

Save Our Regional Centers

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January 6, 2015

Reggie Bicha, Executive Director
Colorado Department of Human Services
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By email: reggie.bicha@state.co.us

Dear Mr. Bicha,

Colorado's Save Our Regional Centers (SORC) and VOR, a national advocacy organization, appreciate this opportunity to submit comments in response to Colorado's Community Living Plan (July 30, 2014) (hereinafter, the "Plan").

As explained below, SORC and VOR represent individuals with profound intellectual and developmental disabilities receiving Regional Center supports, their peers across Colorado, and their families and legal guardians.

We are necessary stakeholders with valuable input.

Given that the Plan "will be monitored and updated," and that "its contents will continually evolve" (Plan, pp. 4-5), SORC and VOR offer input at this time with the expectation that we will be included as key stakeholders in all aspects of Plan implementation going forward.

I. **Introduction: SORC and VOR, Speaking out for people with intellectual and developmental disabilities**

Save our Regional Centers (SORC) is a statewide coalition of concerned families, legal guardians and advocates representing the residents of Wheat Ridge, Pueblo, and Grand Junction Regional Centers. Colorado Regional Centers are state-operated, Medicaid licensed Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID). Regional Centers are home to about 250 of Colorado's most profound disabled citizens, including our family members.

VOR is a national, nonprofit organization advocating for high quality care and human rights for people with intellectual and developmental disabilities (I/DD). We represent primarily families and legal guardians of individuals with I/DD, with members in every state including Colorado. VOR is the only national advocacy organization supporting a full spectrum of care options from own home, family home, community-based options, and licensed facility homes, including ICFs/IID.

II. Summary of Comments

- A. The *Olmstead* Decision:** As indicated in the Colorado Community Living Plan, *Olmstead* does not mandate community-living for all. Rather, *Olmstead* requires the provision of community-based care only when not opposed by the individual and based on the individual's need. Specifically, "the ADA does not suggest that individuals should be moved from institutional settings if unable to handle or benefit from community settings, or if the integrated setting is inappropriate to their needs." (Plan, p. 7)
- B. Family/Guardian Involvement:** Families and legal guardians of Regional Center residents are primary decision-makers and "key system partners" who must be included in the implementation of the Community Living Plan.
- C. Quotas, Person-Centered Planning Protocol and Universal Assessments:** Quotas ("annual targets," pp. 21, 23) are inconsistent with *Olmstead* and true person-centered planning. The State cannot know in advance who wants and would benefit from being transferred from Regional Center homes. Any assessment tool must be available for public inspection and not replace the federally-required Individualized Plan (IP) that is already in place for each Regional Center resident.
- D. Demographics: Community Capacity and Regional Centers as Safety Nets:** To assess demand and related costs, the Plan should include specific information about the demographics of current Regional Center residents, individuals now being served in the community, and those waiting for services.
- E. Waiting Lists:** Thousands of individuals are waiting for services. These individuals deserve priority planning. Closing Regional Centers must be taken off the table – the displacement of these high need individuals will only further stress an already inadequate community system. Regional Centers are a safety net for those who choose to remain at home in a Regional Center, or for those who need to return for respite, stabilization, or long-term supports after failed community placements. Centers could also serve non-residents as "out patients," providing access to highly-trained health care, psychiatric professionals, and other specialists, contributing to a more successful community experience.
- F. Informed Choice:** To ensure individual choice, Colorado's Department of Health should prepare, with opportunity for public input, a simple document/brochure providing information on all service options, including but not limited to family supports, home and community-based waiver services, and psychiatric supports. This document should be automatically available to individuals and their families using the "the No Wrong Door/Single Entry Point" and at any time services are sought.

Detailed comments follow.

III. The *Olmstead* Decision

SORC and VOR applaud the accurate recitation of the *Olmstead* decision's holding and interpretative ("dicta") language:

"On June 22, 1999, the United States Supreme Court found in *Olmstead v. L.C.* that unnecessary segregation of individuals with disabilities in institutions is a form of discrimination based on disability. Referring to the Americans with Disabilities Act (ADA), the *Olmstead* decision holds states accountable for providing community-based care whenever appropriate, rather than placing individuals with disabilities in institutional settings" (Plan, pp. 1, 3, 6, citations omitted)

"The Supreme Court's 1999 *Olmstead* decision directs states to move individuals with disabilities in institutions to more integrated settings when the individuals are qualified and desire such transitions. The Court held that states are required to provide community-based services for people with disabilities who would otherwise be entitled to institutional services when: (a) treatment professionals reasonably determine that such placement is appropriate; (b) the affected person does not oppose such treatment; and (c) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of other individuals with disabilities." (Plan, pp. 6-7, citation omitted)

"The *Olmstead* decision points out that the ADA does not suggest that individuals should be moved from institutional settings if unable to handle or benefit from community settings, or if the integrated setting is inappropriate to their needs." (Plan, p. 7)

We caution that "Colorado's commitment to ensuring that people with disabilities and older adults have the same rights as people without disabilities to live in the home of their choice with the supports and services they need to live independent lives" (Plan, p. 1), stay true to the spirit and letter of the *Olmstead* decision, and not morph into a perceived mandate to serve all people with disabilities in community settings, regardless of need or choice.

Going forward, we caution against Regional Center closures and quotas for community placement, both of which we view as directly counter to individualized choice according to need, as required by the *Olmstead* decision.

IV. Family/Guardian Involvement

Families and legal guardians of Regional Center residents were not involved in the creation of this Plan in any meaningful way.

This must change.

Due to the past and on-going deinstitutionalization activities in Colorado, and the emphasis of the Community Living Plan on proactively assessing Regional Center residents who want to

move to a community living arrangement and proactively preventing Regional Center admissions, SORC and VOR are unquestionably “key system partners.”

As the family and legal guardian representatives of the very individuals most directly impacted by Plan implementation, SORC is most knowledgeable as to the needs and choices of current Regional Center residents. As acknowledged by the Supreme Court in its *Heller v. Doe* (1993) decision, “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” in residential placement decisions (*Heller v. Doe*, 509 U.S. 312 (1993)).

Yet, in the 49-page Plan, the involvement of families is only mentioned eight times and only as caregivers and companions, not as primary decision-makers.

Legal guardians, very often family members of individuals with profound intellectual disabilities such as Regional Center residents, are mentioned twice in the entire document, each time within Goal 6, to “Improve communication strategies among LTSS [Long Term Services and Supports] agencies to ensure the provision of accurate, timely and consistent information about service options in Colorado.”

While we support and appreciate this reference to legal guardians in the context of **receiving** information, the Plan must also expressly indicate the role of legal guardians *and* families in **providing** information and as primary court-appointed decision-makers for individuals with profound intellectual and developmental disabilities.

For example, the strategies relating to Goal 1 include developing a Person Centered Planning protocol that includes a team planning effort and a universal assessment tool to identify Regional Center residents who desire community placement. Legal guardians are court-appointed to represent individuals who are judicially determined to be in need of decision-making assistance due to their disabilities. Legal guardians are very often family members who the most informed about the individual's needs and choices and who have a legal and moral obligation to act in the individual's best interest. Family members, who have life-long relationships with their family members, are also uniquely positioned to provide valuable insights regarding an individual's needs and choices, including with regard to residential options.

Legal guardians and families must be included in the implementation of Goal 1.

Likewise, legal guardians and families must be included in the implementation of Goal 2. For the same reasons, these advocates are best informed about the services and supports required to mitigate crises and identify adequate and necessary supports to ensure a successful community experience.

For the reasons stated herein, families and legal guardians have an important role as “key system partners” and stakeholders to participate in efforts to develop and implement an evaluation tool to assess implementation efforts and improve Plan outcomes, develop evaluation tool, and recommend Plan changes and improvements (**Goals 7-9**). They must be included.

V. Quotas, Person-Centered Planning Protocol and Universal Assessments

The provision of long term services and supports according to individual choice and need is central to the letter and spirit of the *Olmstead* decision, and must also be central to the successful implementation of the Colorado Community Living Plan.

Quotas

While SORC and VOR praise the Plan's correct interpretation of *Olmstead* (see above) both **Goals 1** and **3** contain language which suggests that deinstitutionalization quotas will be a measure of plan "success":

"Annual targets are met on the number of individuals transitioning out of institutional settings" (Plan, pp. 21, 23).

SORC and VOR view quotas as inconsistent with the letter of and spirit of the *Olmstead* Supreme Court decision. Quotas are antithetical to, and prevent, individual choice and person-centered planning. *Olmstead* does not require that individuals be forced out of a good placement against their choice and best interests; indeed the Court required that individuals not oppose transition to the community.

Goal 1 calls for proactively identifying individuals currently receiving "institutional" care, including Regional Center supports, to determine who wants to move to community living options. However, **Goal 1** suggests that deinstitutionalization quotas will be developed and used as a measure of success: "Annual targets are met on the number of individuals transitioning out of institutional settings" (Plan, pp. 21). Goal 3, which calls for increased community capacity to meet the needs of individuals with I/DD who seek community placement, repeats this "quota" goal (Plan, p. 23).

Individualized Assessments

Goal 1 requires the development of a protocol to identify individuals now in Regional Centers who may want to move to community settings and a "universal assessment process" to determine individualized needs.

As noted above, it is imperative that family members and legal guardians of Regional Center residents be involved and consulted, and that any protocol and assessment tools are publicly available.

SORC and VOR are very concerned that person-centered protocols and universal assessment tools when improperly designed and/or improperly implemented will not adequately reflect the different aspects of an individual's unique combination of needed services and supports. The assessment should not take the place of the federally required Individualized Plan (IP) for each Regional Center resident. Doing so may not reflect a true and compelling picture of an

individual's disabilities and needed services and supports. An understated level of disability and the resultant apparent lack of need for certain services can result in a preventable tragedy.

VI. Demographics: Community Capacity and Regional Centers as Safety Nets

Goals 3 and 4 seeks to increase the availability and access to community-based housing (Goal 3) and services and supports (Goal 4) for people who need and choose community settings.

As noted above, we strongly object to any reference to deinstitutionalization quotas – “annual targets” (Goal 3). While residential, service and support capacity must be in place for any individual seeking community placement, deinstitutionalization targets have no place in this document.

Community capacity must be based solely on individual choice and not some arbitrary number that will end up placing undue influence on quotas and not individuals. Additionally, “financing opportunities” to expand the array and availability of community-based services and supports (Plan, p. 27) must avoid “rebalancing” approaches that have the effect of forcing individuals from Regional Centers in exchange for a financing “carrot.” Long-term planning suggests that displacing individuals by force from Regional Center will not lead to increased community capacity and could lead to higher community costs as higher need individuals are forced into settings they did not want in the first place and are more expensive than the Regional Centers.

To help assess community capacity and actual costs, SORC and VOR suggest that the Plan include specific consideration of the demographics of current Regional Center residents, individuals now being served in the community, and those waiting for services.

In particular, a vast majority of current Regional Center residents experience profound disabilities and have complex needs. According to a study by the University of Minnesota, 89.6% have two or more disabling conditions in addition to intellectual disabilities, such as deafness, blindness, cerebral palsy, epilepsy, a psychiatric disorder (86.6%), and/or a behavioral disorder; 88.1% are taking medication for a “mood/behavior” disorder.¹ Between 14-20% of Regional Center residents also have functional limitations, needing assistance in transferring, walking, eating, and toileting, and 10.4% of these individuals cannot communicate basic desires verbally.² Regional Center residents are also an aging cohort,³ with needs increasing as these individuals age.

The Plan should include a section on the needs and process for identifying individual support requirements, including but not limited to consideration of levels of intellectual disability and related disabilities of Coloradans now served in Regional Centers and those who may need Regional Center supports in the future.

¹ Larson, S.A., Ryan, A., Salmi, P., Smith, D., and A. Wuorio (2012) (p. 39, Table 1.18). Residential Services for Persons with Developmental Disabilities: Status and trends through 2010. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

<http://rtc.umn.edu/risp/docs/risp2010.pdf>. **Note:** The State of Colorado **did not furnish** data for resident characteristics for the most recent edition of “Residential Services for Persons with Developmental Disabilities: Status and trends through 2012” (2014).

² Id. at 40 (Table 1.19).

³ Id. at 36 (Table 1.16).

VII. Waiting Lists

SORC and VOR support reference to the waiting list with a goal of ultimately eliminating the waiting list (Plan, p. 27). According to the State, in Fiscal Year 2013 there were 1,955 individuals with developmental disabilities, 761 deemed “High Risk,” waiting for Medicaid Home and Community-Based Services (HCBS-DD) and 6,151 individuals and families, 21 deemed “High Risk,” waiting for Family Support Services. Additional waiting lists for HCBS-Supported Living Services and HCBS-Children’s Extensive Supports account for several hundred more citizens going without adequate services.⁴

SORC and VOR feel strongly all efforts should be applied toward helping the thousands of individuals in need, rather than focusing on Regional Center residents who are receiving high quality care and whose displacement from Regional Centers would only further stress an already inadequate community system of care.

Regional Centers are an important safety net for those individuals who choose to remain at home in the licensed facility, or for those who need to return for respite, stabilization or long-term supports after failed community placements. The Community Living Plan must foresee and plan for this demand while also accommodating individual choice, as *Olmstead* requires.

Furthermore, SORC and VOR encourage consideration of Regional Centers as appropriate homes for some individuals on the waiting list and as “outpatient clinics” for those individuals who do not wish to receive residential care but who could benefit from accessing the Center’s bevy of specialists, not consistently available elsewhere.

VIII. Informed Choice

Goal 6 relates to communication strategies – getting the word out to individuals with disabilities and their legal guardians about long-term services and support options.

Goal 6 is geared toward informing individuals and stakeholders about available community options.

To ensure that eligible individuals have opportunity to make fully informed choices about available services in settings of their choice, SORC and VOR urge Colorado’s Department of Health to prepare, with opportunity for public input, a document/brochure providing information on all service options within Colorado, including but not limited to family supports, HCBS waiver services, Regional Centers, and psychiatric supports by January 1, 2015. This document should be automatically available to individuals and their families using the “No Wrong Door/Single Entry Point,” and at any time services are sought.

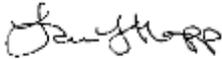
⁴ “Waiting List Report for the quarter ending September 30, 2013,” Colorado Department of Health at <http://www.colorado.gov/cs/Satellite/CDHS-VetDis/CBON/1251617259764>

IX. Conclusion

Families and legal guardians, more than any other stakeholder, are informed about their family members' needs and have a moral and legal obligation to ensure their well-being. Going forward we must be included in the implementation of the Community Living Plan.

Thank you for your consideration of our comments and for including us as "key system partners" going forward.

Sincerely,



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