VOR
Speaking out for people with intellectual & developmental disabilities

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The Honorable Mike McGuire, Chair
Senate Human Services Committee
California State Senate
1020 N. Street, Room 521
Sacramento, CA

Dear Chairman McGuire and Members of the Senate Human Services Committee,

On behalf of VOR, I am writing to ***strongly oppose Senate Bill 639***, which proposes to close Sonoma and Fairview Developmental Centers. Thank you for this opportunity and for your thoughtful consideration of VOR's testimony in support of our opposition to SB 639.

VOR is a national, nonprofit, non-provider organization advocating for high quality care and human rights for people with intellectual and developmental disabilities (I/DD). We represent primary families and conservators of adults with profound I/DD across the country, including many such families of Sonoma and Fairview Developmental Centers.

I. Summary of Testimony

As discussed in detail below, SB 639 is motivated by the typical fallacies associated with the demand and cost for specialized, licensed care facilities, such as Sonoma and Fairview Developmental Centers. To force fragile Californians from their chosen homes based on shortsighted myths associated with the cost of care places affected individuals at enormous risk of harm and potentially higher costs to California taxpayers.

Instead taking such a draconian approach – total closure – California lawmakers are instead encouraged to consider solutions which will better utilize Sonoma and Fairview for residents *and* nonresidents – disabled and non-disabled neighbors – while also increasing the Centers' ability to serve as a safety net for individuals in community settings who are facing a temporary crisis or whose needs, due to aging or illness, have intensified beyond the ability of the community provider to safely accommodate them.

Positioning the Centers as one option of care a true continuum of care to accommodate the diverse and ever changing needs and demands among the disabled population, while expanding shared use opportunities for these beautiful campuses, is far more visionary, holistic, and reasonable than simply closing these necessary resources forever.

II. The Supreme Court's *Olmstead* Decision Does Not Mandate Closure

Although the Supreme Court's *Olmstead v. L.C.* decision is often cited as justification for mandated forced deinstitutionalization, the Court expressly cautioned against such an outcome.

Forced deinstitutionalization is the closure of specialized and congregate residential and work settings in favor of community-based settings for *all* people with intellectual and developmental disabilities (I/DD).

The Court in *Olmstead* held that community placement is only required when not opposed by the individual (i.e., individual choice) and can meet the needs of the individual, according to the individual's treating professionals [*Olmstead v. L.C.*, 527 U.S. 581, 597(1999)]. The Court expressly cautioned against forced deinstitutionalization:

> "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...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." [*Olmstead* at 601-602].

III. Choice is Required: Individual and Family Decision-Making Must be Respected

As noted the Supreme Court in *Olmstead* held that individual choice, with the assistance of legally-appointed conservators,[1] is paramount.

In California, the vast majority of residents of Sonoma and Fairview Developmental Centers, and their families, oppose transition to community settings.

These families and conservators have been very vocal and made their views in support of continued developmental center supports known to the Legislature, the California Department of Developmental Services (DDS), the Developmental Services Task Force, the press and others.

A recent survey by the Parent Hospital Association of the Sonoma Developmental Center (SDC), which was controlled and analyzed by Dr. Markley Sutton, generated 103 responses. A remarkable 100% of developmental center survey respondents were satisfied with the

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[1] *See*, Samuel Bagenstos, "*The Past and Future of Deinstitutionalization Litigation*," Cardozo Law Review (Vol. 34:1) (2012) ("courts have not definitively resolved this question, though a number have suggested that it is the guardian's choice that matters."); Patricia G. Williams, Esq. (2000)("Absent some clear direction from the U.S. Supreme Court to the contrary, we must conclude that the laws pertaining to guardianship, conservatorship, durable powers of attorney and advance directives remain intact"); *U.S. v. Arkansas*, 794 F.Supp.2d 935 (E.D. Ark. 2011) ("All or nearly all of those residents have parents or guardians who have the power to assert the legal rights of their children or wards. Those parents and guardians, so far as the record shows, oppose the claims of the United States.")

services provided at SDC. In contrast, just 42% of respondents whose family members were served in community settings by regional settings were satisfied with their family members' care.[2]

The SDC survey results are very consistent with a survey recently conducted by VOR. From the *Augusta Chronicle's* coverage of the survey results:

> "'In the community, the funding is much more fragmented and a lot of times families have to fill in the gaps,' [Jill] Barker said. 'It can take a long time to get things set. For my children [in a group home], (it is making sure) that they were getting the services that they need and that they were good quality services.'
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> "That could account for the striking difference in the satisfaction scores between those with relatives in the institutions and those in community settings. Of the facility families, 88 percent rated the service exceptional compared with 36 percent that were highly satisfied with community care. The community care respondents were equally split on whether their family members would do better or worse in a facility, while 69 percent of those with a loved one in a state institution said they would do poorly in the community.
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> "Interestingly, nearly the same high percentage of facility families felt their loved one was well-integrated with the community through activities as did those with a family member in community care, 73 percent vs. 72 percent."[3]

Listening to the informed perspectives of family members and legal conservators is not just the law but good policy. Even prior to its *Olmstead* decision, the Supreme Court held high the perspective of families and legal guardians (often family members), in residential placement decisions:

> [C]lose 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, 328-29 (1993) [*see also*, Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. 15001(c)(3)(1993) ("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" (***emphasis added***)].

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[2] See, S.D.C. Family & Friends Questionnaire 2014 – Results (Sponsored by PHA; Presented by Markley S. Sutton, Ph.D.) at parenthospitalassociation.org/forms/info/PHA-2014-Questionnaire-Results.pdf

[3] "Survey reports more families satisfied with care given in state centers; Survey includes facility, community voices," *The Augusta Chronicle* (Sunday, April 19, 2015) at http://chronicle.augusta.com/news/health/2015-04-17/survey-includes-facility-community-voices?v=1429317311

IV. Addressing Hoped For Costs of Care: The Myths and Problems with Cost Comparisons

Hoped-for cost savings associated with the closures of developmental centers is a tempting and often-cited motivation to pursue forced deinstitutionalization. Yet, even closure advocates are now admitting that if quality and comprehensive community-based supports are provided, cost savings will *not* be realized. For example, Samuel Bagenstos, former Principal Deputy Assistant Attorney General in the Obama Justice Department's Civil Rights Division and a key litigator in deinstitutionalization cases, admits in his recent law review article that political expediency related to hoped-for cost savings have denied many people with I/DD quality placements in the community:

> It should not be surprising that the coalition of deinstitutionalization advocates and fiscal conservatives largely achieved their goal of closing and downsizing institutions and that deinstitutionalization advocates were less successful in achieving their goal of developing community services.[4]
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> [A]dvocates have increasingly focused on the creation of high-quality, ever-more integrated services in the community, [and thus] fiscal concerns have become more of an obstacle to their efforts.[5]
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> Although studies of deinstitutionalization have found that people who move from institutions to the community can achieve better outcomes at lower cost, it is reasonable to expect that the cost gap will shrink [or reverse] as people in the community receive more services. This may be especially true because a significant part of the cost gap reflects differences in the wages paid to workers in institutional and community settings.[6]

This shift from closure proponents is consistent with long standing peer-reviewed research regarding cost comparisons:

> "Findings do not support the unqualified position that community settings are less expensive than are institutions and suggest that staffing issues play a major role in any cost differences that are identified."[7]

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[4] Sam Bagenstos, "*The Past and Future of Deinstitutionalization Litigation*," Cardozo Law Review (Vol. 34:1) (2012) at 21.

[5] *Id.* at 39.

[6] *Id.* at 43.

[7] Kevin Walsh, et al, *Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research,* Mental Retardation, Vol. 41, No. 2: 103-122 (April 2003).

V. Demanding Quality: Lessons Learned from Deinstitutionalization

In California and across the country, the failure of the deinstitutionalization experiment as it has impacted people with mental illness is well-known. Likewise, people with I/DD who have been forced from developmental centers and separated from life-sustaining specialized care have suffered well-documented abuse, neglect, death, incarcerations, and isolation.

In Georgia, for example, the State closed two developmental centers in recent years before putting on hold plans to close the remaining two after alarming rates of death, neglect, injuries, incarcerations and elopements were reported. In total, **500 people with developmental disabilities died in community c**are in Georgia in 2013, 62 of whom had been transferred from developmental centers.[8]

Georgia is not alone. VOR has long-reported on the abuse, neglect and death of individuals in unprepared and underfunded community settings, many of whom were forcibly deinstitutionalized.[9] U.S. Senator Chris Murphy from Connecticut, pointing to this national crisis, requested a federal investigation:[10]

> "I write to you today to request that you undertake an immediate investigation into the alarming number of deaths and cases of abuse of developmentally disabled individuals in group homes. In particular, I would like you to focus on the prevalence of preventable deaths at privately run group homes across this nation and the widespread privatization of our delivery system."

In Georgia, these tragic outcomes of forced deinstitutionalization came to light after the State's own reporting of its "Quality Management System" of community outcomes. In sharp contrast, in California there is **completely inadequate transparency of community programs and how people are being served.** Efforts by concerned families to determine mortality rates, chemical and physical restraint data, incarcerations and other outcomes is either not provided by regional centers or not available:

> "Concern is growing among family members and advocates that the safety of those developmentally disabled folks still resident in California's state-run developmental centers is threatened -- not because of conditions at the centers but by the prospect losing the centers' protections when residents are moved into the community. . .

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[8] "Girl's death among 500 in one year in community care," *The Augusta Chronicle* (Sunday, March 21, 2015)

[9] "*Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities*," VOR (rev. March 2015) (1997- current bibliography of investigative media series, state audits and peer-reviewed research detailing detail systemic concerns with regard to quality of care in community-based settings across the country) at http://vor.net/images/stories/pdf/AbuseandNeglect.pdf

[10] Letter from U.S. Senator Christopher Murphy to the U.S. Department of Health and Human Services' Office of Inspector General seeking investigation of deaths of individuals with developmental disabilities in community settings (March 4, 2013).

> "Little data is available on patient deaths, incidents of abuse and neglect, or even the success of residents at the many care homes contracted with by the State's Regional Centers to provide care in the community. What is known is that oversight, reporting requirements and even facility safety requirements are much less stringent -- or nonexistent."[11]

In California, the higher risk of mortality of individuals with I/DD leaving developmental centers, as reported by an extensive *San Francisco Chronicle* series, is well-known.[12] More recently, headlines across California speak to mortality, embezzlement, abuse, neglect, sexual abuse and lack of safety and oversight of individuals with I/DD in community settings.[13]

As reported by the Fairview Families and Friends (FFF) February/March 2015 newsletter:

> FFF members recently learned about problems at two Costa Mesa facilities, licensed to care for clients with developmental disabilities. The problems included filthy homes, spoiled food, inadequate staffing, and mismanagement of clients' funds. These homes were closed, and the clients moved to other settings by Regional Center of Orange County. The homes remain closed, and according to the Regional Center, no clients will ever again be placed in the care of this provider. The decision to revoke the business license of the home owner rests with the Department of Social Services.

These outcomes are predictable. As Medicaid-licensed Intermediate Care Facilities for Individual with Intellectual Disabilities (ICFs/IID), Fairview and Sonoma Developmental centers are uniquely qualified to provide highly specialized care simply not available in any other care setting in California. Community homes are not subject to stringent standards and oversight and do not guarantee access to specialized health and other life-sustaining specialized supports.

Inexperienced, untrained staff and the lack of oversight of community homes exacerbate the concern and invite predicable tragedies. For example, in Northern California, a woman with I/DD died in her group home when staff "willfully administered the wrong dosage of medication." The State fined the group home provider just $150 for this young women's

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[11] "More Information Needed on Level of Abuse and Neglect at California Care Homes," Parent Hospital Association Sonoma Developmental Center Blog (February 20, 2014)

[12] *San Francisco Chronicle*, February, 1997 - August, 1998 (Fifty-six (56) articles were released detailing the abuse, neglect and death that plagued California's system of community-based care for people with mental retardation following the aggressive deinstitutionalization of over 2,000 people. The articles include reference to University peer-reviewed research at http://lifeexpectancy.com/articles.shtml that finds risk of mortality to be higher in California).

[13] "Livermore: A young woman's death and staffing cuts prompt questions over care at home for developmentally disabled," *Contra Costa Times* (August 29, 2014); "Police: Embezzlement from disabled went on for years," *The Press Democrat* (February 22, 2014); "L.A. suit accuses unlicensed care facilities of abuse, *Los Angeles Times* (February 18, 2014); "Safety measure not required in thousands of homes for elderly, Disabled," *NBC Bay Area* (June 4, 2013); "5 Killed in California Group Home Fire," *AP* (November 6, 2011); and "At least two suspected of sex assaults on disabled identified," *Pasadena Star-News* (January 7, 2011).

death and only recommended, not required, training of staff on dispensing medication. Instead, the provider fired 12 nurses and therapists. Remaining staff are reportedly working six days a week, sometimes 12-hour days, risking burnout. Predictably, subsequent reviews stemming from the original investigation have revealed additional errors.[14]

These concerns are just the tip of the iceberg. The full extent of tragedy cannot be known due to the lack of transparency and the inability to secure data on just how people with profound disabilities are doing. **Lawmakers MUST demand this information from regional centers and make the data public before making any determination with regard to the future of Fairview and Sonoma Developmental Centers.**

VI. SOLUTION: Re-Invent Developmental Centers and Community Resource Centers to Serve Current Residents, Non-Residents, and Neighbors

Fairview and Sonoma Developmental Centers in Southern and Northern California now provide highly specialized care to Californians with profound I/DD, who are also medically fragile and experience extremely challenging and dangerous behaviors.

Situated on beautiful campuses, these centers are fully integrated with their surrounding communities of Costa Mesa and Sonoma. The campuses are enjoyed by volunteers, visitors and outdoor enthusiasts, and residents enjoy the amenities of their homes and the surrounding communities. Closure is forever and to take away this favored resource will impact directly the residents and the communities who have come to love their neighbors.

California lawmakers are encouraged to consider solutions which will better utilize, not eliminate, Sonoma and Fairview Centers for residents *and* nonresidents – disabled and non-disabled neighbors – while also increasing the Centers' ability to serve as a safety net for individuals in community settings who are facing a temporary crisis or whose needs, due to aging or illness, have intensified beyond the ability of the community provider to safely accommodate them.

Both Centers could serve as resource centers providing medical care; dental care; assessments; respite; wheelchair adjustments; adaptations and technology; orthopedic devices; crisis support (transitional or long-term); therapies; recreation; and more to non-residents with disabilities. Both Centers could continue to welcome non-disabled neighbors to enjoy the campus green spaces, to volunteer and to visit. Sonoma could investigate housing on campus for non-disabled residents, consistent with Harbor Village at Fairview.

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[14] "Livermore: A young woman's death and staffing cuts prompt questions over care at home for developmentally disabled," Contra Costa Times (August 29, 2014)

The opportunity for crisis housing, as is being developed now at Sonoma, could be expanded at both campuses.[15]

The Task Force on the Future of the Developmental Centers addressed unmet needs and the ability of the current system to safely accommodate the individuals with I/DD who have complex medical needs or very challenging behaviors. Rather than invest in a new, untested, possibly more expensive, smaller "community" option, it is far more prudent and fiscally sound to utilize the existing infrastructure and professional experience of Fairview and Sonoma Developmental Centers. These centers are presently under-utilized, resulting in manipulated cost inefficiencies. Expanded use, not closure, addresses thess inefficiencies and serves a great many more people across the disabled continuum now and in the future.

California lawmakers are urged to OPPOSE SB 639, reject closure, and support a re-purposed Fairview and Sonoma Developmental Centers for residents, non-residents and neighbors.

Thank you for your consideration. I welcome any questions you may have.

Sincerely,

Tamie Hopp
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[15] The Parent Hospital Association of SDC survey found that a high percentage of respondents would support using SDC as a specialized medical clinic (83%); a Behavioral Crisis Unit (74%); a "Zero Reject" behavorial facility (69%); and for long-term behavior group homes (68%).