

### **Testimony at DD Council on the use of restraints**

My name is Lowell Arye and I am the Executive Director of the Alliance for the Betterment of Citizens with Disabilities (ABCD), a statewide advocacy organization comprised of 13 member agencies that provide an array of community based services to more than 8,000 people with developmental disabilities and their families. Most of the people served by these agencies are medically complex, have ambulation issues, and require frequent monitoring and assistance with their daily needs. A significant number of these individuals have swallowing and/or seizure disorders.

Although I am here to testify on behalf of my member agencies, I am also here because of my work over the years on this issue in Washington, DC. For example, I served for more than a year as principal staff to an internal working group within the Office of the Secretary in the U.S. Department of Health and Human Services on the use of restraints and aversives, as well as serving for several years on an intra-agency taskforce on disability issues, including the use of restraints, within the Department. I recently served on the Division of Developmental Disabilities (DDD) regulations workgroup on the use of restraints.

The use of restraints is a difficult one for all individuals who care about the health and safety of people with disabilities. Some individuals would like to see the use of restraints be eliminated except for emergency purposes. Others see a need for restraints to be used in treatment plans and emergencies to protect an individual from self-mutilation, and/or to protect others, including staff, from the individual's injurious behavior.

For some individuals, the use of restraints is requested by the individual to prevent them from their self-destructive behavior. Lesch-Nyhan Syndrome is a rare genetic disorder. Individuals affected by this disease present an abnormal compulsion toward self-mutilating behavior. Self-inflicted damage includes partial to complete amputation of fingers, nose, and tongue. According to research, these individuals are reported to be very aware of their disability and aggressive behavior toward themselves and those around them and often request to be restrained. According to the research, physical restraints remain the sole reliable resource for preventing self-mutilative behavior in individuals with Lesch-Nyhan Syndrome. Restraints do not eliminate injury but cloth body-restraints and cloth mittens have been useful in reducing the frequency of self-injury.

According to the U.S. Department of Justice's recent letter on Woodbridge Developmental Center (November 12, 2004): "Consistent with generally accepted professional practices, highly restrictive interventions are only to be included in a behavioral program only when justified by the results of an adequate formal functional analysis and only when there is evidence that less restrictive procedures have been ineffective or unsafe."

According to current regulations, each facility or service provider approved by the Division to use restraints must submit comprehensive written procedures governing their use.

ABCD is concerned that some definitions of restraints may be too broad. For example, Mechanical Restraint is by some as the application of a device that restricts a person's freedom of movement either partially or totally. Given that some individuals need devices to support their body position or posture, this definition would preclude their use. ABCD recommends using the term Highly Restrictive, so as not to preclude the use of all protective and adaptive supports and devices.

One of the primary procedures is the use of informed consent, meaning a formal expression of agreement with the proposed course of action. If an individual is not able to give informed consent on their own, their parents and/or legal guardians, as part of the Interdisciplinary Team, responsible for development of the Individual Habilitation Plan (IHP) must provide consent to the use of restraints.

In conclusion, ABCD agrees with the U.S. Department of Justice that generally accepted practice is that restraints should not and cannot be used as punishment or for the convenience of staff. Restraints and other safeguarding equipment should be used on a hierarchy basis and should only be used after less restrictive measures have been attempted. These measures should range from most positive or least intrusive to least positive and most intrusive. The use of restraints must be justified as an effective treatment.

Regulations on restraints and safeguarding equipment are important to assure that their use is appropriate for the intended purpose and is employed in a safe and effective manner. These regulatory protections should define principles and policies that clearly outline when and how restraint may be used. We need strong management commitment and leadership on the use of restraints. We need a requirement to report the use of restraint. We need staff training in safe use of and alternatives to restraint. We also need oversight, monitoring and tracking of the use of restraints.