lead to great isolation and tragedy.** Cristy and Hugh shared information on a New York report of, **1,200 deaths from unknown or unnatural causes in group homes.**

Across the country, these same tragedies have played out, as reported in studies and newspaper articles. Not surprisingly, these tragedies correspond to greatly expanding community services and significant downsizing of developmental centers. Many states have embraced closure believing it would save money. And, maybe it has but at what cost? People suffering or dying to save the state a buck.

This Task Force should not accept that fate and not view human life as line item!

- **Waiting lists WILL get longer if developmental centers close.**

There are already 8,000 people on the waiting list. As one of them, I appreciate having this discussion now because these individuals have been waiting a very long time for services. I was recently told by DDD that we will reach the top of the list in 16 years I reach 70 if make it! Good news is that if I die they will move my son up the list! There is the belief that closing developmental centers will miraculously free up more funding to serve more people. As noted savings are just not possible if necessary services are provided. If all necessary services are provided, they WILL cost more in scattered community settings and people leaving

centers will be the first served anyway. People on the waiting list will continue to wait. Also more and more people in need will be placed at great expense, out of state without ever having the option of one of our own centers. That is a criminal waste of state resources and misleading to taxpayers.

So what is the solution? What can this Task Force recommend to fix our system? 8,000 people should not be forced to wait and developmental center residents should not be displaced and placed at great harm and at great cost to the state.

The solution is clear: Developmental centers are an undervalued, underused resource. Downsizing over the past two decades or more has increased costs but the infrastructure remains and could provide out-patient professional services to many individuals now in the community or on the waiting list for community-based care. Admissions should also be allowed; certainly some of the 8,000 people waiting for services many would choose and be well-served in our licensed developmental centers. The option is not available to them, there are offered a 6 figure budgets to stay home and or placed at 6 figure Centers out of state. The leadership within Health & Human Services should be held accountable for where we are, not our loved one's.

I ask you to have courage and **I am challenging you.** Now is the time to find the courage to reject a rubber stamp outcome. To realize the fact that a Developmental Center once closed will be sold and the proceeds put in the

general treasury not follow the people. What I am asking you to do is not easy, but it is the right one for all citizens with intellectual and developmental disabilities, save all the developmental centers.

Despite the short notice, thank you for listening. Thank you in advance for your courage. Please do the right thing. I welcome any questions you may have.