

PLAIN LANGUAGE SUMMARY

Administration on Intellectual and Developmental Disabilities - AIDD

Monitoring and Technical Assistance Review System Report (MTARS) of the California State Council on Developmental Disabilities conducted January 14 – 17, 2013

Introduction

The State Councils on Developmental Disabilities exist because of a federal law known as the Developmental Disabilities Assistance and Bill of Rights Act (also known as the DD Act).¹ This act describes what a Council is, who should be on it, what kinds of work they should do and so forth. This act also describes the role of Protection and Advocacy agencies (in California this is known as Disability Rights California) and the University Centers for Excellence in Developmental Disabilities.

In California, the Lanterman Act² also discusses the role and activities of the Council and the Area Boards. In some cases, the Lanterman Act has requirements that are not in line with the DD Act. Over the years, some changes have been made to correct this because state laws cannot go against federal laws. There are still some parts of the Lanterman Act that need to change to match up with the DD Act.

The Administration on Intellectual and Developmental Disabilities (AIDD) is the parent organization at the federal level for all of the State Councils on Developmental Disabilities. They control the money that comes to the councils through grants and they visit every few years to make sure that each council is doing what the DD Act requires of them.

The AIDD visited the California Council in 1994, 2006 and 2013. In both of the two earlier visits they found some problems with how the California Council applies the DD Act. When they returned in 2013 they found many of the same issues as well as some new ones.

Summary of the 1994 and 2006 Visits

In the earlier reviews of 1994 and 2006, AIDD found problems in these areas:

1. The Lanterman Act requires that the Council fund the area boards even though they were not a part of Council operations (until 2003)
2. The Area Boards seem not to be under the control of the Council
3. Deputy directors for the Council are appointed by the Governor
4. The Council did not have all of the required members
5. The Governor's office had been slow to fill Council vacancies
6. Attendance at Council meetings was very low making it difficult to get work done
7. It appears that the Area Boards do some of what Disability Rights California should do

The Council responded to each of these areas.

Some of the changes that the Council agreed to make included:

1. Ensuring that the Council has all required members including people with developmental disabilities, their family members, people from various ethnic backgrounds, members from the UCEDDs
2. Establishing a membership committee who would work with the Governor's Office to make good appointments

¹ For information on the DD Act, please go to the end of this report

² For information on the Lanterman Act, please go to the end of this report

3. Collaboration between the Governor's Office and the Council's executive director about all appointments to Deputy Director positions.
4. The biggest change that was made came in 2003 when the Area Boards merged with the Council and became regional "arms" of the Council thus placing them under direct control of the State Council.

How AIDD Conducted the Review in 2013

For more detail see Attachment A of the MTARS

Seven people were on the review team. Two of them came from AIDD. Three of them were from other councils as peer reviewers. Two of them were from the Administration for Community Living. *See page 5 of the MTARS for the names and titles of the review team.*

This team interviewed council members and staff. They held a public forum. After their visit they interviewed Area Board executive directors and staff of Disability Rights California and the three University Centers for Excellence in Developmental Disabilities.

What AIDD Found in 2013

In 2013 there were many of the same issues that AIDD found before as well as new ones. These are issues because they violate the DD Act.

1. Hiring of Council Staff

- a. The Governor still appoints some of the council staff. The DD Act requires that the Council Executive Director should hire all staff.

2. Council Membership

- a. The nomination and appointment process often gets stuck in state rules and procedures.
- b. The make-up of the Council does not meet diversity requirements. It should have representatives from all parts of the state and of different ethnicities.
- c. There are several long-standing vacancies for Area Board representatives on the Council.
- d. There should be a policy that allows an expired member to continue until a new member is appointed.
- e. The method for notifying the Governor that there are vacancies is not efficient or clear.

3. Program Administration

- a. Development of the 5-year state plan:
 - i. The plan does not seem to be driven by data.
 - ii. The plan appears to be developed by the Area Boards instead of the Council.
 - iii. The Council has two contracts with the State of California, Clients Rights Advocacy and Volunteer Advocacy. These contracts seem to mean that the state is interfering with the content of the Council's State Plan.
- b. Budget
 - i. Part of the money that the Council receives from AIDD is given to the state to support the operations of the Council. The DD Act sets limits on how much money can be used for that purpose. The team was unable to figure out whether California spends more than it is permitted to on this purpose.
 - ii. Each state is required to help pay for the activities included in the Council's plan. It is unclear how much California contributes.
- c. Conflict of Interest
 - i. A large part of the Council is made up of members of Area Boards.

- ii. Since the Council makes decisions about how money should be spent and Area Boards sometime receive that money, it appears that there may be a conflict of interest. AIDD is concerned that Council members may vote to have money sent to their regions.
 - d. Staff assignments
 - i. Because the Council has two state contracts, it appears that staff may be working at times for the state and not for the Council.
 - ii. Council staff are not permitted to provide direct services. However, through the state contracts Council staff conduct assessments and monitoring of residents in developmental centers which is seen as direct services.
 - e. Interference of the State in Council operations
 - i. It is very difficult to be sure that the state is not interfering in the operations of the Council or its staff.
- 4. **Implementing the State Plan**
 - a. The plan does not seem to promote advocacy, capacity building and systems change at the State level, only at the regional level through the Area Boards.
 - b. Providing direct services through the two state contracts appears to overlap with the functions of Disability Rights California.
- 5. **Evaluation and Reports**
 - a. The Council submits a report every year to AIDD about progress made in achieving the goals in the State Plan.
 - i. It is difficult to see how the plan is being measured and evaluated.
 - ii. The 13 regions have different ways of implementing and evaluating the state plan. This makes it very difficult to see how progress is being made.
 - b. The Council submits documents to show how the federal money is being spent. The documents are not clear in how the budget is developed or implemented.
- 6. **Fiscal (managing the grant money)**
 - a. Council members said they wanted more training on fiscal policy and on the budget development and implementation process. They were especially unclear about the difference in state and federal money policies.
 - b. The budget development process should be more open for people to see.
 - c. The Lanterman Act limits the authority of the Council to develop a budget by making the Council fund two things:
 - i. It requires that the Council fund the Area Boards.
 - ii. It requires that staff be hired at the deputy director level.
- 7. **Fiscal Policies**
 - a. The Council could not prove that it has accurate accounting and record keeping procedures.
 - i. At the time of the visit, there was no specific staff person who manages the Council's finances.
 - ii. There was very little information on the Council's fiscal policies.
 - iii. The previous executive director did not use proper procedures when awarding contracts to Board Resource Center.
 - iv. The state auditor confirms that the Council needs better financial management systems.
- 8. Responsibilities of the designated state agency (DSA)

In California, the Dept. of Social Services is assigned by the Council's DSA to provide services to the Council such as accounting, human resources, payroll etc. The Council pays DSS a portion of its funds to provide these services.

 - a. The DSA needs better processes and policies including:
 - i. Accurate accounting records

- ii. Better control over money paid out
 - iii. Access to accounting records needed by the Council
 - iv. Timely financial reports
- b. The Council needs to develop a memorandum of understanding with the DSA that describes what the DSA is responsible for.
- c. The Council has never evaluated the DSA.
- d. Some Council staff positions appear to have the same function as DSA functions.

Additional Findings

For more detail see Attachment B in the MTARS

AIDD discussed several other areas of concern.

1. There are no plans to work with the UCEDDs or Disability Rights California.
2. Council staff
 - a. Staffing has not been stable. There is a severe lack of management level staff at the Council level.
 - b. There is low morale due to problems with the last executive director, the problems with the Board Resource contract and a sense that there will be retaliation against staff who speak up about problems.
 - c. Staff have a need to better understand the DD Act and what the DD Act requires from the Council.
3. Membership
 - a. Area Boards should not have members on the Council but should attend to provide information and reports.
 - b. The Council should have a standard orientation process for new members and the new Chair.
 - c. Representatives from state agencies that sit on the Council do not understand their roles on the Council.
 - d. People with disabilities who are members seem to lack proper supports.
4. Program administration
 - a. The Council does not appear to be the leader in the state on issues affecting people with developmental disabilities.
 - b. The Council appears to operate as a loose association of local offices (the Area Boards) rather than one organization that provides leadership to the local offices. If Area Boards are maintained, they need to come under the leadership of the Council which should set standard policies and procedures for implementing the state plan.
 - c. The Council needs to develop standard orientation practices for both members and staff.
 - d. While there is a statewide self-advocacy network, it is not clear how the Council will partner with that group. It is not clear if the Council really promotes self-advocacy in practice.
5. Evaluation and reports
 - a. Local offices were not trained in a consistent manner in how to use the data collection system known as DDSuite.
 - b. The kinds of data collected varied from office to office.
6. Designated State Agency
 - a. The DSA (Health and Human Services Agency) and the Council need a memorandum of understanding.

DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT OVERVIEW (DD Act)

The Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106-402 (the DD Act) defines “developmental disabilities as a severe, chronic disability of an individual that

- (i) is attributed to a mental or physical impairment or combination of mental and physical impairments;
- (ii) is manifested before the individual attains age 22;
- (iii) is likely to continue indefinitely;
- (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
 - (I) Self-care,
 - (II) Receptive and expressive language,
 - (III) Learning,
 - (IV) Mobility,
 - (V) Self-direction,
 - (VI) Capacity for independent living,
 - (VII) Economic self-sufficiency, and
- (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated”.

The DD Act authorizes grants for State Councils on Developmental Disabilities (DD Councils), State Protection and Advocacy Systems (P&As), and University Centers for Excellence in Developmental Disabilities Education, Research and Services (UCEDDs). These three grant programs are often known as the State Developmental Disabilities Network (The DD Network). Their purpose is to increase the independence, productivity, self-determination, and inclusion and integration of individuals with developmental disabilities into their communities.

To ensure that the missions and functions of the funded grant programs are carried out in accordance with the DD Act, AIDD uses the MTARS to monitor the activities of the Network grantees in each state and territory and provide stewardship and technical assistance. The MTARS promotes and monitors the effectiveness of the funded grantees, in addition to assessing and promoting collaborative relationships among the grantees.

LANTERMAN DEVELOPMENTAL DISABILITIES SERVICES ACT

The Lanterman Developmental Disabilities Services Act (Lanterman Act) is a California law that describes the rights and responsibilities of persons with developmental disabilities, and creates the agencies, including regional centers, responsible for planning and coordinating services and supports for persons with developmental disabilities. The Lanterman Act outlines how the regional centers and service providers can help individuals with developmental disabilities, what services and supports they can obtain, how to use the individualized program plan to get needed services, what to do when someone violates the Lanterman Act, and how to improve the system.

The Lanterman Act states:

Because of its size and diversity, California faces unique challenges. Neighborhoods and communities lack the support necessary to monitor system functions. Thus, the Lanterman Act established local Area Boards on developmental disabilities to conduct the local advocacy, capacity building and systems change activities of the Developmental Disabilities Assistance and Bill of Rights Act of 2000. CALIF. WELF. & INST. CODE § 4543(a).

The Lanterman Act is unique in that it is a state law that both mandates certain services to individuals with developmental disabilities and governs the activities and structure of the State Council.

Summary of the Grant Award Letter

Because of the on-going problems with SCDD, AIDD has placed the Council in a “high-risk” category. This means several things:

1. Payment on a reimbursement basis:

In the past the Council has received grant money in advance as a lump sum. Because of the high risk status, the Council must now pay all of its expenses out of reserve money and submit a request for reimbursement to AIDD afterwards. Every expenditure over \$500 must have some sort of documentation such as receipts, payrolls, attendance records etc. attached to the request. The Council has 45 days to request reconsideration.

2. Additional project monitoring:

The Council must:

- a. Submit a corrective action plan by Friday February 14, 2014 that describes how the Council will make all of the corrections needed.
- b. Provide monthly program progress reports on the corrective action plan starting March 17, 2014.

3. Obtaining technical or management assistance:

The Council is required to seek assistance to address the compliance issues through:

- a. Regular, on-going assistance from experts with regard to issues of program administration, organizational administration and fiscal management.
- b. Quarterly calls with the AIDD staff to review progress on the Corrective Action Plan.