

From ***Options to Meet the Future Needs of Consumers in Developmental Centers***, (Appendix 19) prepared by the Department of Developmental Services in June 2002 in response to a requirement of Chapter 93, Statutes of 2000, Section 104 (AB 2877 - Thomson). Section 104 required that:

a) The State Department of Developmental Services shall identify a range of options to meet the future needs of individuals currently served, or who will need services similar to those provided, in state developmental centers. (b) The department shall establish a workgroup consisting of system stakeholders to assist in examining the various options including, but not limited to, renovation of existing developmental centers, smaller state owned and operated facilities, state operated leased facilities, privately owned and operated facilities, and services and supports provided in consumer owned or leased homes. (c) Options shall be evaluated for their appropriateness in meeting consumers' needs, compliance with requirements of federal and state laws, and efficient use of state and federal funds. (d) The department shall report on these options and the recommendations of the workgroup to the Legislature by March 1, 2001.

September 29, 2000

SUMMARY COMMENTS OF CALIFORNIA ASSOCIATION FOR THE RETARDED (CAR)

Participants: Les Gary, CAR member, and Maureen Fitzgerald, CAR Executive Director

A. Values

1. *Values present in state-operated services that should be preserved*

- Stability through consistent care givers
- Safety
- Quality
- Permanence
- The baseline should be the same level of effort and quality as exists in the developmental center. Services should only be enhanced.

2. *Values that should be enhanced*

- Placement decisions should be based upon human issues rather than philosophical issues. There is a tendency to move on philosophy and let the person follow.
No human being should be sacrificed to philosophy.

- The values listed in number 1 need to continue across all facets of the service system. Apply the value placed on developmental center employees as professional staff to the community at large. The current reimbursement system for community care services should be modified to enable the offering of programs which reflect the values of stability, safety, quality and permanence now present in the developmental centers.
- Regardless of where it occurs, i.e., integrated or congregate, parents/family want their child or adult to be happy and safe.

B. Principles

1. *General comments*

- CAR supports the five concepts (with a caveat on the four or less principle). The budget language calls for an examination of a range of options. To start out considering only settings of four persons or less is not in keeping with the study requirements.
- CAR is an advocate for policies and practices that support a full continuum of services that should be available for persons with mental retardation and their families.
- To fulfill the study requirements, we believe the study must identify changes needed in the community system that would have the effect of benefitting all individuals and their families, not just those currently living in the centers. These changes should include identification of unmet and/or inadequately met needs of individuals and families.

2. *No major capital outlays to rebuild developmental centers*

- CAR's support for this principle is predicated on the assumption that comparable or better services will be provided in community settings in lieu of rebuilding the centers.
- It is reasonable that some present structures may, with minor change, continue to offer utility in a restructured environment.
- In lieu of rebuilding the centers, the state needs to make a substantial investment of funds in the purchase and long term lease of homes to be either state operated or state owned/maintained and leased to a provider. Individuals should not have to move because their provider retires or goes out of operation for financial or licensing reasons.

3. *Homes limited to four persons or less*

- The principle that persons should be served in settings of four persons or less may be both appropriate and feasible for some, but not all, individuals. Many of the people in the centers are fragile and have major medical needs. It will be very difficult to arrange for needed nursing and medical care if the model of service is limited to settings of four persons or less. Due to economies of scale, the best way to serve some persons, especially those with major medical needs, may be to build new facilities of varying capacities ranging from 50 to 100 beds to several hundred.
- Starting with the size of the home is the wrong end. Need to know more about people and their needs.

4. *Capture and extend developmental center resources in the community*

- Regional resource centers, with dental, medical, and other services, which are hard to access in the community, could be created as a means of retaining experienced state employees. Such centers would then also provide services to those in the community.
- The state also could operate homes to meet unmet or inadequately met community needs such as for crisis care and care for those dually diagnosed. Crisis teams of one or more persons could also be created to assist in the community as needed. An example is providing additional temporary support to person(s) in a new placement or a newly opened facility.

5. *Leverage the developmental center land to create new resources*

- It would be ill advised for the state to sell land when, in the long run, land values keep increasing. Also, many of the developmental center sites are advantageously situated by major population areas where the need for services is the greatest. The potential exchange or the sale of property must be very carefully assessed. Preferably, the transaction should not only meet our system's needs but also generate ongoing revenue for the state (to be put back into the system).

6. *Conduct highly individualized personal assessments and resource development before the move to the community*

- It is essential that services equal to or better than those provided in the developmental centers must be in place prior to persons leaving the developmental centers. Moves to the community should not be a "given."
- Personal assessments must continue to dictate each individual's "best interests."
- The services must not only be of the same quality, but they must be in the same

quantity as they are currently getting.

C. Planning

1. Who should be involved?

- Involvement should include individuals with developmental disabilities and their families, public and private advocacy organizations, provider groups, legislative representatives, DDS and the Departments of Finance, Social Services, Health Services and Rehabilitation.

2. Planning questions/issues

- The Legislature's study language focused on the needs of persons now in developmental centers and those who might need developmental center services in the future. A master plan should be developed which addresses the needs of all the individuals and families in the entire service system.
- The plan has to avoid developing options on a "one size fits all" theory.

D. Concerns

1. The study needs to reflect the full array of capabilities and limitations of persons. CAR believes strongly that the current trend to start with philosophy that consumers should live in supported living and have jobs regardless of the severity of the disability, rather than focusing on the needs of the individual, is arbitrary and inconsistent with the Lanterman Act.

2. CAR is very concerned about "dignity of risk." In part, CAR was created because we believe that not enough is being done to protect some of our lower functioning persons from possible exploitation, neglect and abuse. The notion of risk and attendant opportunities needs to be tailored to the individual and his/her capabilities. Risk should be minimized and caution applied.

E. Options

General Comments

- CAR supports a continuum of care including congregate living arrangements of varying size and workshops. We object to describing living or working settings as either integrated or segregated.
- The continuum should include all choices, none of which is judged to be better or worse than any other. People and families should be able to choose a congregate or integrated opportunity if that is what they want.

F. Other Comments

Many developmental center families and consumers enjoy optimal services which, in this case, we define as their family member receiving or having immediate access to services that meet their needs. All individuals and families should receive this level of services. Many parents have witnessed or are aware of bad experiences in the community. For some, the bad experience directly involved their family member. Families shudder to think that developmental centers will close. It is a very serious situation. Almost all of the people who live in developmental centers are fragile or have behavioral challenges. Moving these individuals is a very serious undertaking. We seek to get the task accomplished because of the reality. Where justification exists, it must be done carefully and with full awareness that it is a life and death situation.