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(COCO)**

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Alameda County Network of Mental Health Clients

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California Foundation for Independent Living Centers

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United Autism Alliance

WCIL

World Institute on Disability

Hon. Grantland Johnson, Secretary
Agnes Lee, Deputy Secretary
Department of Health and Human Services
1600 Ninth Street, Room 460
Sacramento, CA 95814

March 21, 2003

RE: Response to Complete Olmstead Plan

Dear Secretary Johnson and Deputy Secretary Lee:

We are responding to the final draft Olmstead Plan, released earlier this week. As you know, until this release, we had seen only Section V, so this is our first and, evidently, our last opportunity to comment on the other sections. Nevertheless, at your request, we will confine our remarks to inaccuracies and technical issues, and primarily to sections other than V.

We want to make clear that although we are limiting the scope of these remarks, no endorsement of the plan overall is implied. We were very pleased to see that you adopted many of our recommendations from our Consolidated Comments, but many of them were not adopted, and our most fundamental concerns about the adequacy of the plan remain. With no fiscal or programmatic analysis, no budget projections, no designated staff, few timelines, and no goals for moving people out of institutions, this plan cannot be said to be effective.

I. INTRODUCTION

Page 2:

- a. Persons with developmental disabilities living in institutions

The statement that California is a “national leader” in supporting the integration of people with developmental

“A Coalition of Californians working toward community inclusion through the implementation of the *Olmstead* decision”

disabilities into community life is inaccurate or at a minimum misleading. California currently has 3,600 plus people living in the DCs – Sonoma DC is the *single largest* state operated institution for people with developmental disabilities in the nation. Several of the other DCs are also among the nation’s largest. California opened two new institutions for people with developmental disabilities within the last five years. The 40% reduction in DC residents so proudly claimed was, in fact, achieved during the five years that the State was operating under a court order in the *Coffelt* case. In three of the five years since 1998, when the settlement period ended, more people have been admitted to, than placed out of, the DCs. Conversely, there are eleven states which operate no state institutions for people with development disabilities.

In addition to those in California’s DCs, there are 5,000 people with developmental disabilities who reside in a variety of other public and private institutions who need to be counted in *Olmstead* planning.¹

b. Citation of Ruling in *Sanchez v. Johnson*

The citation to *Sanchez v. Johnson* is also misleading. First, the *Sanchez* case deals *only* with people residing in DCs. The *Olmstead* rights of the 5,000 plus people with developmental disabilities who live in other institutions were not before the court, thus the court’s ruling in no way finds there is a comprehensive plan to place them in more integrated settings.

Second, the *Sanchez* case is not over and advocates believe the Court did not have all the relevant evidence on the Community Placement Plan (CPP). Fewer than 200 DC residents have been included in the CPP each year. At that rate it would take in excess of 18 years to even properly assess the 3,600 people currently residing in DCs. This is a glacial *not* a reasonable pace and is not consistent with the remainder of the draft *Olmstead* plan. We recommend removing the citation to *Sanchez v. Johnson*.

If the reference to *Sanchez* remains, then in the spirit of fairness, the state should cite other litigation, which challenges the state’s efforts to implement *Olmstead*.

Davis v. CHHS challenges the unnecessary institutionalization of people in Laguna Honda Hospital – the largest single skilled nursing facility in the nation.

¹ 2002 DD Institutional Population based on DDS data: DCs 3,635; SNFs 1,479; ICF-DDs 1,063; CCFs (over 16 beds) 2,049; State Mental Hospitals 34; Psychiatric Facilities 200. This data should be included in the Plan
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Capitol People First v. Department of Developmental Services challenges the unnecessary institutionalization of over 8,000 people with developmental disabilities in the DCs and other private and public institutions.

Page 2: People living in institutions

a) If left intact, this may be the only Olmstead plan in the country which does not even estimate the number of people living in institutions. Californians who reside in nursing homes are the largest single group affected by Olmstead; there is no controversy about the number of nursing home beds. Our information shows that with approximately 132,000 nursing home beds, and an average occupancy of 80%, there are approximately 105,000 Californians in nursing homes on any particular day. Over the course of a year, the total is significantly larger.

III. OLMSTEAD PLAN DEVELOPMENT PROCESS

Page 1: The plan approved by the Long Term Care Council on July 25, 2002, did **not** include Work Groups. It called for a Steering Committee, composed primarily of state staff. Consumers and advocates complained strenuously about the timeline for the forums and surveys, the composition of the Steering Committee, the absence of translated materials, and the total lack of support for consumers to participate. In the interest of accuracy, we would like to see acknowledgement that the original plan and process were changed, in part at least, as a result of community interest and pressure. It is also true that the plan never accounted for participation of people in institutions; with a few exceptions, their voices were never heard.

Page 2: Of the 1,228 completed surveys, 687 were COCO surveys, not state surveys, and we request that clarification.

Page 3, facilities: This is a small but significant point: consumers provided input about logistical problems to make the meetings accessible, not “comfortable”.

IV. Current Programs and Efforts:

Activities of the Long Term Care Council, Page 1,

Activities should not be equated with results. Having participated in many of these activities, COCO requests a more accurate picture of the outcomes:

Public Forums: *No reports or results were ever released.*

Analyzed barriers to information: *with what results for consumers?*

Established a workgroup to create an assessment tool: *Disbanded with no final report.*

Established a workgroup to examine licensing requirements:

1) which excluded people who live in licensed facilities, and

2) which disbanded with no final report.

Worked with departments on federal grants:

And when the nursing home transition grant, which the disability community supported, was received, the state returned the money to the federal government.

Convened a task force to identify barriers to mental health treatment

Where is the report of the task force, and where are any results?

Department of Developmental Services

This section contains an overview of Lanterman Act requirements for the developmental disability system and makes it appear that all is working smoothly. However, the fact that over 8,000 people with developmental disabilities reside in institutions shows otherwise. Thus, this section is inaccurate in tone and in specifics. Some details are set forth below.

Page 3: Cost of Services

There is currently a requirement for parents of minor children with developmental disabilities to share the cost of diapers (for children under 3) and of day care as well as for out-of-home placement. Further, the Governor has put before the legislature a proposal for fees for all services to parents of minors.

Page 3: Planning Teams

The draft indicates that the planning effort includes regional center representatives. While this is required by law, the reality is regional center representatives do not regularly attend the planning meetings of most DC residents. This is an important “current” fact as it results in a lack of professionals with community knowledge at these planning meetings – contrary to the principles in the *Olmstead* plan and requiring remediation.

Page 4: Admission to DCs

The draft plan states that admission to the DCs (including the two smaller state operated facilities) requires “either a formal determination that the individual meets stringent admission criteria or a court order.” In fact, the Courts have held that no adult should be confined in a state operated institution absent a Court order. Only minors can be admitted absent court order with the consent of their parents.

Pages 4 and 5: DC Assessment and Planning Teams/Information to Consumers

As stated above, the annual assessments at the DCs are currently done in many instances without participation of any professional with knowledge of the community.

Similarly, while the law requires information to be provided in an understandable form and allows for the opportunity to visit different community options, COCO does not believe that the reality meets these mandates – thus the need for further efforts in the *Olmstead* Plan.

Page 4: DC Population, Community Placement Plan and Citation to Federal Court *Sanchez* decisions

See comments to Introduction and more detailed critique of the CPP in COCO’s letters of February 24 and March 11, 2003.

Page 6: Agnews Closure Plan

Moving the Agnews Closure Plan activities to Current Efforts instead of Future Actions seems odd. Of greater concern is the elimination from the plan of the statement that all Agnews residents will be assessed to determine the services and supports needed for transition.

Department of Mental Health (comments pending)

Department of Health Services

Page 12: DD Waiver

The draft plan states that under California’s Medicaid Waiver the cost of care must be no greater than what MediCal would spend in an institutional setting. The DD waiver, in fact, has no individual cost cap. Rather it uses an aggregate cost neutrality calculation.

Page 13.

“All Medi-Cal eligible individuals being placed in nursing facility, with the exception of short-term patients requiring minor medical treatment, receive an assessment evaluating the appropriateness of an individual for community-based living options.”

If by this DHS is referring to the PASRR Level I screening, DHS below describes the Level I screen as being “Designed to identify any individual having, or suspected of having, mental illness or developmental disability.”

Question II on the Level I screen – the **only** item about community living– is “Why Community Placement is Not an Option” and the choices are:

1. Change in Medical, Mental and Physical Functioning Capability
2. Caregiver Unavailability
3. Community Resources Unavailable
4. Client or Family Choice

“In calendar year 2001, 52,000 Medi-Cal beneficiaries were admitted to nursing facilities, and several thousand more to sub-acute care. The assessment process for nursing facilities consist of the Level I and II Preadmission Screening and Resident Review (PASRR).

First, federal regulations require that all people admitted to nursing homes - not just Medicaid beneficiaries – receive a PASRR Level I.

In 2001, Office of the Inspector General (OIG) of the federal Department of Health and Human Services issued a report entitled **Younger Nursing Facility Residents with Mental Illness: Preadmission Screening and Resident Review (PASRR) Implementation and Oversight**, based on information from five states, including California. Among the findings:

“State and nursing facility respondents indicate that the PASRR is what the States use to determine residents’ nursing facility eligibility. ...As such, most nursing facilities we visited view the Level I PASRR as a tool to determine Medicaid eligibility rather than as an evaluation tool. ...they view the Level I PASRR as a formality...”

The following DHS statement confirms the OIG findings:

Level I: A screening completed on admission to any Medi-Cal-certified nursing facility. Designed to identify any individual having, or suspected of having, mental illness or developmental disability, the Level I is completed by nursing facility staff, licensed or unlicensed. A PASRR Level I screening is required for Medi-Cal reimbursement for cost of care.

As indicated above, California allows nursing home personnel to complete the PASRR, **after admission**. Since the facility cannot get paid by Medi-Cal until the PASRR is completed, and since the facility has a vested interest in retaining the resident, characterizing the PASRR as any sort of diversion or transition tool is false. For example, at Laguna Honda Hospital in San Francisco, 100% of the PASRR II evaluations reviewed recommended the resident stay in a facility. In no way can PASRR be characterized as an” assessment evaluating the appropriateness of an individual for community-based living options”.

Further, the OIG found significant non-compliance with the requirement to administer PASRR to all nursing home residents. Does DHS represent that all California nursing home residents receive the PASRR Level I?

The reality: California has no policy or practice for diverting people from nursing homes. It would be appropriate for this Plan to acknowledge that.

Page 14: Transition Activities for People with Developmental Disabilities

The reference to DDS downsizing eleven large residential facilities belongs in the Current Efforts section. The reference to identifying additional facilities for downsizing should remain here, however, as stated in COCO’s prior comments a mere survey for identification purposes does not comprise effective *Olmstead* action.

DHS Activities for 2003: Page 15

“The DHS will provide training on the use of the PASRR for those who will use it to ensure that they recognize those individuals who want to leave a nursing home and are able to do so with the appropriate supports.”

Does this refer to PASRR I or II?

What is meant by “those who will use it? Does this mean the nursing home personnel who administer the PASRR I? Is DHS going to train nursing home personnel on supports available in the community?

Considering that PASRR is supposed to be pre-admission, how will this be used to identify people who want to leave nursing homes? Is DHS going to initiate a regular re-assessment of all nursing home residents?

California Department Of Aging Page 18: MSSP

It is misleading to list the services that MSSP clients may use when, in fact, 71% of MSSP funds pay for case management, and most clients get very little, if any, of the rich array of services allowed under the waiver. The MSSP program is so underfunded that with annual expenditures of approximately \$2300 per client per year, and 71% of that paying for case management, only a pittance is available for other services. Here is the description of MSSP on CDA’s own website:

“Local Multipurpose Senior Service Program (MSSP) sites provide social and health case management for frail elderly clients who are certifiable for placement in a nursing facility but who wish to remain in the community.”

California Housing Programs, Page 19

While accurate, this section is certainly not complete. It fails to discuss some additional programs, including but not limited to :

State controlled Community Development Block Grant (CDBG) program,
HOME program,
self-help housing programs,
farmworker housing programs,
Emergency Shelter Grant Program and other homeless programs, and
mobile home programs.

Further:

It fails to discuss the state obligation under the CDBG and McKinney programs to do a state fair housing planning document called the Analysis of Impediments, which does address (and should expand on) barriers to housing for underrepresented groups, including people with disabilities.

It fails to address the state role in housing plans and housing planning.

It also fails to discuss the state role in enforcing building codes and accessibility standards to ensure physically accessible housing.

It does not mention the role of state Dept. of Fair Employment and Housing, responsible for preventing housing discrimination.

It does not mention redevelopment funds, which are a huge source of money for affordable housing and which are regulated at the state level even though the funds are local.

It mentions but glosses over the state role in operating Section 8 and other federal programs in rural areas (we have no idea whether they do a good job dealing with people with disabilities).

Also, while it describes some of the major programs, it only partially addresses how they serve people with disabilities and fails to identify the number of units for people with disabilities are actually made available under these programs.

V. RECOMMENDED FUTURE ACTIONS

Page 14: ICFs

It would be more accurate if the plan distinguished between ICF-DDs – which are institutions – and the small community ICF—DD-H and Ns. The plan also fails to mention the newest model of ICF-DD-CNs which are part of a pilot waiver.

We will have additional comments about the Long Term Care Inventory plan appendix.

Sincerely,

Deborah Doctor, for COCO

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