VOR
Speaking Out for Individuals With Intellectual Disabilities

Toll free
877-399-4867

www.vor.net

Executive Director
Julie M. Huso
836 S. Arlington Heights Rd, #351
Elk Grove Village, IL 60007
605-370-4652 Voice
605-271-0445 Fax
jhuso@vor.net

Dir. of Govt. Relations & Advocacy
Tamie Hopp
PO Box 1208
Rapid City, SD 57709
605-399-1624 Voice
605-399-1631 Fax
thopp@vor.net

Washington, D.C.
Larry Innis
529 Bay Dale Court
Arnold, MD 21012-2312
410-757-1867 Voice/Fax
LarryInnis@aol.com

March 13, 2012

Honorable Carol Liu, Chair, and Members
Senate Human Services Committee
1020 N. 521
Sacramento, CA 95814

Original by U.S. Mail

Copy By email: senator.emmerson@sen.ca.gov; senator.hancock@sen.ca.gov; senator.strickland@sen.ca.gov; senator.Yee@sen.ca.gov; senator.Wright@sen.ca.gov; senator.Berryhill@sen.ca.gov

Re: VOR written testimony for the Senate Human Services Committee, March 13, 2011 informational hearing, "Examining Investigative Practices Within Developmental Centers."

Dear Chairman Liu and Members of the Senate Human Services Committee:

In response to the troubling report by *California Watch*, **please listen to the families**. They will implore a **"fix it, don't close it"** response.

VOR is a national advocacy organization representing individuals with intellectual disabilities (ID/DD) and their families. Unlike other national advocacy organizations, VOR recognizes that individuals with ID/DD and their families are the primary decision-makers regarding services and supports. We recognize that legitimate choice and person-centered supports are only possible in a system that offers a full array of quality residential and support options, from small homes to Medicaid-funded and licensed Developmental Center homes.

As noted in the Senate Human Services Committee background paper, the 1,800 individuals with ID/DD who reside in California's Developmental Centers are among the most vulnerable California citizens. The vast majority have severe to profound ID/DD, in addition to complex medical conditions and physical disabilities, or dangerous behavioral challenges.

Families of developmental center residents follow a moral charge to do what is best for their loved ones. Their family members are like small children, and absent evidence to the contrary, the law presumes that parents and family members of minor children and intellectual disabled adults, will act in the best interest of their loved ones:

> "Individuals with developmental disabilities and their families are the ***primary decisionmakers*** regarding the services and supports such individuals and their families receive and play

> decisionmaking roles in policies and programs that affect the lives of such individuals and their families." DD Act, 42 U.S.C. 15001(c)(3)(1993) (*Findings, Purposes and Policies*) (***emphasis added***).

We would no more tell parents of minor children where they should seek professional health care and educational supports than we should dictate or judge the care and support decisions of parents of adult children of individuals whose cognitive abilities equate to that of infants and small children.

Trusting families to act in the best interest of their profoundly disabled love ones is a moral tenet codified in state and federal law. California Conservatorship law recognizes that the cognitive disabilities of some citizens require surrogate decision-makers to ensure the provision of adequate services, supports and advocacy. Many families of developmental center residents have been appointed by California courts to carry out this important legal charge. Likewise, the California Lanterman Act embraces the choice and provision of adequate supports, regardless of setting, as central among the legal rights and responsibilities guaranteed by federal and state constitutions and laws.

Legitimate choice is also preserved in federal law. The federal Americans with Disabilities Act (ADA), as interpreted by the U.S. Supreme Court's *Olmstead* decision, embraced the provision of services based on choice and need, regardless of setting:

> "We emphasize that nothing in the ADA [Americans with Disabilities Act] or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." 527 U.S. 581, 601-02 (1999).

Specifically, the Supreme Court instructed that community placement is only required when:

> "…the State's treatment professionals have determined that community placement is appropriate, ***the transfer from institutional care to a less restrictive setting is not opposed by the affected individual***, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." Id. at 587 (***emphasis added***). (*See also*, "The Olmstead 'choice' provision and guardianship rights," by Patricia G. Williams, Esq. (2000) ("Where a court has exercised its judgment through judiciary proceedings to authorize an individual [conservator] to make decisions on behalf of a person with a disability, that individual's authority must necessarily carry greater legal weight than any other individual purporting to speak on behalf of the person with a disability. California law pertaining to the involvement of parents, guardians and conservators in decision making pertaining to institutional and community residential placement of individuals with developmental disabilities is undisturbed by the Olmstead decision.")

Families Demand Quality of Care Regardless of Setting and Oppose Dismantling Developmental Centers and Displacing Fragile Residents in "Community Care" which is Fraught with Tragedy In California and Nationally

Families, including those who are court-appointed conservators, have a moral and legal charge to make decisions in the best interests of their family members with profound ID/DD. They are uncompromising in their demand and quest for ever-improving, high quality and safe supports for their loved ones. Families simply will not, as it is sometimes claimed, put up with poor quality care in exchange for the specialized services provided at California's Developmental Centers.

As noted above, they demand attention to the claims raised by *California Watch* with regard to the reported shortcomings of the developmental centers' protective police force. However, they are gravely concerned that the *California Watch* report will result in calls for more developmental center closures. **Such an overreaching response to the *California Watch* findings could prove far more tragic for many displaced residents than the reported problem.**

In California and around the country there are widespread reports of abuse, neglect and death in community-based settings serving people with ID/DD. Consider these examples from California:

a) A late night fire at a California home care facility for the disabled killed five people; staff escaped unharmed. Four bodies were found shortly after the fire, and a fifth body was found by investigators the morning after the fire. The cause of the fire has not been determined, but investigators with the federal Bureau of Alcohol, Tobacco, Firearms and Explosives are investigating. Records with the California Department of Social Services show the home was licensed with the state and was operating under the name of the Mt. Carmel Adult Residential Facility, a single family group home. (Associated Press, November 6, 2011)

b) More than 100 hours of video footage, which was dropped off at Sheriff's Headquarters Bureau in Monterey Park in March, show what appear to be 10 female patients at non-ICF/MR residential care facilities being raped. At least one of the suspects was believed to be an employee of a residential care facility and another of the suspects appeared to be a patient. All of the victims appear to be severely disabled. One of the suspects also appears to have been disabled because he used a wheelchair. The attacks involved force with no consent from the disabled victims. (Pasadena Star-News, January 7, 2011)

c) A caregiver worked at a non-ICF/MR dependent-care facility for at least five months before a cellular phone surfaced that contained videos police said show him beating and taunting developmentally disabled men who cannot speak. "This isn't an isolated incident," Anaheim police Detective Cherie Hill said. "I think there's a lot more going on than we already know." (*Orange County Register*, February 7, 2007)

d) The death of a severely retarded man is the latest flashpoint in a battle between families and the state over its developmental centers. Donald Santiago's mother and sister didn't want the state to move him out of the Agnews Developmental Center in San Jose, the state hospital where he had lived for nearly four decades. But state officials got a court order to move him into Justin's Home in Union City in 2005 over his family's objections. Santiago, 63, died of pneumonia in a Fremont hospital three weeks ago. The death of Donald Santiago -- being investigated by the California Department of Health Services -- is one more flashpoint in a wrenching battle between some parents of developmental center residents and the state. . Some family members say they fear the state is hastily moving people into existing community homes that are ill-prepared to care for the severely disabled and don't have medical staff on-site, as developmental centers do. Disability Rights California, a federally-funded organization that has assisted others in getting court orders but was not involved in Santiago's case, sees it differently. "It was our understanding that he got to court because he really wanted to move," Ellen Goldblatt, DRC's the-Executive Director said. "It's tragic that he then died. It's also nice that he got to move after so many years of living in an institution." (*Sacramento Bee*, January 1, 2007).

e) Some 26,000 of California's 200,000 developmentally disabled residents — people who are intellectually disabled, have Down syndrome, are autistic or have other disabilities — get some type of community-based care, state data show, and many of them are in licensed care homes, which are in residential neighborhoods all over the state. Many have been placed in care homes over the past dozen years, as the state emptied its developmental centers. Some former residents are getting good services; but many are being poorly cared for, according to the investigation of 300 care homes in Alameda, Contra Costa and San Mateo counties, which included more than 100 interviews and analysis of thousands of pages of public licensing reports and other documents spanning back to 1999. The investigation shows a care system whose low standards, poor funding and limited oversight spell trouble for the more severely disabled people it is now expected to serve — people the system was never set up for in the first place. And it shows that the state agency ultimately responsible for the welfare of the developmentally disabled — some of the state's most vulnerable people - has little direct involvement in their care. (*Inside Bay Area*, July 3 – 5, 2006 ("Broken Homes")).

f) Perhaps the most thorough and recent study relating to the risks of abuse and neglect of people with intellectual disabilities upon their transfer from ICFs/MR to community placement was performed by Robert Shavelle, David Strauss, and Steven Day. See Deinstitutionalization in California: Mortality of Persons with Developmental Disabilities after Transfer into Community Care, 1997-1999, JOURNAL OF DATA SCIENCE 3 (2005). Using information that the authors gathered on 1,878 children and adults who were moved from the ICF/MR setting to community placement between April 1, 1993 and December 31, 1999, they analyzed the increased mortality rate between those that moved into community placement as compared to those that stayed in ICF/MR settings. In performing their study, the authors compared the California Development Evaluation Report data base (1997-1999) with information from the California Department of Health Services (1999). They also took into consideration factors such as age, sex, feeding and mobility skills to predict the probability of death for each of the individuals involved. Based on the data they collected and analyzed, the authors found a 47% increase in mortality in community placement settings over that expected in ICFs/MR. The authors reasoned that the higher mortality rates for community placement individuals were due to lack of continuity of care, the absence of centralized record keeping, the reduction in intensive supervision, and limited access to immediate medical care. Although the article does not focus on the political issues often involved in the decisions to deinstitutionalize, it did touch on them, citing two primary factors: (1) the cost of savings of deinstitutionalization, as well as (2) the "social value" of integration. The authors noted that these issues needed to be weighed against the increased risk of mortality that was readily apparent from the years of studies they conducted.

In a related article written by Shavelle and Strauss in 1998, the authors point out there is no reason to believe that the problems of increased mortality are confined to California. (*see*, Policy Implications of Mortality Research: Authors' Perspectives, What Can We Learn From the California Mortality Studies?, Mental *Retardation*, p. 407 (October 1998)). VOR's own report, *Media coverage highlighting the increasing need for more effective federal and state protections in the ever-expanding community system of care for people with intellectual disabilities* (rev. Nov. 2011) (www.vor.net/images/AbuseandNeglect.pdf), confirms widespread, systemic problems with quality of care in community-based (non-ICF/MR) settings:

New York: "1,200 Deaths and Few Answers," exposes 1,200 preventable mortalities in state-run community group homes over a period of 10 years. Deaths are attributed to no statewide system of staff training and oversight to prevent reoccurring tragedies such as choking, drowning in bathtubs, wandering, and falling. It is remarkable that these deaths, averaging more than 100 a year, occurred during a period of significant deinstitutionalization in New York, and occurred without raising any apparent concern or investigation by P&A or DOJ, which is charged to protect and advocate for these vulnerable citizens. The apparent apathy could speak to P&A and DOJ's bias in favor of community settings, no matter the outcome. (*New York Times*, November 6, 2011, http://www.nytimes.com/2011/11/06/nyregion/at-state-homes-simple-tasks-and-fatal-results.html)

Washington State: A 30-year-old former resident of Frances Haddon Morgan Center, an ICF/MR, died Sunday after swallowing liquid laundry detergent, state officials confirmed Monday. He had transferred from the center in March. The Morgan Center, a home for patients with autism and other disabilities, is in the process of closing as part of state budget cuts. The center is scheduled for closure by the end of the year, with residents expected to be out by the end of November. (*Kitsap Sun*, October 17, 2011)

Utah: A sixteen-year old was brutally attacked at a place his mother thought was safe. The teen was severely beaten by another patient at a group home in late August. "It was more like an animal attack rather than what a human would do," said Stacie Pitcher, mother of Brock, the teen attacked. She said she didn't know the older patient – a 200 pound 22 year old – who also suffers from extreme autism was so violent. State regulations require round the clock supervision at these group homes. However, the attack on Brock was in the living room in plain sight when the employee finally appeared. (*ABC 4 News*, September 21, 2011)

Massachusetts: A possible medication error has lead the death of a 54-year old man with ID/DD just days after he was transferred from a Templeton Developmental Center, a state ICF/MR, to a state-operated group. The man had lived for years at the Templeton. He had been in excellent health prior to his transfer, according to a letter of concern from state Sen. Stephen M. Brewer, D-Barre, to the state Department of Developmental Services. In another case questioning the quality of group-home care, a man who had lived most of his life at the Fernald Developmental Center in Waltham died last month of aspiration pneumonia after swallowing a plastic shopping bag at the group home in which he had been living for about a year. In each case, questions have been raised about the level of supervision the men received in the group homes, with concern that lack of adequately trained staff may have contributed to their deaths. (*Telegram & Gazette*, August 13, 2011)

For more national examples of systemic quality of care problems and tragedies in community settings for people with profound ID/DD from a majority of states, including California,, see http://www.vor.net/images/AbuseandNeglect.pdf.

Conclusion

Unlike other advocates and stakeholders, families have no ulterior motives other than the desire to ensure high quality, safe supports for their family members with ID/DD. Furthermore, families have unmatched insights regarding their family members' individualized choices and service requirements:

> ". . . close relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person's abilities and experiences, have valuable insights which should be considered during the involuntary commitment process." *Heller v. Doe*, 509 U.S. 312 (1993)

It is appropriate then, for the Senate Health Human Services Committee, to consider the insights of families and conservators as "primary" and paramount to other advocates, providers, and regional centers, all of whom may have self-serving motives (such as federal funding, provider reimbursement, community-placement objectives, etc.) and cannot claim insights, as families can, of *individual* needs, choices, abilities, and experiences that come only from a lifelong interaction with these individuals and, in many cases, a court-appointed conservatorship for these individuals.

The revelations by *California Watch*, which focuses on the shortcomings of the developmental center's police force, warrant close investigation and reform.

VOR strongly cautions, however, against an overreaching response which recommends closure instead of improvement. Indeed, eliminating the federally-licensed, life-sustaining services only available in California's Developmental Centers will result in many more tragedies in scattered locations around the State, making effective oversight and reform nearly impossible. Lessons learned from other states heed caution.

For more information or additional questions, please contact Tamie Hopp, VOR's Director of Government Affairs & Advocacy, directly at thopp@vor.net or 605-399-1624.

Thank you for your consideration and for your leadership on behalf of individuals with intellectual and developmental disabilities (DD).

Sincerely,

Sybil Finken
VOR, Co-President

Ann Knighton
VOR, Co-President

cc/email committee consultants and assistants: Mareva.Brown@sen.ca.gov; Sara.Rogers@sen.ca.gov; Robert.Oakes@sen.ca.gov; Mark.Teemer@sen.ca.gov; Teresa.Trujillo@sen.ca.gov