

Association of Regional Center Agencies Position Statement on Department of Developmental Services Developmental Center Options Study

Background

The Association of Regional Center Agencies (ARCA), representing twenty-one regional centers who serve over 160,000 consumers with disabilities and their families across the state of California, has been asked to respond by the Department of Developmental Services (DDS) to a document developed by the Department entitled “The Developmental Center Options Study.” Accompanying this document were instructions for a consultant to conduct interviews and focus sessions with representative groups of people in the community. The consultant would analyze the results of this process. DDS would deliver a report based upon the analysis to the Legislature by March 2001.

ARCA provides the following position statement in response to the questions raised by the Department in its Developmental Center Options Study.

Key Assumptions

The Developmental Center Options Study is constructed to describe the state’s role in the future design and implementation of the California’s developmental services delivery system. ARCA believes it is very clear that the Department assumes the state will be the essential direct provider of service and ultimate administrator of the system.

ARCA is concerned to find the Department’s document lacking in specifics, and almost silent on the relationship of developmental center options to the existing community system.

The study questions seem to suggest that the State should engage in entire range of community-based services currently provided by the private sector. ARCA is strongly opposed to any initiative on the part of the state which would offer such services as case management, clinical diagnosis and assessment and any other services that is required under the Lanterman Act to be provided by regional centers.

Most importantly, the document and many of the questions seem designed to promote the idea of a “dual” community system. That is, the materials which describe state provided services for those residing in the state developmental centers also outline a hierarchy of identical state-run residential or day programs placed in community integrated settings. There seems to be a bias that state-run, community-based programs would offer a qualitatively better group of program options to persons who have lived in the developmental centers. There is no objective evidence that state-run, community based programs would be the best option for any or all consumers. Moreover, there is very strong evidence that programs must be chosen individually after highly individualized planning and opportunities to experience, in a concrete manner, what certain choices can mean.

Based on these assumptions, ARCA passed the following motion at its October 11, 2000 meeting:

That ARCA go on record as absolutely, unalterably opposing the creation of a two-tiered system of community-based services. The regional centers are here to provide community based services.

Principles

Within its pre-developed framework the Department of Developmental Services appears committed to seeking public input in its effort to develop options to meet the future needs of individuals served or to be served, in state developmental centers. ARCA has found value in the two meetings to date sponsored by DDS dealing with this subject matter and has endorsed the five project principles:

- No major capital outlays to rebuild developmental centers
- Homes should be limited to four people or less
- Capture and extend developmental center resources into the community
- Leverage DC land to create new resources
- Conduct highly individualized person assessments and resource development before moving people into the community. (ARCA believes when conducting an assessment, it is important to note that people usually do not demonstrate the same cluster of behaviors that they have in the developmental centers in the community. Designing a treatment program which is successful in one environment rarely, if ever, is successful in another environment. Consumers do not transfer skills or knowledge from one artificial place to another “real” place. Individuals are unable to make choices when they have never actually experienced the options available to them.)

ARCA would like to suggest five additional principles:

- At their discretion, each consumer has a choice of his or her own private bedroom
- Only those consumers for whom an appropriate private sector, community-based setting cannot be found, as determined by the planning team, should be served in state-operated homes.
- Persons served by regional centers in the community should have equal access to state-operated services, provided that appropriate private sector, community based settings cannot be found, as determined by the planning team.
- Regional centers will vendorize all community-based services, including those services which are state-owned, state-leased or state-operated.
- The state is the provider of last resort.

Planning Process

The planning process appears to be top-down with the state at the top of the planning pyramid and the community at the bottom. While questions are asked of key constituents about how state resources will be used, these queries clearly assume that state resources will be used and implementation is a matter of filling in the details. Such a process bypasses the highly individualized planning required by one of the key principles to restructuring the state developmental centers endorsed by many community organizations and the Department of Developmental Services.

ARCA supports a planning process that generates its ideas and momentum from a grassroots process such as that required by the *Olmstead v. L.C.* decision. Further, the planning for the future needs of persons who reside in developmental centers needs to be regional center or multi-regional center in nature. **An essential step is that regional centers need to develop local developmental center plans individually and integrate those plans into the range of resource needs within their local communities and then submit coordinated proposals to the Department.**

The regional center(s) would negotiate with the state for funding, resources and the ultimate objectives of the plan. The plan for the region could include the role of the state, both as a service provider, resource developer, and consultant. The state's level of participation would differ from plan to plan. Some regional center planning areas may wish the state to take a more active role, including resource development and direct service operations.

The key factor, however, is the concept of individualized, decentralized planning that is community-based. ARCA rejects the notion that a "one-size-fits-all" approach will work in a state as large and diverse as California.

Stability in the Community System

ARCA appreciates the needs and fears of families with loved ones currently being served in the state's developmental centers. All families deserve a service system they can trust to provide for their children when they are no longer able. ARCA endorses the idea of community programs that provide quality services with performance-based outcomes. For that reason, ARCA strongly supports efforts to ensure direct service providers and community operated programs receive wages that allow for a stable and professional workforce. The success of the DDS's System Reform effort to achieve this objective is fundamental to providing viable developmental center options within a stable community-based system. To attempt to do otherwise will surely maintain a dual system and provide unequal treatment.

Legal Considerations

The civil right of an individual to live in his or her own community has recently been affirmed in *Olmstead v. L.C.*, a Supreme Court decision in June 1999, which clearly stated the right of persons with disabilities to receive public benefits and services in the most integrated setting appropriate to their needs. The Court emphasized that resources available to the state are not limited to those already invested in the community system. At a minimum, they include the resources invested in the institutions in which individuals reside. The Court supported the notion that a state can be required to fund community placements by moving resources from institutions to the community.

Neither the Lanterman Act nor the Supreme Court in *Olmstead* envision a separate and unequal system of community-based services: one for those who have resided in state institutions, staffed and administered by state employees (paid significantly higher wages and benefits); another system for those persons with developmental disabilities, who have never lived in a developmental center (staffed by those working in the private sector for a significantly less pay and benefits). In fact, in *Olmstead*, the Court specifies, "the State's need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities and the State's obligation is to administer services with an even hand." *Olmstead* appears to require that equal resources be expended for community-based options whether they are State-staffed and -administered or staffed by privately employed personnel and vendored through the regional center. *Olmstead* also clearly provides that services of equal value must be made available to those persons at risk of placement into a developmental center.

State Provided Treatment Settings

Within the framework of the legal considerations mentioned above, ARCA does not oppose the idea of state operated services. The general principle which should provide the basis for living

arrangements for persons with developmental disabilities should be, "...that communities and the people living in them are healthiest with fullest possible inclusion of all members including people with developmental disabilities." (Ryan, 1999)¹

Ryan goes on to quote Frank Menolascino M.D., a noted expert in developmental disabilities, who states,

The current preferred placements are individualized and avoid the obsolete 'readiness' model now thoroughly disproven approach that suggests that people can be prepared ("made ready") for a preferred situation, such as paid employment, in some other, non-similar setting. Programming persons in setting A prepares them for setting A and does not help them toward preparing for setting B. The concept of the institutional setting as a center of excellence has been expanded. Common practice had been to send the challenging individual to the institutional center of excellence to be fixed and sent back to his or her community. Workers in a number of states...have focused on the concept of the traveling team, moving the expertise into the person's community, collaborating with the community team, and providing on-site consultation and on-going teaching and follow-up. The center of excellence may be a useful setting for completion of thorough physical, neurological and laboratory evaluations as well as numerous medical consultations. Persons who are a danger to self or others and do not voluntarily accept supports in the community may benefit from temporary placement in institutional settings. The primary emphasis is on facilitation of independence through linkage with the person's family and home community and avoidance of permanent institutionalization.

Within the clinical framework discussed above, ARCA supports the following concepts:

- The state should operate programs for people who are dangerous to themselves and others and who need temporary support in a secure environment to address behavioral issues that cannot be served effectively by community-based programs.
- The state should provide services for individuals who are extremely medically fragile and without existing alternatives for services within the community.
- For certain populations ARCA supports the idea of involving the state in a multiplicity of local programs at the local level which are used as the placement of last resort.

¹Ryan, Ruth M. M.D., *Neuropsychiatry and Persons With Developmental Disabilities*. Edited by Fred Osview, M.D. Neuropsychiatry and Mental Health Services Washington, D.C., American Psychiatric Press, 1999

ARCA DC Options Task Force

ARCA has formed a task force whose mission it is to formulate a strategic plan incorporating specific demographic information and the values and techniques of Person Centered Planning as the basis for designing an individualized program for each person who resides in a state developmental center or who is at risk of placement in a more restrictive state owned and operated environment. A draft of this regional plan will be available in December 2000.

Cmte\LC\Misc\DC Options.wpd