

This my testimony from yesterday's Public Comment Session on New Jersey's Statewide Transition Plan – a plan that may eliminate all campus based settings for individuals with disabilities. It also establishes rules for day programs which many believe are nearly impossible to meet. For example the plan mandates that in order to receive funding, adult programs must have all participants in the community, not at their vocational site, for 75% of the day. There will be another Public Input on February 19th at 10:00 am at the DCF Training Facility, 30 Van Dyke Ave, New Brunswick. If you would like to testify or even just attend, you can register with DHS by calling Diane Flynn at (609) 689-6714 or by email at diane.flynn@dhs.state.nj.us. If quality service for adults with developmental disabilities is a concern of yours I urge you to participate. For additional information on how to submit comments, visit Autism New Jersey's website at http://autismnj.org/DDD_HCBS_STP.

Good Morning. My name is Lisa McCauley Parles. I am a partner in Parles Rekem, a law firm representing individuals with disabilities and their families. I am also the mother of a 24 year old young man with autism and have several concerns regarding the limited options for individuals with challenging behaviors offered under New Jersey's proposed State Transition Plan.

I would like to state, however, that the state's plan to make available state funds for non-disability specific settings is an interesting development although I believe that limiting the disabled population to 25% is discriminatory. If we were to say that no more than 25% of a community can be comprised of African Americans, or women, or Jews we all would recognize that anti-discrimination laws have been violated. I have heard of residential projects that have units for both low income seniors and the developmentally disabled. My son, Andrew, has worked in a number of vocational projects assisting seniors such as Meals on Wheels and a shopping program for home based seniors. However, in addition to working on projects for seniors, Andrew has tragically:

- gone 3 days without sleeping;
- 6 days without eating;
- lost 100 pounds in three months; and
 - suffered a self-inflicted traumatic cataract.

More recently, he detached retinas in both eyes due to self-injury and had to undergo two separate surgeries. Andrew requires intensive staffing and supervision and was not successful

in a community group home. It also was not an experience that led to more community integration. For all practical purposes, the only interaction the residents had with neighbors was when the neighbors complained that the music therapist was too loud. The notion that simply placing individuals in group homes leads to an inclusive experience is a fiction.

Andrew currently lives on a campus which provides him with appropriate support and supervision. On site behaviorists are a key component as is the ability to remain productive on days that his behaviors make it impossible to go to a job site in the community. In addition, in a campus setting if a crisis occurs the response time of additional staff is significantly shorter than in a group home. His campus is not an institution and his experience there on many days is much more inclusive than life in a group home.

In a non-disability specific setting I fear that other tenants separated by just a wall would not tolerate his loud and destructive behaviors. I understand and recognize the other tenants' rights to a good night's sleep. Unfortunately when in "close" quarters with other members of the community such as in a hotel our family has had the police arrive and ask us to quiet him down, a task that often is literally impossible. There are many "Andrews" out there whose needs cannot be met in apartment settings or community group homes.

The CMS final regulations governing HCBS settings allow for campus settings and settings where individuals live and work in the same location. In a December 3, 2014 letter, CMS Director Barbara Coulter Edwards stated "It is important to note that the regulation does not prohibit site specific settings..." Under the final rule, campus based communities are not prohibited. Criteria set by CMS are not based on physical characteristics or density of persons with disabilities. All regulation and licensing characteristics should be based on outcome oriented criteria. New Jersey's proposed plan, which is more restrictive than the federal regulations, will serve to limit options for the disabled and in many circumstances could endanger the life and health of New Jersey's developmentally disabled.

I urge New Jersey to work towards the goal of giving recipients of waiver services choices from among a spectrum of settings. This was the intent of CMS's final rule. New Jersey should not be more restrictive than the federal final rule or other states. In addition to the

right of integration, our disabled citizens also have the right to be adequately supported in programs that meet their actual needs, to be presented with options and most importantly to be safe.

One final point. To those who say that all campus based programs should be barred, I ask the following. If other citizens may choose among options such as living in an over 55 community, or on a college campus why should my disabled child not have the option to live within a campus community where he is happy and safe?

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