6-15-1989

SR 9: An Overview of the Study of the Lanterman Developmental Disabilities Service Act

Senate Health Subcommittee on Mental Health, Developmental Disabilities and Genetic Diseases

Senate Subcommittee on the Rights of the Disabled

Assembly Health Subcommittee on Mental Health and Developmental Disabilities

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CALIFORNIA LEGISLATURE

SENATE SUBCOMMITTEE ON MENTAL HEALTH, DEVELOPMENTAL DISABILITIES AND GENETIC DISEASES
Dan McCorquodale, Chairman

SENATE SUBCOMMITTEE ON THE RIGHTS OF THE DISABLED
Milton Marks, Chairman

ASSEMBLY SUBCOMMITTEE ON MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES
Richard Polanco, Chairman

Joint Hearing on

SR 9: AN OVERVIEW OF THE STUDY OF THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICES ACT

June 16, 1989
Sacramento, California

172-J

MEMBERS
SENATOR ED DAVIS
SENATOR DIANE WATSON

JULI WINESUFF-KAUFFMAN
CONSULTANT

1036 STATE BUILDING
350 MCALLISTER STREET
SAN FRANCISCO, CA 94102
(415) 557-3162
TTY 557-3164

MARIN OFFICE
30 N. SAN PEDRO ROAD
SUITE 160
SAN RAFAEL, CA 94903
(415) 479-6612

California Legislature

Senate Subcommittee
on
The Rights of The Disabled

SENATOR MILTON MARKS
CHAIR

AGENDA

June 16, 1989

Upon Adjournment or 1:00 p.m.

State Capitol, Room 112

Joint Hearing of

The Senate Subcommittee on Mental Health, Developmental Disabilities and Genetic Diseases;

The Senate Subcommittee on The Rights of The Disabled;

The Assembly Subcommittee on Mental Health and Developmental Disablities

SR 9: AN OVERVIEW OF THE STUDY OF THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICES ACT

CALIFORNIA DECADE OF DISABLED PERSONS (1983-1992)
DESIGNATED BY S.C.R. 15 INTRODUCED BY SENATOR MILTON MARKS

I. OPENING REMARKS:

Senator Dan McCorquodale, Chair
Senate Subcommittee on Mental Health, Developmental Disabilities and Genetic Diseases

Senator Milton Marks
Senate Subcommittee on The Rights of The Disabled

Assembly Member Richard Polanco, Chair
Assembly Subcommittee on Mental Health and Developmental Disabilities

II. SCHEDULED TESTIMONY

State Department of Developmental Services
  Gary Macomber, Director

State Council on Developmental Disabilities
  Marta Saragoza-Diaz, Legislative/Program Analyst

Association of Regional Center Agencies
  Dr. Raymond Peterson, Executive Director
    San Diego Regional Center
  Jim McDermott, President
    Lanterman Regional Center

Organization of Area Boards
  Bethel Coffman, Vice-Chairperson

Protection and Advocacy, Inc.
  Al Zonca, Executive Director
  Connie Lapin, Chair
    Public Policy Committee

Capitol People First
  Sandra Jensen, President
  Tom Hopkins, Board Chair

Association of Retarded Citizens-CA
  Joan Taugher, President

California Association of Residential Care Homes
  Joshua White, President
  Elizabeth Halahan, Vice-President

Society of Community Care Operators
  Willie Hausey, Lobbyist

California Public Administrators, Public Guardians & Public Conservators Association
  Douglas A. Kaplan, President

California Association of State Hospital Parents
and Counselors of the Retarded
  George DeBell, President

California Association of Psychiatric Technicians
  Dan Western, Legislative Consultant

California Association of Rehabilitation Facilities
  Christine Daly, Executive Director
   ARC-Stanislaus

United Cerebral Palsy, Inc.
California Association of Residential Resources
  Lonnie Nolta, Director

III. OTHERS

Lotte E. Moise
Linda Leahy
F. Burns Vick, Jr., J.D.
David Sokoloff, Regional Center Clients' Action League
Paul Ferrario
Stephen W. Dale, P.T.
M. J. Ketring
Lucie Van Breen, Epilepsy League of the East Bay

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Senate Resolution No. 9

Introduced by Senators McCorquodale and Marks
(Coauthor: Senators Montoya, Petris, Presley, Rosenthal,
and Watson)

January 19, 1989

Senate Resolution No. 9—Relative to the Lanterman Developmental Disabilities Services Act.

WHEREAS, The State of California has accepted an obligation under the Lanterman Developmental Disabilities Services Act (Division 4.5 (commencing with Section 4500) of the Welfare and Institutions Code) (the Lanterman Act) to ensure that persons with developmental disabilities receive services that enable them to live more independent and productive lives in settings least restrictive of their personal liberties; and

WHEREAS, Many Californians with developmental disabilities have been able to remain and participate meaningfully in their family homes and other community settings with services provided by regional centers under the Lanterman Act; and

WHEREAS, These services are so highly cost-effective that, during the 1987–88 fiscal year, regional centers served about 75,000 clients, including those with multiple and severe disabilities, in their own homes or other community settings at an approximate cost of $410 million, while about 6,800 persons were served in state developmental centers at an approximate cost of $489 million; and

WHEREAS, Recent reports to Members of the Legislature by the Auditor General, the Legislative Analyst, regional centers and regional center clients and their families indicate that, as a result of a marked scarcity of specialized community-based services, a growing number of clients are inappropriately remaining in or being admitted or committed to developmental centers, and a growing number of clients are not receiving the services that they need to remain in community settings and develop their capacities for more independent, productive participation in society; and

WHEREAS, The above-mentioned reports to Members of the Legislature as well as recurring litigation and administrative appeals indicate that the scarcity of community-based services which is jeopardizing the human and fiscal benefits of the Lanterman Act service system may stem from inadequate and improper policies, practices, and procedures used to administer the system, including administrative policies, practices, and procedures for planning, developing, budgeting, setting rates, vendorizing, licensing, and assuring the quality of services; now, therefore, be it

Resolved by the Senate of the State of California, That the Senate Subcommittee on Mental Health, Developmental Disabilities, and Genetic Diseases, and the Senate Subcommittee on the Rights of the Disabled, are requested to conduct a complete joint investigative hearing to study all aspects of the administration of the Lanterman Act service system for persons with developmental disabilities; and be it further

Resolved, That the Senate Subcommittee on Mental Health, Developmental Disabilities, and Genetic Diseases, and the Senate Subcommittee on the Rights of the Disabled are requested to file a joint report of their findings and recommendations to the Legislature; and be further

Resolved, That the Secretary of the Senate transmit a copy of this resolution to the chairpersons of the Senate Subcommittee on Mental Health, Developmental Disabilities, and Genetic Diseases, and of the Senate Subcommittee on the Rights of the Disabled.

O

MEMBERS
DAN McCORQUODALE
CHAIR
WILLIAM CAMPBELL
HERSCHEL ROSENTHAL

COMMITTEE ADDRESS
STATE CAPITOL
ROOM 2191
SACRAMENTO, CA 95814
(916) 445-5965

JANE UITTI
CONSULTANT

SILVIA ZETTER
COMMITTEE SECRETARY

California Legislature

Senate Subcommittee
on
Mental Health, Developmental Disabilities and Genetic Diseases

JUNE 16, 1989

JOINT HEARING OF
THE SENATE SUBCOMMITTEE ON MENTAL HEALTH, DEVELOPMENTAL
DISABILITIES AND GENETIC DISEASES;
THE SUBCOMMITTEE ON THE RIGHTS OF THE DISABLED;
THE ASSEMBLY SUBCOMMITTEE ON MENTAL HEALTH AND
DEVELOPMENTAL DISABILITIES

SR 9: AN OVERVIEW OF THE STUDY OF THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICE ACT

OPENING STATEMENT

THIS STATE ACCEPTED RESPONSIBILITY FOR ITS CITIZENS WITH DEVELOPMENTAL DISABILITIES WHEN IT APPROVED THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICES ACT OVER A DECADE AGO. THE ADOPTION OF THIS ACT, WHICH ESTABLISHES RIGHTS AND SERVICES FOR THIS SPECIAL POPULATION, WAS A PROUD MOMENT FOR THIS STATE AND CUT TO THE CORE OF WHAT GOOD PUBLIC POLICY MAKING IS ALL ABOUT.

HOWEVER, SINCE THE LANTERMAN ACT BECAME LAW, THIS SYTEM HAS BEEN PLAGUED WITH CRISES. JUST A FEW OF THE SERIOUS ISSUES THE LEGISLATURE HAS ATTEMPTED TO ADDRESS IN PAST YEARS INCLUDE FUNDING AND PROGRAM STANDARDS FOR COMMUNITY-BASED AND DEVELOPMENTAL CENTER PROGRAMS; LACK OF SUFFICIENT COMMUNITY

RESOURCES; THE EFFECTIVENESS OF ADVOCACY ORGANIZATIONS; EMPLOYMENT PROGRAMS; FAMILY SUPPORT AND CONSUMER RIGHTS. YET DAILY, I SEE EXAMPLES OF A SYSTEM WHICH CONTINUES TO ERODE. THESE ISSUES SHAKE THE VERY FOUNDATION OF A SYSTEM WHICH ONCE PROMISED STABILITY AND DIGNITY.

THROUGH THE PASSAGE OF SENATE RESOLUTION 9 AND THE SOON-TO-BE-PASSED ACR 52, THESE COMMITTEES HAVE BEEN CHALLENGED TO EXPLORE THE INTENT AND ADMINISTRATION OF THE LANTERMAN ACT WITH THE PURPOSE OF BUILDING A STRONGER AND FAIRER SYSTEM OF CARE AND SUPPORT. TODAY, WE FORMALLY BEGIN THAT PROCESS. WE WILL HEAR FROM THE DEPARTMENT OF DEVELOPMENTAL SERVICES, ALONG WITH STATEWIDE ORGANIZATIONS AND INDIVIDUALS, WHO WILL SHARE THEIR PERSPECTIVES ON WHERE OUR SYSTEM STANDS TODAY AND WHAT DIRECTION THEY WOULD LIKE THESE COMMITTEES TO GO IN THEIR WORK. ONCE THIS HEARING IS OVER, THE REAL WORK BEGINS.

OVER THE COURSE OF THE NEXT FEW MONTHS, WE WILL BE ENCOURAGING THE FORMATION OF SMALL, REGIONAL WORKING GROUPS TO IDENTIFY AND PRIORITIZE KEY ISSUES AND PROPOSE AVENUES FOR CHANGE WHERE NECESSARY. WE FEEL STRONGLY THAT AN HONEST EXAMINATION OF THE LANTERMAN ACT CAN ONLY BE ACHIEVED WITH THE PARTICIPATION AND SUPPORT OF THOSE WHO KNOW THE SYSTEM BEST--CONSUMERS, FAMILIES, AND DIRECT-CARE PROVIDERS AND ADVOCATES. IN THE FALL, WE WILL BEGIN A SERIES OF LEGISLATIVE HEARINGS TO EXPLORE THOSE SPECIFIC ISSUES IDENTIFIED THROUGH THIS PROCESS. HOPEFULLY, IN THE END, WE WILL HAVE THE MEANS TO DO WHAT IS NECESSARY TO HAVE THE LANTERMAN ACT FULFILL ITS ORIGINAL COMMITMENT.

WE WILL HEAR FROM SCHEDULED WITNESSES FIRST AND THEN ANYONE ELSE WHO WISHES TO MAKE COMMENTS AS TIME ALLOWS. LET ME ASSURE YOU NOW THAT WE WE INTEND THIS PROCESS, TODAY AND THROUGHOUT THE COURSE OF OUR WORK, TO BE OPEN AND TO ENCOURAGE PARTICIPATION.

INTRODUCE PANEL
OPENING STATEMENT FROM SENATOR MARKS
OPENING STATEMENT FROM OTHER LEGISLATORS
CALL FIRST WITNESS-GARY MACOMBER

OPENING STATEMENT: SENATOR WATSON
REVIEW OF THE LANTERMAN ACT FOR DEVELOPMENTAL DISABILITIES
June 16, 1989
Sacramento

I WANT TO EXTEND MY WARM WELCOME TO THIS FIRST "SR 9" HEARING ON THE GOVERNANCE AND ADMINISTRATION OF THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICES ACT.

FIFTEEN YEARS AGO, A SERIES OF TEN BILLS WERE PASSED, LINKED TOGETHER AND KNOWN AS THE "AB 3800 SERIES." THIS PACKAGE OF TEN BILLS ESTABLISHED THE LANTERMAN ACT THAT WE RELY UPON TODAY, TO GOVERN THE PROVISION OF SERVICES TO DEVELOPMENTALLY DISABLED PERSONS.

IT IS NOW TIME TO REVIEW THAT ACT. ARE ITS PRINCIPLES AND PHILOSOPHIES STILL RELEVANT IN A VERY DIFFERENT CALIFORNIA? ARE OUR SERVICE STRUCTURES AND GOVERNMENTAL RESPONSIBILITIES STILL RELEVANT TO THE NEEDS OF HANDICAPPED PEOPLE? DOES THE ADVOCACY SYSTEM FUNCTION EFFECTIVELY AS A BALANCE TO LIMITED RESOURCES?

THESE ARE SOME OF THE QUESTIONS WE WILL BE ASKING OVER THE NEXT YEAR AS WE PROCEED WITH THESE HEARINGS. PUBLIC INPUT FROM AROUND THE STATE WILL BE TAKEN AT A SERIES OF LEGISLATIVE HEARINGS, TO HELP US DETERMINE WHETHER THE LANTERMAN ACT IS STILL WORKING EFFECTIVELY FOR THE POPULATION IT INTENDS TO SERVE. YOUR COMMENTS WILL HELP US DETERMINE WHAT ADMINISTRATIVE, BUDGET, OR LEGISLATIVE ACTIONS MIGHT BE NECESSARY TO STRENGTHEN OR CHANGE SOME OF THE STATUTES GOVERNING THIS PROGRAM.

I WELCOME YOUR COMMENTS AND THANK YOU FOR YOUR PARTICIPATION IN THIS PROCESS.

# # #

California Cares

THE DEPARTMENT OF DEVELOPMENTAL SERVICES

INITIATIVES, 1983-1989

DEPARTMENT OF DEVELOPMENTAL SERVICES

During this Administration, the Department of Developmental Services has taken the initiative to strengthen the service system in a number of ways. A list of major projects and accomplishments is given below. A description of each is attached.

A. IMPROVING THE COMMUNITY SERVICE SYSTEM

1. *Alternative Residential Model (ARM): Establishing Quality Assurance Standards and Reforming the Rate System*

2. *Small Health Facilities: Intermediate Care Facility for the Developmentally Disabled-Habilitative (ICF/DD- H) and Intermediate Care Facility for the Developmentally Disabled-Nursing (ICF/DD-N)*

3. *Residential Service Provider Training Curriculum*

4. *Early Intervention Program (PL 99-457)*

5. *Prevention Program*

6. *Improving Housing Financing Options*

7. *Serve Elderly Regional Center Clients Through Generic Senior Services*

8. *Community Placement Plan (CPP) and Regional Resource Development Plan (RRDP)*

9. *Resource Development Plan (RDP)*

B. IMPROVING ACCOUNTABILITY AND EFFICIENCY

1. *Client Assessment and Services Effectiveness (CASE) Reviews of Regional Centers*

2. *Uniform Fiscal System (UFS)*

3. *Medicaid Waiver for Home and Community-Based Services*

4. *Targeted Case Management*

5. *Facility Monitoring*

6. *Transportation Coordinators in Regional Centers*

7. *Fiscal Monitor Positions in Regional Centers*

C. DEVELOPMENTAL CENTER SERVICES

1. *Mobility Engineering Department, Sonoma Developmental Center*
2. *STRETCH Curriculum*
3. *Curriculum Resource Center, Camarillo Developmental Center*
4. *Accreditation, Certification and Licensing of Developmental Centers*

D. PROJECTS WITH SYSTEMWIDE IMPACTS

1. *State Developmental Research Institutes*
2. *Long Range Plan*
3. *Improving Interagency Coordination*
4. *Family Support Services Study*
5. *Independent Living Program Study*

INITIATIVES, 1983-1989

DEPARTMENT OF DEVELOPMENTAL SERVICES

A. IMPROVING THE COMMUNITY SERVICE SYSTEM

1. Alternative Residential Model (ARM): Establishing Quality Assurance Standards and Reforming the Rate System

The Alternative Residential Model (ARM) is a major Department of Developmental Services' (DDS) initiative to strengthen and improve the residential care program. Two major features of ARM are: quality assurance standards which clearly state what is expected of residential providers; and rates based on the cost of implementing the quality assurance standards, and which reflect the findings of recent departmental studies of facility costs.

ARM has been examined in three independent studies, all of which concluded that it represented a significant advance in program design.

A consultant evaluating the ARM pilot project in 1987 found that it improved clients' quality of life, skill development, and behavior; it focussed providers on a more professional role; and it increased the correlation between assessed client need and the actual level of service provided:

- In 1987, the National Association of State Mental Retardation Program Directors (NASMRPD) published a nationwide study of payment for community services. The report used ARM to illustrate a number of important principles and considerations in reimbursement system design, calling ARM "a sound, holistic approach to (reimbursement) system development."
- In 1988, the accounting firm Price Waterhouse did an in-depth study of facility costs and made long-term rate system recommendations for Department use. Price Waterhouse concluded: "ARM provides inducements to supply, access, and efficiency. ARM appears to have advantages in quality of care, accuracy, and payment equity among facilities."
- The Department is now developing regulations containing the ARM quality assurance standards. A draft of the regulations has been released for public comment. The ARM system is being phased in and will be implemented statewide by 1-1-91. As of the end of this fiscal year, 47% of all regional center residential care clients will be covered by ARM.

2. Small Health Facilities: Intermediate Care Facility / Developmentally Disabled-Habilitative (ICF / DD-H) and Intermediate Care Facility / Developmentally Disabled- Nursing (ICF / DD-N)

DDS has taken the initiative to develop two new categories of licensed residential facilities for persons with developmental disabilities. These are licensed health facilities to serve persons with serious health-related needs in small, homelike settings: Intermediate Care Facility for the Developmentally Disabled-Habilitative (ICF/DD-H) and Intermediate Care Facility for the Developmentally Disabled-Nursing (ICF/DD-N). These facilities serve clients with significant needs in a community setting, while providing services consistent with rigorous standards. Under Medi-Cal, they are eligible for 50% federal participation in the cost of services. The Department has taken a number of actions to promote the development of small health facilities:

- Established a unit in DDS-headquarters that provides technical assistance to regional centers and providers and serves as an advocate with state and federal officials.

- For ICF/DD-Ns, the Department surveyed the state to identify the need for this program, completed a successful demonstration program funded by a federal grant, sponsored enabling legislation in 1985, and developed regulations.

- Provided training and resource material for persons interested in establishing new facilities.

- Established an agreement with DHS to assure the prompt licensing and certification of new facilities.

- Advocated for an adequate rate through legislation, the budget process, and by improving the cost reporting system.

- Maintained communication with providers through newsletters, participation in their organizations, and frequent contacts.

- Provided start-up funds for new facility development; over $2 million in FY 1988-89.

These efforts have paid off. For ICF/DD-Hs, there has been a tenfold increase since 1983: there has been an increase from 30 facilities serving 222 clients to 311 facilities serving 2,111 clients. Rates per client per month have increased 65% during the same period.

For ICF/DD-Ns, proposed final regulations were filed with the Office of Administrative Law in April 1989. The Department anticipates that residents will come from existing community settings, developmental centers and acute hospitals. Five hundred thousand dollars ($500,000) in grant funds are available to assist community facilities in meeting the conversion costs. DDS expects the program to grow at rate of approximately 24 facilities per year, serving 144 clients.

3. Residential Service Provider Training Curriculum

To ensure that residential service providers have the skills necessary to deliver services that are stable, secure, caring and of high quality, the Department has initiated the development of a competency-based curriculum that can be used throughout the state to train residential service administrators and staff. In 1987, the Department convened a statewide task force to make recommendations for training content. The task force recommended that provider training cover two main areas: planning and providing client programming including adhering to the ARM quality assurance standards, and administrative activities including business operations and personnel management. The Department identified a qualified contractor to develop detailed training materials and expects completion of the Residential Service Training (RST) curriculum by March 1990. In addition, the Department will issue an RFP for "Training for Trainers" to ensure that the new curriculum is systematically implemented statewide by June 1991. The training will be mandatory for residential providers and available to other developmental service professionals through the community college system.

4. Early Intervention Program

In October 1986, the Education of the Handicapped Act Amendments (P.L. 99-457) was signed into law. Part H of P.L. 99-457 authorized the federal Department of Education to make grants to states to assist in developing and implementing a statewide, coordinated, interagency system of comprehensive early intervention services for handicapped infants and toddlers (birth to 36 months) and their families.

The Governor has designated the Department of Developmental Services as the lead agency for the program in the state. California was awarded a total of $13.6 million under P.L. 99-457 for two federal funding cycles.

The Department's major first step under this grant was to identify and select agencies in 26 local planning areas (LPAs) that will serve as the central coordinators of services in their areas. These agencies—regional centers, school districts, or other human service agencies—are responsible for developing collaborative relationships with all agencies within their areas that provide early intervention services to handicapped infants and toddlers and their families. Through such collaborative arrangements, each LPA will determine service availability as well as possible duplications or gaps in services.

Other major activities under this project include establishing a statewide technical assistance network; surveying all state agencies to determine the programmatic impact of proposed definitions of "developmental delay;" studying the feasibility of developing a statewide client tracking system; and studying the personnel requirements of programs that provide early intervention services.

5. Prevention Program

Prevention of developmental disabilities and birth defects was selected as a top priority by DDS in this Administration. In 1983, DDS launched the prevention initiative. The goal of the initiative is to ensure that all infants born in California are able to develop to their full potential and, to the extent possible, are free from birth defects or developmental disabilities.

One of the first actions of the new Administration was to establish the Office of Prevention within the Department's Community Services Division. Working with an interagency task force, this office developed the first comprehensive statewide prevention plan, "Prevention 1990: California's Future - A Plan for the Prevention of Developmental Disabilities and Birth Defects." Many of the recommendations of this plan have been implemented. The following are the major accomplishments of the Department in this area:

- Established three-person prevention teams in each regional center to coordinate and carry out the prevention effort. Funding for a three-member prevention team was included in the approved state budget for FY 1985-86. Each regional center received an allocation sufficient to fund a Prevention Coordinator, a High-Risk Infant Case Manager, and a Genetic Associate. Funding for these positions has continued in each subsequent fiscal year. While regional centers had been doing prevention work for years, this augmentation of staff allowed them to raise this activity to a top priority and to greatly expand the services offered.

- Increased by 183 percent the number of high-risk infants who are served by the regional centers. High-risk infants are infants who have conditions in the perinatal period that could lead to developmental disabilities if nothing is done to prevent them. Included among the conditions that can place an infant at risk are prematurity, low birth weight, metabolic problems or congenital anomalies, prolonged hypoxemia or other medical complications at birth, maternal exposure to or abuse of toxic substances, and a variety of other medical or socio-cultural indicators of developmental delay or abnormality. In June 1985 the regional centers served 2,192 high-risk infants. In February 1989, they served 6,207 such infants. These infants receive a wide range of services from the regional centers including extensive medical, psychological and other assessments, and infant development programs.

- Provided genetic counseling services to increasing numbers of persons. Part of the responsibility of the prevention team in each regional center is to provide genetic counseling services to persons at risk of parenting a child with developmental disabilities. The caseload for these services has increased approximately 30% since 1985. By far, the most common reason for seeking genetic counseling services is advanced maternal age. Persons who have a history of developmental disabilities in their families also are frequent requesters of these services.

- Produced Public Service Announcements and brochures on prevention. Since 1984 the Department has produced a series of Public Service Announcements for use by television and radio stations. These have included a series on the prevention of drowning, one on the importance of immunizations and another on prenatal care. The Department also produced brochures on water safety, "Water Watch...Safety Hints for Parents," and on "Caring for Your Special Child." Tens of thousands of these brochures have been distributed all over the state. The Department's efforts to prevent drowning and near-drowning accidents also included the production of posters, in English, Spanish and various Asian languages, which have been widely distributed across the state.

The Department received an award from the Consumer Product Safety Commission for its efforts in the drowning-prevention campaign, and Department staff were interviewed by the television programs, "20/20" and "60 Minutes."

6. Improving Housing Financing Options

Available and affordable housing is a necessity. DDS has worked with the Legislature and the Administration to improve access to the Loan Guarantee Program and tax-exempt bonds through the Health Facility Financing Agency. The Department, in consultation with the Office of Statewide Health Planning and Development (OSHPD), developed a simplified workbook that permits small nonprofit organizations to apply for a Loan Guarantee through OSHPD. The Department also supported legislation that makes small health facilities as well as other community licensed facilities eligible for this program. In addition, DDS has assisted organizations needing low cost financing or other financial assistance from local, state and federal authorities. As a result, over $130 million in government funds have been secured since 1983 for regional center client housing.

7. Serve Elderly Regional Center Clients Through Generic Senior Services

Along with the increase in the number of elderly persons within the general population, there has been an increase in the number of persons with developmental disabilities who live well into their "retirement" years. Programs and activities that focus on training and skill development are not appropriate for these persons. To actualize its value of ensuring that the lives of persons with disabilities are as similar as possible to those of non-disabled persons, the Department of Developmental Services signed an interagency agreement in FY 1985-86 with the California Department of Aging (CDA) calling for a demonstration project involving two regional centers and their respective local Area Agencies on Aging (AAA). The goal of the agreement was to provide older regional center clients with access services that were available to the general population of senior citizens. These "generic services" have two benefits: first, they integrate elderly regional center clients into the community, and second, they are more age-appropriate than employment and training-related day programs designed for younger adult clients.

Using the state interagency agreement as a model, Eastern Los Angeles and North Bay Regional Centers pilot tested this effort during FY 1985-86. Additional regional centers and their local AAAs have since adopted comparable agreements. DDS expects that by 1990 each of the 21 regional centers will adopt a cooperative planning and service agreement with at least one AAA serving its area.

8. *Community Placement Plan (CPP) and Regional Resource Development Plan (RRDP)*

In FY 1983-84, the planning process for the CPP was initiated. The objective of the CPP is to identify and place into the community those developmental center clients who no longer need the intensity of services provided in the developmental centers. FY 1984-85 was the first fiscal year of full funding for the plan.

The Regional Resource Development Project (RRDP) was implemented in 1986 following a special consultant's report that identified significant barriers to CPP placements. This component of the CPP has been highly successful in eliminating the identified barriers, utilizing a joint planning process between the developmental centers and regional centers.

Since FY 1984-85, a total of 2,674 developmental center clients have been placed into the community. An additional 530 clients are projected for placement in FY 1989-90.

9. *Resource Development Plan (RDP)*

The resource development planning (RDP) process was initiated at the local level in 1986 to support client- specific planning and to promote the integration of program development and budgeting. The RDP process directs the area board and regional center to complete a client needs assessment and to develop service and expenditure plans in response to those needs. The process coordinates the purchase of service allocation with the approval of start-up funds from the Program Development Fund (PDF). Since its inception, the RDP process has resulted in an allocation process that is responsive to local priorities and a PDF process that tripled the number of new programs developed. We are in the process of "streamlining" the procedures to reduce the administrative burden on regional centers.

B. IMPROVING ACCOUNTABILITY AND EFFICIENCY

1. *Client Assessment and Services Effectiveness (CASE) Reviews of Regional Centers*

During 1984-85, the Department developed and tested a methodology and system for conducting comprehensive program evaluations of the regional centers. This review methodology is entitled, "Client Assessment and Service Effectiveness (CASE)" and its purpose is to determine if regional centers are providing or arranging for essential services for persons with developmental disabilities in accordance with the requirements of the Lanterman Act and state regulations. CASE also assesses if regional centers are fulfilling their advocacy responsibilities and ensuring that their clients are afforded the necessary protections.

Eighteen of the 21 regional centers have been evaluated using CASE. Reports have been released documenting the review findings. The three remaining regional centers will receive their first evaluations by the end of September 1989.

The Department's CASE reports identify what systems within the regional centers are working well and where there are problems or deficiencies. When problems are identified, regional centers are required to develop a plan of corrective action (POCA) indicating how and by when they will correct the problems. The Department monitors, conducts follow-up reviews, and provides technical assistance to regional centers to ensure that the objectives in the regional centers' POCAs are met.

In the fall of 1989, the Department expects to start the second cycle of reviews of regional centers using a revised CASE instrument. Departmental staff are currently working on the revisions of the CASE instrument utilizing the knowledge and experience that was gained in doing the reviews in the first cycle.

2. *Uniform Fiscal System (UFS)*

Legislation was passed in 1979 (AB 1165, Felando) mandating the Department to develop an automated uniform accounting, encumbrance and budgeting system for regional centers. The Uniform Fiscal Systems (UFS) was implemented in all twenty-one regional centers on July 1, 1984. It has improved the efficiency and accuracy of the billing process throughout the state. The Department also implemented the following enhancements, beyond the mandated UFS:

Management Information System. Department staff working with regional center consultants were instrumental in the development of a management information system currently used by four regional centers. The system utilizes data from the UFS to help case managers. Among other things, It provides a "tickler" of due dates for Individual Program Plan (IPP) reviews, facility license renewals, and cost statement reporting.

Automated Client Development Evaluation Report (CDER). In the past, regional centers completed required client data forms (CDER) and forwarded "hard copies" to the Department, where the data were key- data entered for computer analysis. A system was implemented in 1986 allowing centers to input the CDER data directly into the centers' computers and send the data via UFS communication lines to DDS. This has improved both efficiency and accuracy of the data and has allowed a few centers to build sophisticated Management Information Systems using CDER data.

Diagnostic Information on CDER. In 1986 the CDER instrument also was revised significantly to provide comprehensive diagnostic information on the clients served by DDS. This section of CDER collects information on the clients' specific diagnoses— including their developmental disabilities, medical conditions, and psychiatric disorders—and on the etiologies or causes of those conditions. These data have enhanced the Department"s ability to plan for the prevention of developmental disabilities.

Alternative Residential Model (ARM). The Department developed and implemented an automated system to determine the ARM rate for participating centers.

3. *Medicaid Waiver For Home and Community-Based Services*

In 1981, Congress passed a law allowing states to waive certain statutory limitations and use Medicaid funding for a broad array of home and community-based services. This waiver authority applies only to individuals who would otherwise be placed in a long term health care facility, such as a developmental center. DDS has used this waiver authority for the following community services for eligible clients: personal support services, habitation services, adult day training, homemaker and home health services, respite care, and regional center direct client support services. The Department received the original approval or the Medicaid Waiver in October 1982. In 1984, this Administration expanded the Waiver from 870 clients to 3,360 clients. Federal reimbursements from the Medicaid Waiver program have increased from approximately $6.0 million in FY 1982-83 to an estimated $22.0 million in FY 1989-90, an increase of 267%.

4. *Targeted Case Management*

When Congress enacted a law giving states the option to claim federal Medicaid matching funds for case management services provided to targeted populations including persons with developmental disabilities, DDS took the initiative to develop a program under which these funds could be claimed. In July 1988, the Department and regional centers implemented the Targeted Case Management program. Once federal approval is obtained for this program, the Department will claim federal reimbursement of upwards of $25 million annually. This will be retroactive to the beginning of the program, and will apply to regional center case management services provided to developmentally disabled clients who are eligible for Medi-Cal benefits. This is an opportunity for California to obtain a significant amount of federal revenue for services that have been fully funded by the state for many years.

5. *Facility Monitoring*

The Department remains committed to assuring that residential services are stable and high quality. At the local level, regional centers monitor services to assure that they are consistent with client needs, and provide technical assistance to facility administrators. Historically, regional centers have had insufficient staffing to fulfill all their monitoring and technical assistance responsibilities. The Governor's Budget for FY 1989-90 provides over $3 million for additional regional center staff to perform quality assurance activities, and the Department has revised its contracts with regional centers for FY 1989-90 to require them to perform this vital function. As ARM is phased in statewide, regional centers receive additional funds for ARM quality assurance activities— an average of 17 hours/facility/year.

6. *Transportation Coordinators in Regional Centers*

Expenditures for client transportation services rose rapidly in the early 1980s and reached $26 million by FY 1984-85. Transportation Coordinator positions were created that same year to assist in monitoring and controlling transportation expenditures and to increase client benefits through improved services. Activities which the Transportation Coordinators perform to achieve these objectives include transportation vendor monitoring, improved vendor selection, promoting mobility training, ensuring adequate driver training, participating in public meetings, coordination between day programs and transportation services, selection of most appropriate transportation modes, securing alternate program funding, and performing day-to-day operational activities effectively.

7. *Fiscal Monitor Positions in Regional Centers*

Fiscal Monitor positions were created in each regional center in FY 1985-86 to assist in the verification of billed services, verification of vendor cost statements and review of the use of clients' Personal and Incidental (P&I) monies in residential facilities. Prior to this time, the regional center core staffing formula did not provide for these activities; thus, the regional centers had been unable to adequately ensure appropriate and necessary fiscal accountability. These positions have generated Purchase of Service (POS) savings exceeding their costs. The savings have been realized in two areas: (1) more accurate monthly billings from vendors with respect to attendance, route-miles, hours of programming and staffing levels which were not subject to on-site verification by regional center personnel; and (2) on-site verification of vendor cost statements which has led to more accurate data being submitted to the Department.

Monitoring of the expenditures by clients' P&I funds ensures that the centers fulfill their responsibilities as representative payees for Supplementary Security Income and reduces the likelihood of large-scale audit exceptions from the Social Security Administration. The Fiscal Monitors complement the efforts of departmental auditors who audit vendors as well as perform an oversight role in relation to the Fiscal Monitors.

C. DEVELOPMENTAL CENTER SERVICES

1. *Mobility Engineering Department—Sonoma Developmental Center*

The goal of the Mobility Engineering Department at Sonoma Developmental Center is to custom design and construct a wide range of assistive devices, including custom seating and mobility systems, for disabled clients. Approximately 50 percent of the people who live and receive care at Sonoma Developmental Center require assistive devices. There are many such clients statewide in both the developmental centers and the community. These people include the very young and the elderly; all but a few have multiple handicaps resulting from severe orthopedic and/or neuromuscular disorders.

Although originally developed to serve Sonoma Developmental Center residents, the Mobility Engineering Department now provides its assistive devices to community clients, too. Working in consultation with the individual's physician, orthopedic consultants, physical and occupational therapists, and nursing staff, the supportive equipment adaptors bring expertise in metal and plastic fabrication, woodworking, upholstery and electronics to the evaluation, design, and construction of customized seating systems to maximize the functional capacity of the client.

Also, it is noteworthy that the Department provides an apprenticeship program for students interested in becoming supportive equipment adaptors and has recently entered into an agreement with the Department of Corrections at San Quentin where inmates will mass produce some parts for the seating systems. This latter arrangement assists Sonoma in providing seating systems comparable to the finest available anywhere at a fraction of the cost to the recipient, while providing meaningful jobs at San Quentin.

2. *STRETCH Curriculum*

STRETCH is a Life Skills Curriculum for person with developmental or mental disabilities. STRETCH was developed by the staff at the developmental centers and state hospitals, and teachers from adult schools. This came as a result of a desire to provide age-appropriate life skills training activities which will allow each individual to achieve the highest possible level of independence. The name STRETCH was selected because it encourages "stretching" for independence.

STRETCH is a six volume collection of training materials, organized to reflect the activities we encounter in our normal lives: 1) Domestic Self-Care; 2) Domestic Home Care; 3) Vocational; 4) Recreation and Leisure, and 5) Community Resources. First, STRETCH describes the way the average person accomplishes each identified task. Then it provides a list of ways to assist people with special needs to complete all or part of the task in the same way. These recommendations are called Strategies or Adaptations and are intended to motivate trainers to be creative in presenting "normal tasks" versus "handicapped methods". A thorough field test completed this year indicated that STRETCH is applicable to a wide range of users. It is anticipated that STRETCH will be utilized in homes, small residential units and schools, as well as our facilities.

The Department of Developmental Services is proud of the achievement of its staff in producing this important training tool. Camarillo State Hospital and Developmental Center has undertaken the production of STRETCH. Not only does this provide a vocational work training opportunity for clients, but it keeps the cost at approximately $300 a set, thereby making STRETCH widely available.

3. *Curriculum Resource Center, Camarillo Developmental Center*

One of the major problems faced by all education and training programs that provide services to individuals with mental or developmental disabilities is a scarcity of appropriate curricula, assessment and training materials. Several other factors increased the problem for developmental centers and state hospitals: the recent adoption of the "Life Skills" or "Functional Skills" approach to training, the involvement of all disciplines in the training process, and the preponderance of adult clients with severe and profound disabilities.

Utilizing existing resources, a curriculum center was opened at Camarillo State Hospital and Developmental Center. Collections were started on a rather limited scale and developmental centers and state hospitals began accessing the materials. With the addition of lottery monies, the Center for Curriculum Development will be fully implemented. Work is already underway to provide for a computer network to allow for immediate statewide access to the collected materials. It is expected that the center's services will be made available to all providers of education or training programs for the adult learner with special needs.

4. Accreditation, Certification and Licensing of Developmental Centers

Under the present Administration, all seven of California's state developmental centers have been continuously licensed by the state, federally certified, and accredited by a private agency called ACDD (Accreditation Council on Services for People with Developmental Disabilities). As we noted in the Department's Long Range Plan 1988-93, "Although developmental centers have been successful to date in maintaining accreditation, some new challenges have been posed to the system." These challenges are in the form of the revised—and more stringent—"1987 Standards." The first surveys under the revised standards occurred in May and June 1988, and both developmental centers involved passed. That was not the case with surveys in February and March 1989; one center received a deferred decision, and the other was placed in the category of "working toward reaccreditation." The Department is currently implementing an aggressive action plan which will lead to reaccreditation of these two developmental centers by Summer 1990.

D. PROJECTS WITH SYSTEMWIDE IMPACT

1. State Developmental Research Institutes

The State Developmental Research Institutes (SDRI) was initiated in 1985 by the Department of Developmental Services to link the research potential of physicians, psychologists, educators and other clinicians assigned to developmental centers, and the scientists of various colleges or universities that have expertise and interest in various areas related to developmental disabilities.

Linking the scientific community with clinical staff of developmental centers who possess expertise in the area of care, treatment and development of individuals, creates the potential of an explosion of significant scientific information for parents, providers of service, and resource managers in the field of developmental disabilities. This information also being transmitted to community providers of services through the usual academic and vocational channels of communication. A journal, SDRI Research Digest, containing the research activities and findings of these scholars, is published by the Department on a quarterly basis.

The current 26 SDRI research projects have the potential for strong impact on the following typical difficult problems existing among the handicapped:

- Prevention of developmental disabilities that occur during pregnancy and the time of delivery because of body toxins in the mother.
- Prevention of developmental disabilities caused by inborn mistakes of metabolism.
- Controlling self-abusive behavior that can result in blindness and severe disfiguring conditions.
- Reduction of neurological damage from psychotropic medications.
- Prevention of mental retardation from environ- mental poisons.
- Reduction of liver damage from Hepatitis B.

- Identification of cerebral defects and their causes that result in learning impairment.
- Utilization of Vitamin E therapy to prevent and treat tardive dyskinesia.
- Examining age-related loss of memory and the impact of programs like Foster Grandparents.

Approximately 25 institutions of higher learning and the developmental centers are involved in the above research results.

2. *Long Range Plan*

The Department has, at its own initiative, developed and published a long range plan describing its major goals and objectives for the developmental services system. This plan is designed to provide direction to the service system as a whole by serving as the "blueprint for action" for the next five years. To develop the plan, the Department solicits and analyzes public comment and reviews Department activities and priorities. The plan includes background (narrative and statistics) and proposed objectives covering a wide range of activities, both legislatively mandated and Department initiated. Each edition also includes a chart reporting on the outcome of the objectives in the preceding plan. Copies of the plan are distributed to numerous interested organizations and individuals throughout the state. Each copy includes a comment form and a request for feedback from readers.

The plan is currently in its third edition, covering the years 1988-93. The next edition (1990-95) is scheduled for publication in July of 1990.

3. *Improving Interagency Coordination*

In FY 1988-89 the Department of Developmental Services developed a number of memoranda of understanding and interagency agreements with other departments, including Alcohol and Drug Programs, Education, Mental Health, Health Services, Social Services, and Aging. These agreements have been designed to develop new programs (CDA and elderly persons, ADP and services for "substance abuse babies"), remedy areas of conflict or confusion (DHS and DSS licensing), develop coherent policies (DR and supported work), and, generally, to ensure closer more effective working relationships among departments.

In its role as "lead agency" for the early intervention program, DDS works closely with various state and local agencies to plan services at the local level, and provides staff support to the Interagency Coordinating Council.

In addition, DDS has participated in interdepartmental workgroups with the Departments of Social Services, Rehabilitation, and Education; the Governor's AIDS Leadership Committee and its Subcommittee on Pediatric AIDS; and the California Medical Association's task group studying medically fragile and technologically- dependent children.

4. *Family Support Services Study*

A major premise of the Department's policy is that children with developmental disabilities should be given the opportunity to remain in their parental homes until at least age 18, as is true of the majority of non-disabled persons. In support of that premise, the Department has undertaken a study of the adequacy of services that support parents who care for their children with developmental disabilities at home. This study is being conducted jointly by the University of California at Riverside and the Department. More than 2,600 parents and more than 225 regional center employees have been surveyed to determine the strengths and weaknesses of the current family support service system. The study, which is now in its final phases, was initiated by the Department as part of its long- range planning process. The intent of the study is to identify innovative approaches to enhancing the services now available to families.

5. Independent Living Program Study

The Department is presently conducting a study of independent living as the most normal and least restrictive residential option for our clients. The study will establish what factors are associated with success in independent living for a large group of clients between 1983 and 1987, and examine the types and amounts of services that were purchased for them. It will also incorporate information about the service delivery system obtained through a survey of case managers and independent living service providers. Finally, consumer input has been sought through a variety of sources. The completed study will result in a report that recommends ways of expanding the number of clients who can live independently in the community.

Total Expenditures on Regional Center Clients

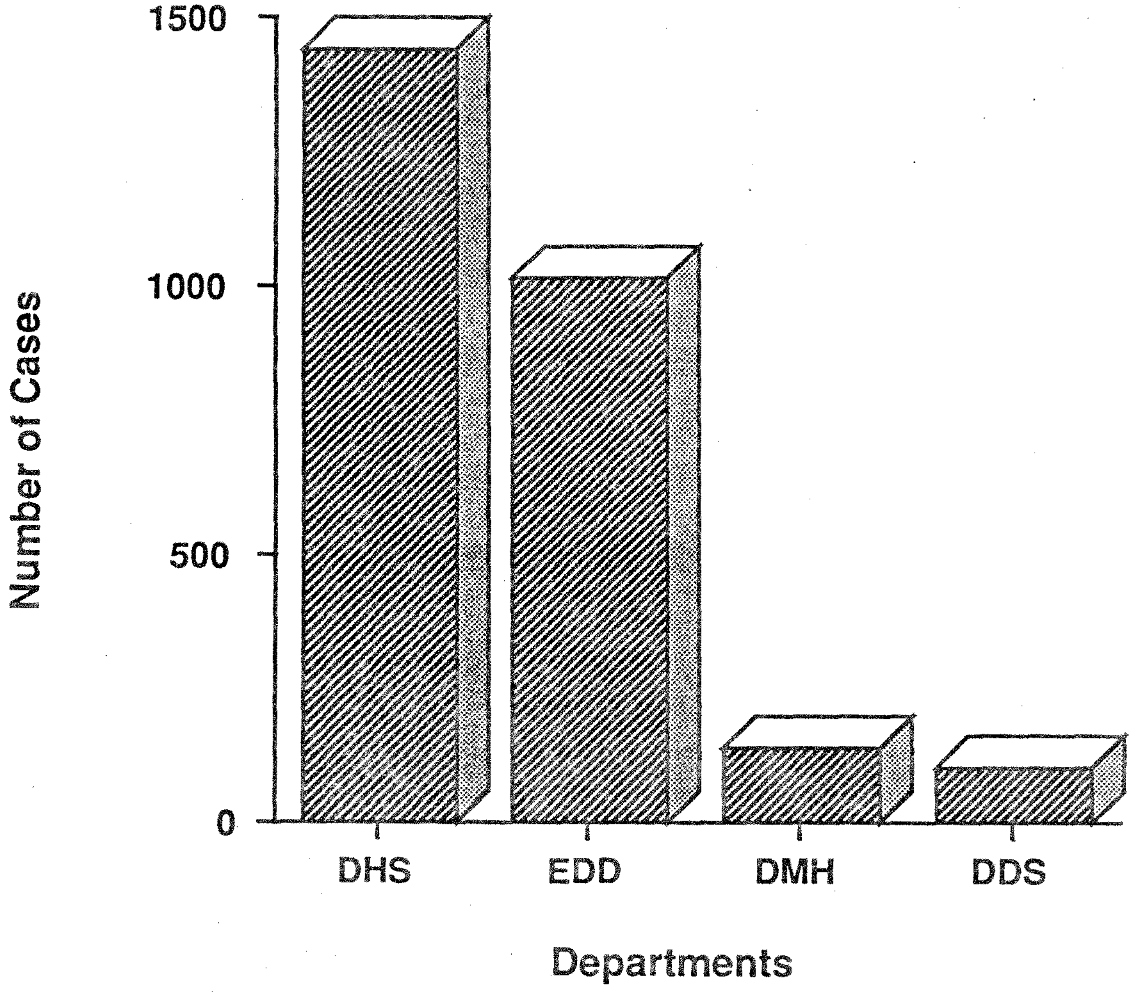
Community vs Developmental Centers

(FY 1987-88)

	Community Services	*Developmental Centers*
	Dollars in Millions	
DDS Budget	$404.09	$439.4
SSI/SSP	$115.7	—
Habilitation	$63.0	—
Medi-Cal	$173.6	—
Special Education	$131.3	0.8
Housing	$10.0	—
Total	$898.5	$440.2

Litigation

Open Cases*

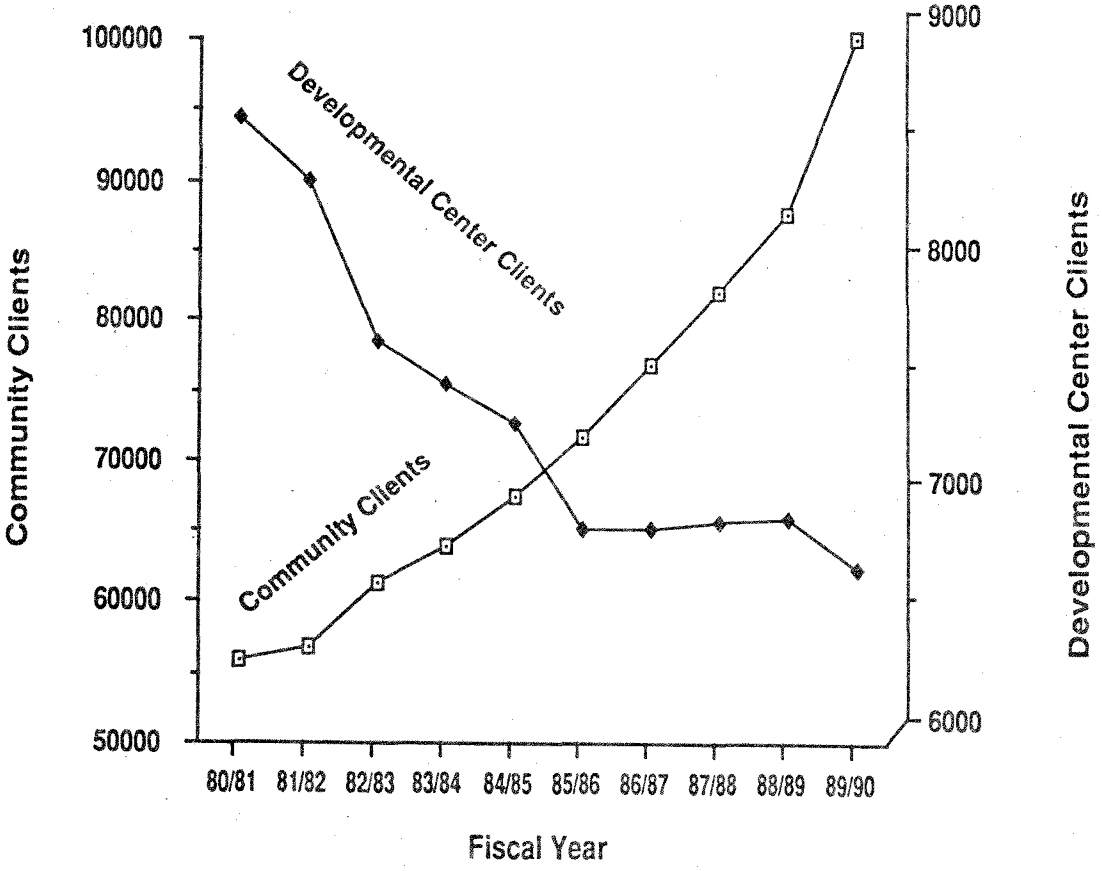


* All numbers are currently open cases

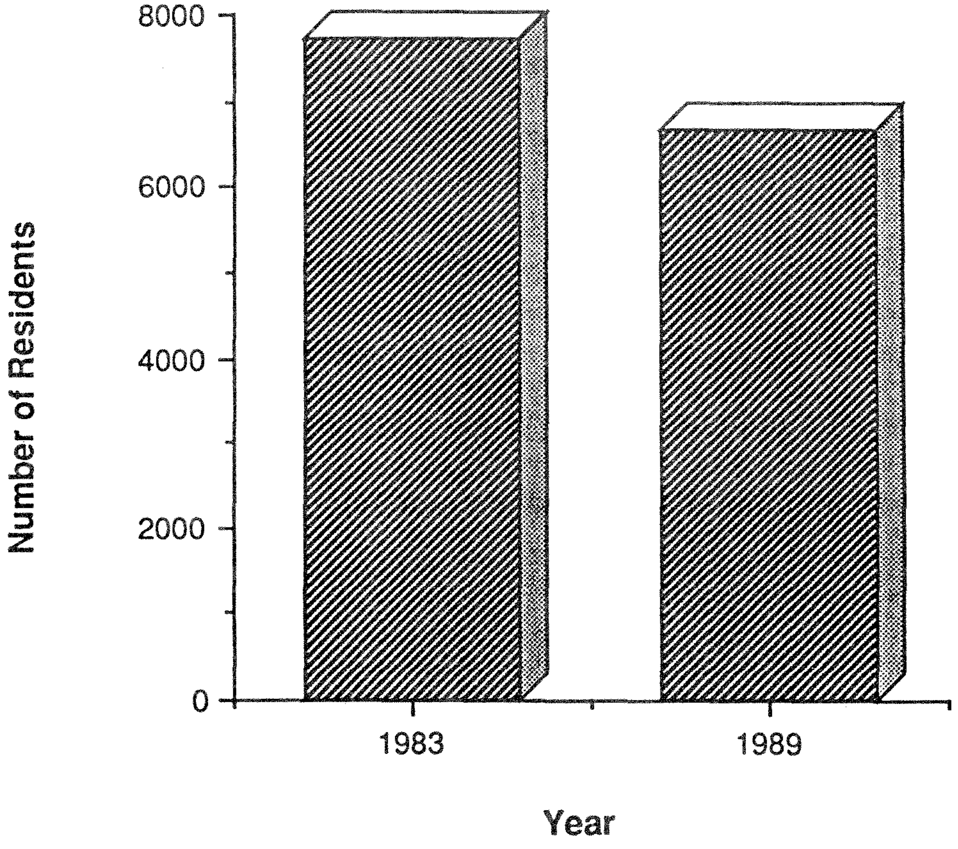
Client Fair Hearings

Subject	*Number of Clients*	*FY 1987-88 Number of Hearings*
AFDC	**1,809,429**	**24,255**
Food Stamps	**1,762,048**	**19,516**
Medi-Cal	**3,036,938**	**18,525**
Developmental Services	**81,417**	**60**

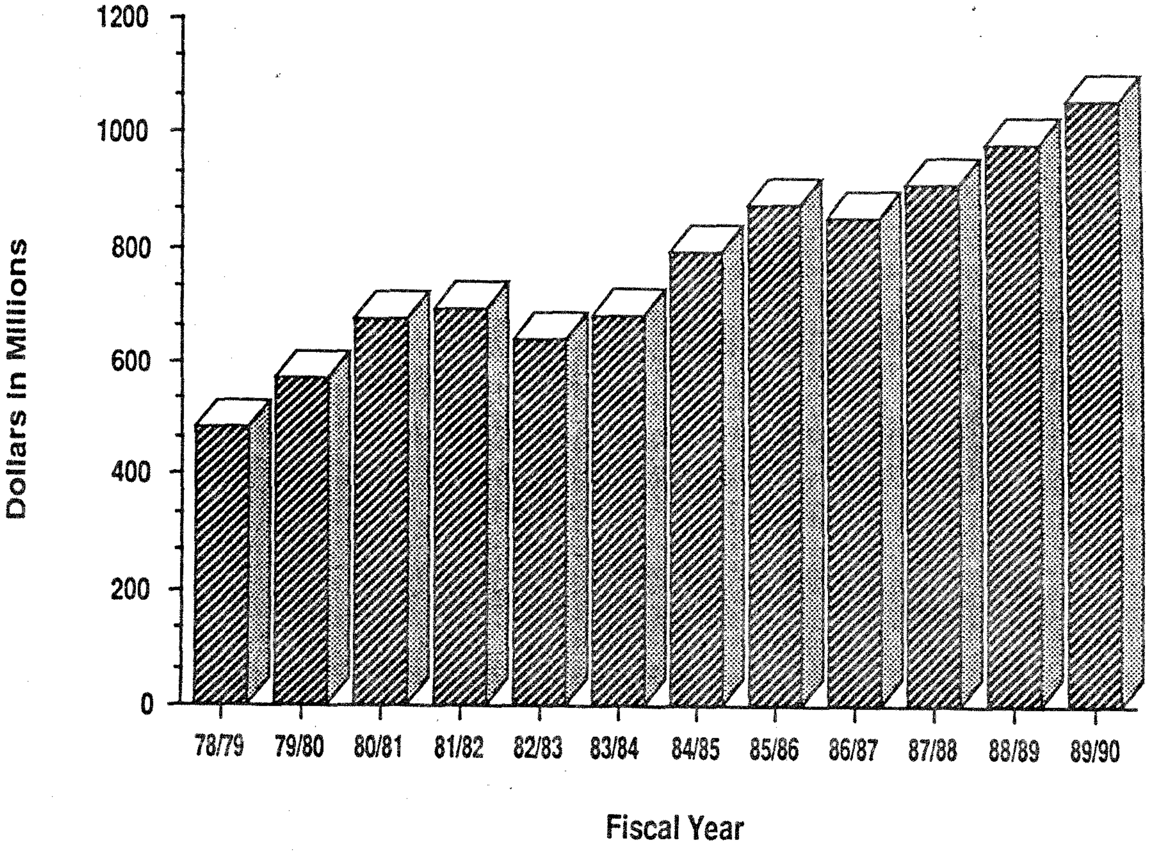
Changes in Numbers of Community Clients/ Developmental Center Clients



State Developmental Center Population

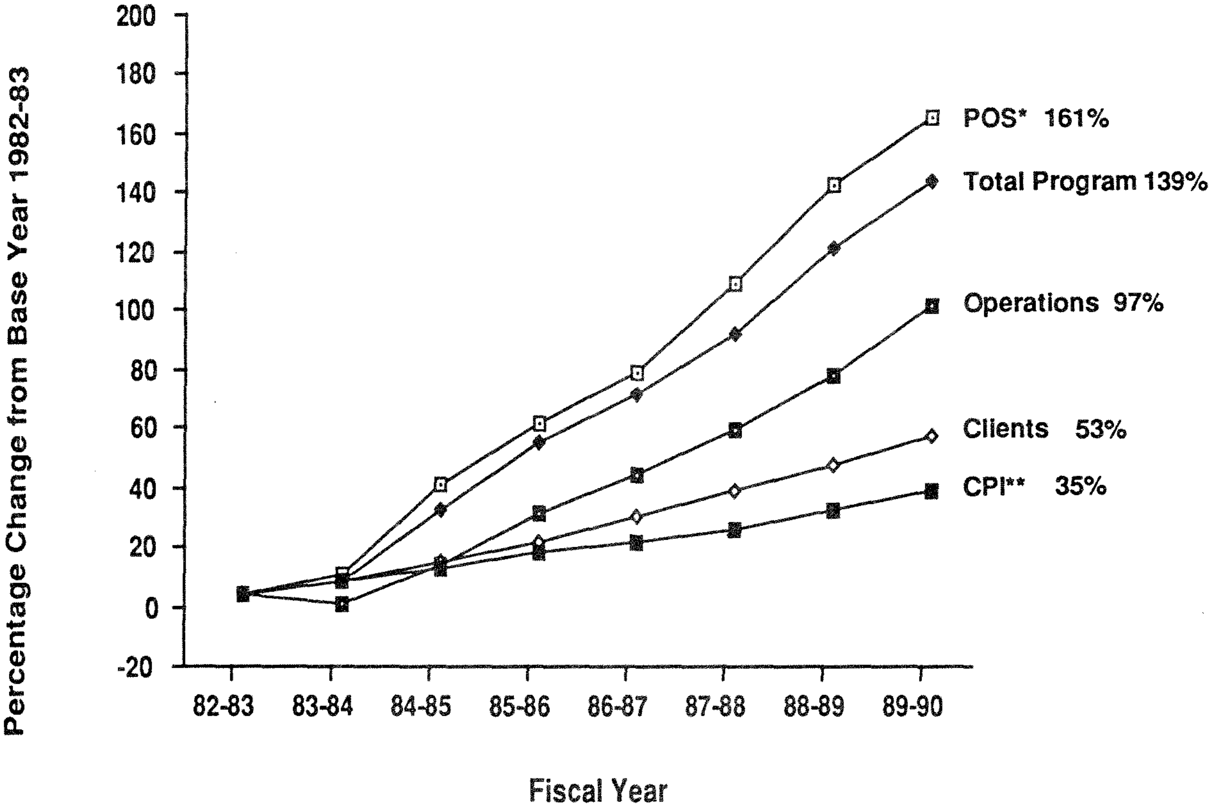


Department of Developmental Services Fiscal Year Expenditures



Community Program Growth

Percentage Change From Base Year 1982-83 By Fiscal Year



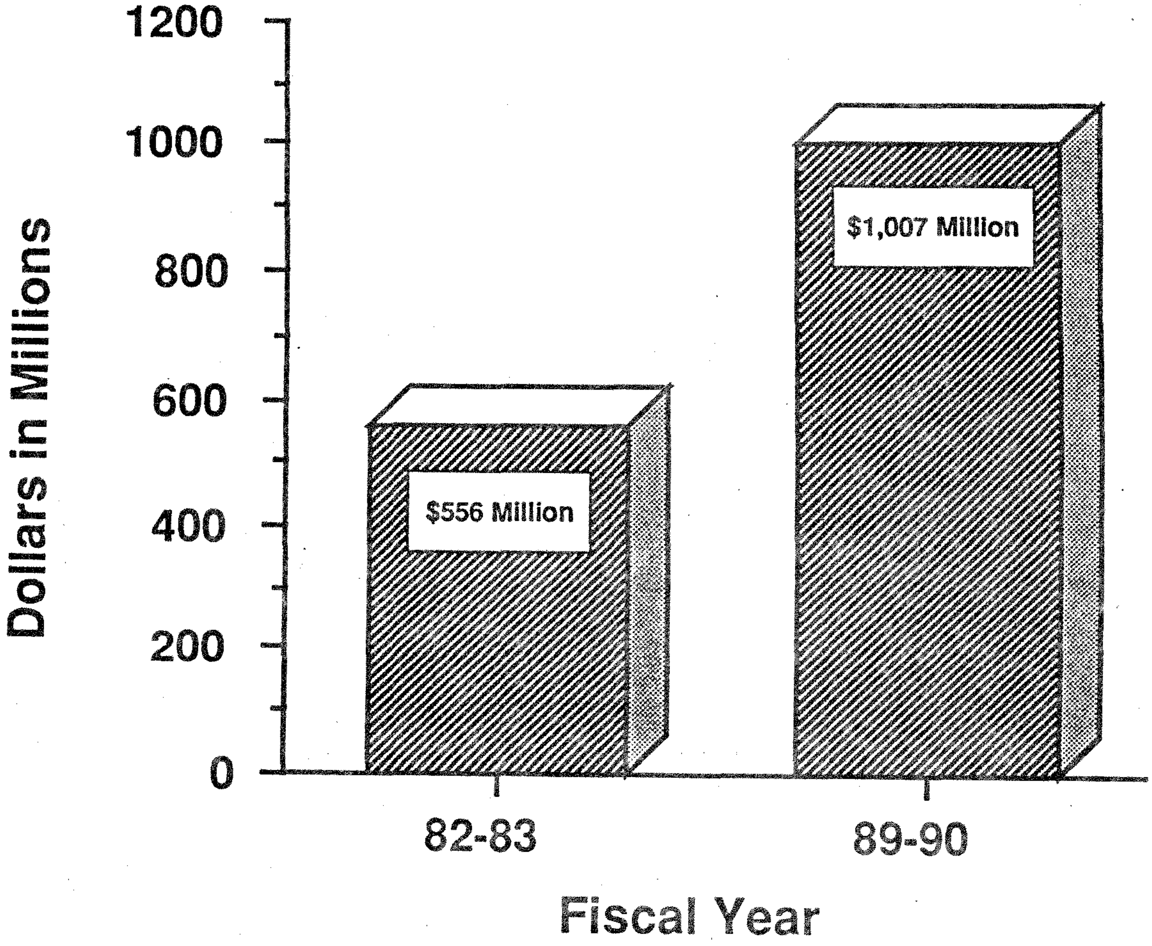
* POS — Purchase of Services

** CPI — California Consumer Price Index

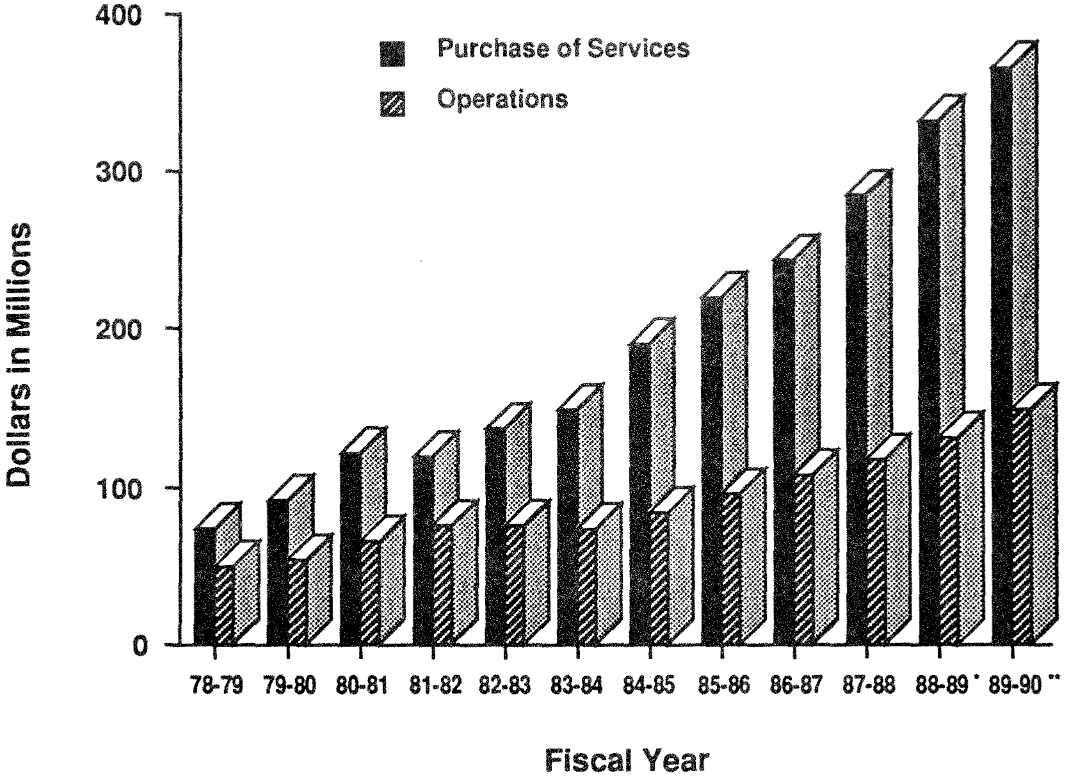
Budget Comparison by Fiscal Year

1982-83 and 1989-90

(Developmentally Disabled Costs Only)



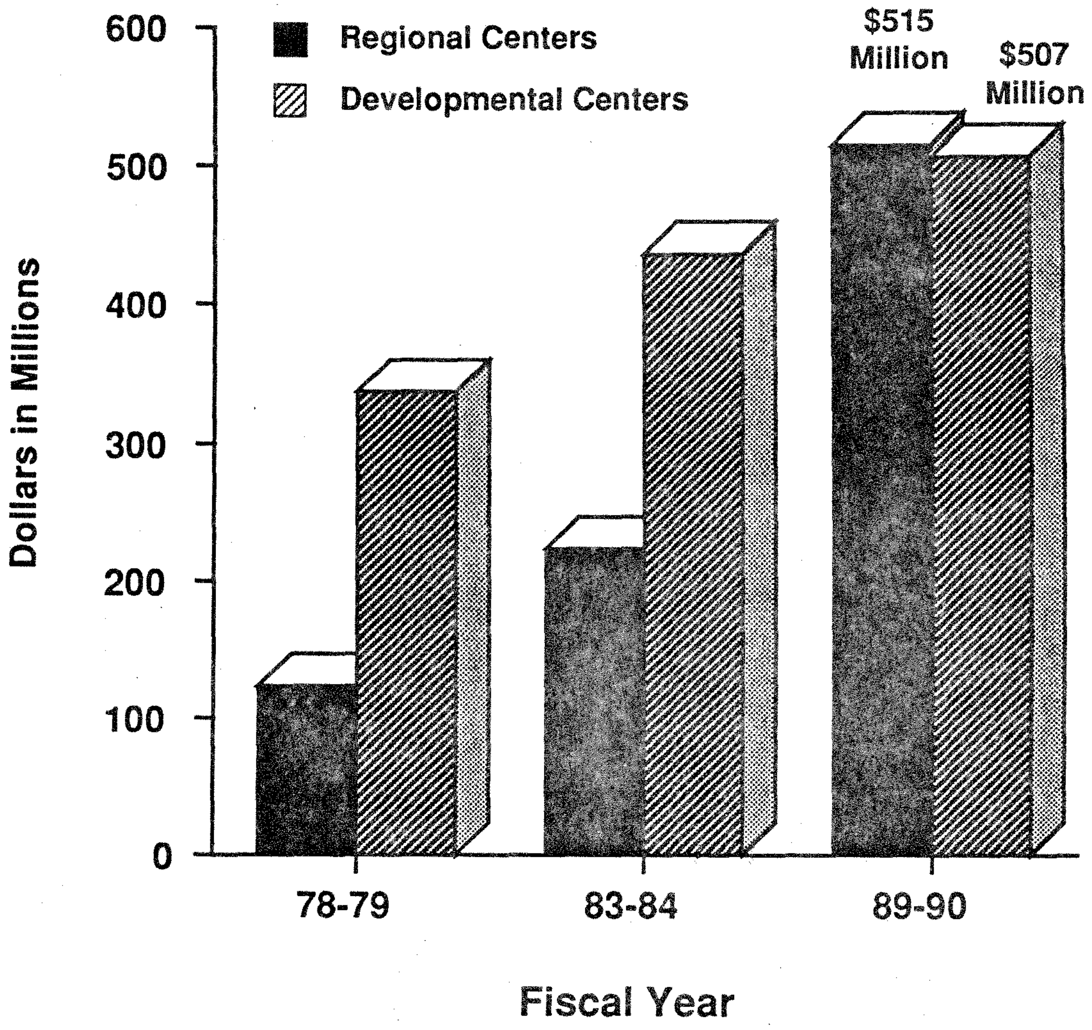
Regional Center Expenditures



- **Purchase of Services — 495% Increase**
- **Operations — 298% Increase**

* FY 88-89 — estimated
** FY 89-90 — projected

Regional Centers/ Developmental Centers Budgets

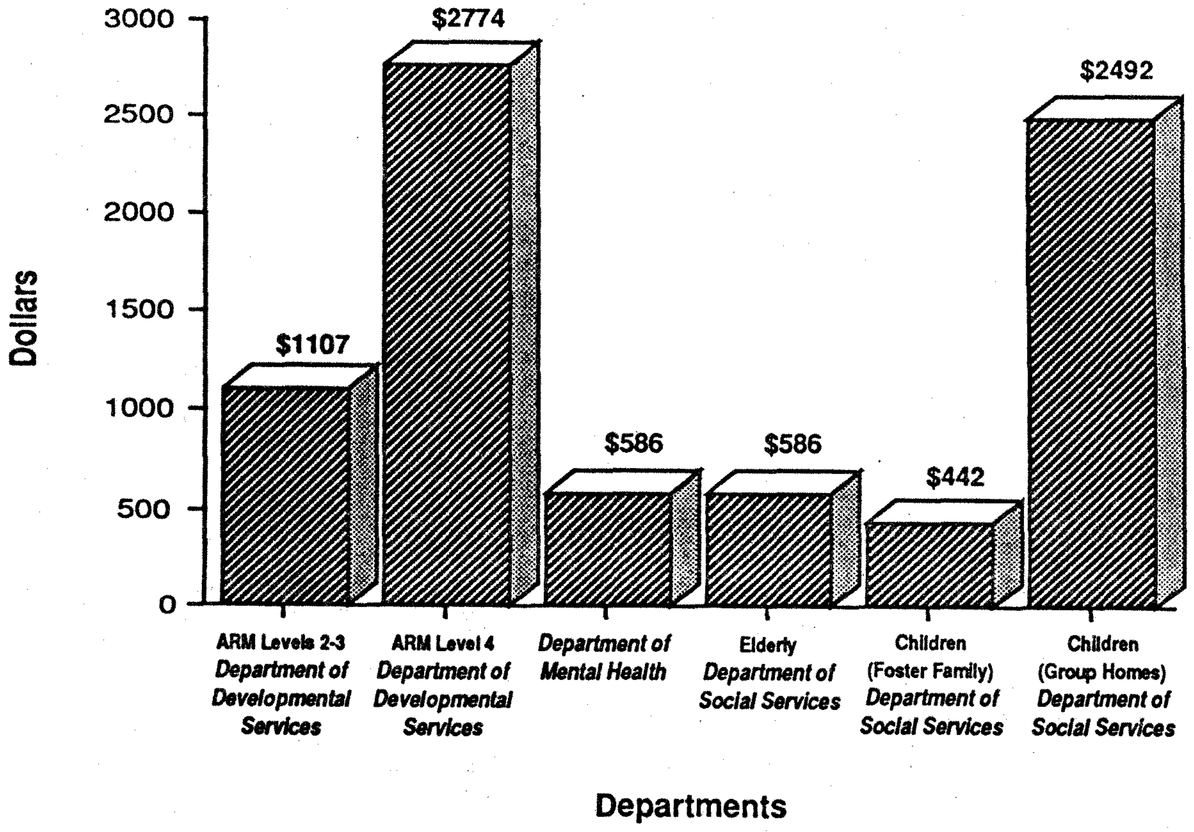


Major Characteristics of Clients in Developmental Centers versus in the Community

Percent of Developmental Center Clients		*Percent of Community Clients*
71%	Are Profoundly Retarded	9%
38%	Have Severe Behavior Problems	6%
13%	Are Frequently Violent	1%
49%	Do Not Understand Spoken Words	17%
37%	Are Wheelchair or Bedridden	19%
26%	Must Be Fed	10%
17%	Have Severe Loss of Sight	5%
9%	Have Severe Loss of Hearing	3%
80%	Need Help Toileting	39%
73%	Have Major Medical Problems	10%

Comparison of Residential Rates Paid by DDS and Other Departments

(FY 88-89 rates paid per client per month)



Growth in Average Residential Care Rates FY 82-83 to FY 88-89

(Dollars per client per month)

Population	*FY 82-83*	*FY 88-89*	*% Growth*
DDS (ARM*)	$764	$1243	63%
DSS-Elderly	$455	$586	29%
DSS-Children (Foster Family)	$372	$442	19%
DSS-Children (Group Homes)	$1606	$2492	55%
DMH-Mentally Ill	$455	$586	29%

Statewide
Jan 1991

* **Half of the DDS community facilities are currently ARM facilities**

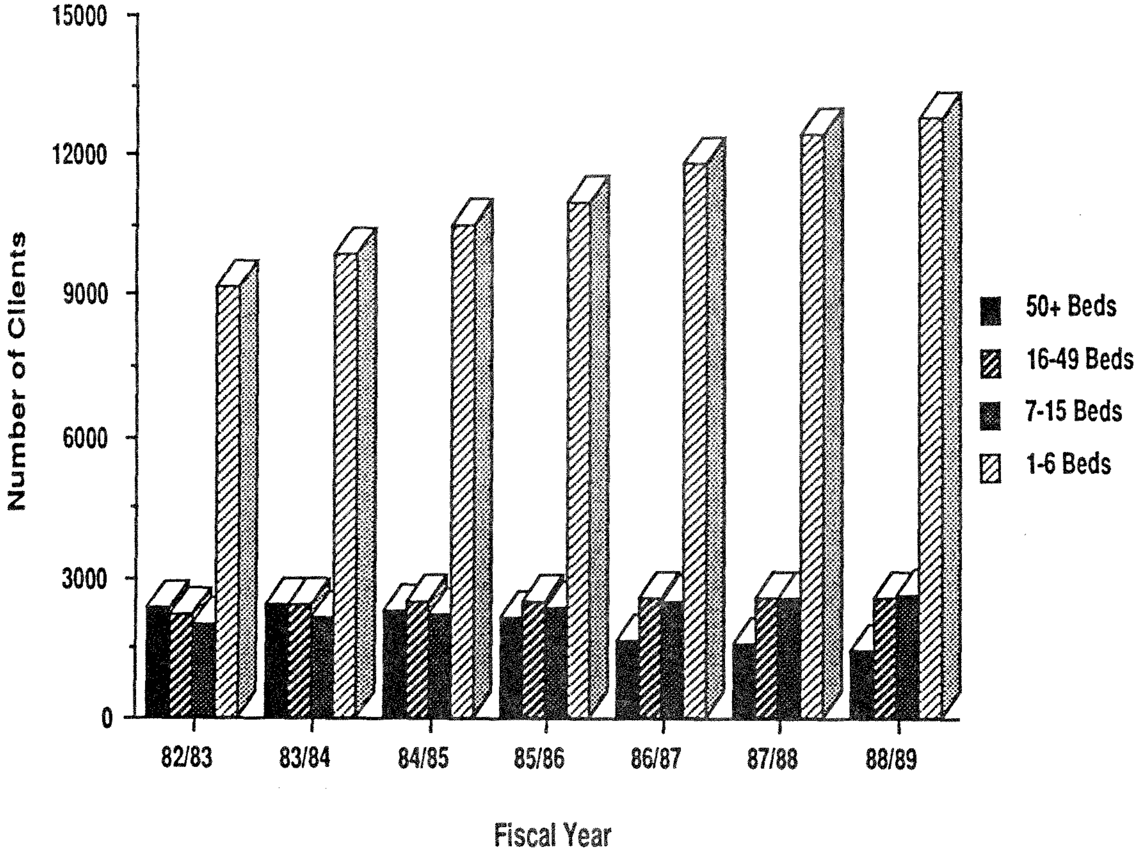
Growth in Community Placements and Facilities

(Residential and Small Health Facilities)

	FY 1983/84		*(estimated) FY 1988/89*	
	Facilities	Clients	Facilities	Clients
Community Care Facilities	3,471	16,641	3,783	18,197
ICF/DD-N	0	0	2	12
ICF/DD-H	30	222	311	2,111
Total	3,501	16,863	4,096	20,320

Clients Living in Community Care Facilities

(By Size of Facility)



STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

TESTIMONY
JUNE 16, 1989

AN OVERVIEW OF THE STUDY OF THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICE ACT

GOOD AFTERNOON MR. CHAIRMAN AND MEMBERS, MY NAME IS MARTA ZARAGOZA-DIAZ. I AM REPRESENTING THE STATE COUNCIL ON DEVELOPMENTAL DISABILITIES. MR. JIM BELLOTTI, THE EXECUTIVE DIRECTOR WAS UNABLE TO BE HERE DUE TO THE FACT THE STATE COUNCIL IS MEETING WHILE WE SPEAK.
I WOULD LIKE TO THANK YOU FOR PROVIDING US WITH THE OPPORTUNITY TO COMMENT ON THE ADMINISTRATION OF THE LANTERMAN ACT.

THE STATE COUNCIL IS A FEDERALLY FUNDED STATE AGENCY; GENERAL FUND MONIES ARE NOT USED TO SUPPORT THE COUNCIL. THE COUNCIL HAS MANDATED RESPONSIBILITIES UNDER BOTH FEDERAL AND STATE LAW. FEDERAL LAW (P.L. 100-146 -THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT) GOVERNS THE ROLE AND FUNCTIONS OF THE COUNCIL.

THE PURPOSE OF THE LAW IS THREEFOLD: 1) TO ASSIST STATE, AND PUBLIC AND PRIVATE NONPROFIT AGENCIES AND ORGANIZATIONS TO ASSURE THAT PERSONS WITH DEVELOPMENTAL DISABILITIES RECEIVE THE SERVICES AND OTHER ASSISTANCE AND OPPORTUNITIES NECESSARY TO ENABLE SUCH PERSONS TO ACHIEVE THEIR MAXIMUM POTENTIAL THROUGH INCREASED INDEPENDENCE, PRODUCTIVITY AND INTEGRATION INTO THE COMMUNITY; 2) TO ENHANCE THE ROLE OF THE FAMILY IN ASSISTING PERSONS WITH DEVELOPMENTAL DISABILITIES TO ACHIEVE THEIR MAXIMUM POTENTIAL AND 3) TO SUPPORT A SYSTEM IN EACH STATE TO PROTECT THE LEGAL AND HUMAN RIGHTS OF PERSONS WITH DEVELOPMENTAL DISABILITIES.

FEDERAL LAW STATES THAT THE COUNCIL IS TO SERVE AS AN ADVOCATE FOR ALL PERSONS WITH DEVELOPMENTAL DISABILITIES. SPECIFICALLY THE COUNCIL IS TO:

- DEVELOP A STATE PLAN THAT DESCRIBES THE EXTENT AND SCOPE OF SERVICES BEING PROVIDED, OR TO BE PROVIDED, TO PERSONS WITH DEVELOPMENTAL DISABILITIES

- TO MONITOR, REVIEW AND EVALUATE ANNUALLY THE IMPLEMENTATION OF THE STATE PLAN

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- TO REVIEW AND COMMENT TO THE MAXIMUM EXTENT FEASIBLE ON ALL STATE PLANS WHICH RELATE TO PROGRAMS AFFECTING PERSONS WITH DEVELOPMENTAL DISABILITIES

- TO ALLOCATE FEDERAL FUNDS THAT WOULD BE USED FOR THE DEVELOPMENT OF A COMPREHENSIVE SYSTEM AND A COORDINATED ARRAY OF SERVICES THROUGH THE CONDUCT OF APPROPRIATE PLANNING AND COORDINATION OF ADMINISTRATIVE . FEDERAL AND STATE PRIORITY ACTIVITIES.

THE COUNCIL IS ALSO MANDATED TO CONDUCT A ONE-TIME COMPREHENSIVE REVIEW OF THE EXTENT , SCOPE AND EFFECTIVENESS OF, AND ELIGIBILITY FOR SERVICES PROVIDED TO PEOPLE WITH DEVELOPMENTAL DISABILITIES. (1990 STUDY)

IT SHOULD BE NOTED THAT THE STATE COUNCIL HAS ADOPTED THE FOLLOWING FEDERAL PRIORITIES:
COMMUNITY LIVING (INCLUDING FAMILY AND OTHER NONFINANCIAL SUPPORTS)AND EMPLOYMENT.

THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICES ACT. REITERATES FEDERAL MANDATES OF THE COUNCIL: I.E. IT OUTLINES SPECIFIC PLANNING AND EVALUATION FUNCTIONS THE COUNCIL MUST DO. HOWEVER THE LANTERMAN ACT GOES A STEP FURTHER BY PROVIDING THE COUNCIL WITH MONITORING AND INVESTIGATORY AUTHORITY SPECIFIC TO THE PROVISIONS OF THE ACT. THE COUNCIL HAS BEEN GIVEN AUTHORITY TO CONDUCT INVESTIGATIONS OR PUBLIC HEARINGS TO RESOLVE DISAGREEMENTS BETWEEN STATE AGENCIES OR BETWEEN STATE AND REGIONAL OR LOCAL AGENCIES OR BETWEEN PERSONS WITH DEVELOPMENTAL DISABILITIES AND AGENCIES RECEIVING STATE FUNDS. THESE INVESTIGATIONS ARE TO BE CONDUCTED ONLY AFTER ALL OTHER ADMINISTRATIVE REMEDIES HAVE BEEN EXHAUSTED.

THE COUNCIL IS COMPRISED OF NINETEEN MEMBERS . ITS MEMBERSHIP IS DICTATED BY FEDERAL LAW AND CONSISTS OF THE FOLLOWING: FIVE PRIMARY CONSUMERS (HOWEVER ONE PRIMARY CONSUMER VACANCY EXISTS). FOUR PARENTS OF PERSONS WITH DEVELOPMENTAL DISABILITIES (ONE OF WHICH REPRESENTS AN INDIVIDUAL WHO RESIDES IN STOCKTON DEVELOPMENTAL CENTER). ONE RELATIVE OF A PERSON WITH DEVELOPMENTAL DISABILITIES. ONE PERSON REPRESENTING A NON-PROFIT GROUP CONCERNED WITH DEVELOPMENTAL DISABILITIES. ONE PERSON REPRESENTING THE PROTECTION AND ADVOCACY ORGANIZATION. THE CHAIRPERSON OF THE ORGANIZATION ON AREA BOARDS. ONE PERSON REPRESENTING THE UNIVERSITY AFFILIATED PROGRAMS. ONE PERSON REPRESENTING THE SECRETARY OF THE HEALTH AND WELFARE AGENCY AND THE AGENCY ADMINISTERING TITLE XIX FUNDS OF THE SOCIAL SECURITY ACT. AND DIRECTORS FROM THE STATE DEPARTMENTS OF DEVELOPMENTAL SERVICES. AGING. AND REHABILITATION. THE SUPERINTENDENT OF PUBLIC INSTRUCTION IS ALSO REPRESENTED ON THE STATE COUNCIL.

THE COUNCIL HAS 13 STAFF MEMBERS AND A BUDGET OF 4.7 MILLION OF WHICH 2.2 MILLION FUNDS AREA BOARDS AND 1.7 MILLION GOES TO THE PROGRAM DEVELOPMENT FUND. THE REMAINDER OF THE BUDGET FUNDS COUNCIL STAFF AND OPERATIONS.

THE COUNCIL MEETS THROUGHOUT THE STATE FOR THE EXPRESS PURPOSE OF SOLICITING LOCAL INPUT. AN EXAMPLE OF THIS WAS WHEN THE COUNCIL MET IN REDDING CALIFORNIA. SEVERAL PARENTS WITH CHILDREN REQUIRING GASTROSTOMY CARE SOUGHT ASSISTANCE FROM THE COUNCIL IN RESOLVING A PROBLEM THEY WERE HAVING IN PROVIDING CARE TO THEIR CHILDREN WITHOUT THE ASSISTANCE OF A REGISTERED NURSE. AS A RESULT OF THEIR PRESENTATION AND REQUEST FOR ASSISTANCE, THE COUNCIL IS WORKING TO FACILITATE A SOLUTION TO THEIR PARTICULAR PROBLEM.

TWO MAJOR DIVISIONS EXIST WITHIN THE COUNCIL: THE MONITORING AND SYSTEMS REVIEW AND PLANNING AND EVALUATION.
THE COUNCIL ANNUALLY DEVELOPS A WORK PLAN THAT ADDRESSES FEDERAL AND STATE MANDATES. CURRENT WORK PLAN ACTIVITIES OF THE MONITORING AND SYSTEM REVIEW DIVISION INCLUDE BUT ARE NOT LIMITED TO THE FOLLOWING:

- ISSUING OF A HOUSING AND TRANSPORTATION REPORT
- DEVELOPMENT OF A FAIR HEARING REPORT
- CALIFORNIA CHILDRENS SERVICES FOLLOW-UP (A.B. 297-STATHAM)
- DEVELOPMENT OF A PILOT FAMILY SUPPORT PROJECT SPECIFIC TO RESPITE SERVICES.

PLANNING AND EVALUATION ACTIVITIES INCLUDE BUT ARE NOT LIMITED TO:

- DEVELOPMENT OF THE 1990 STUDY/1990/91 STATE PLAN
- PDF EVALUATION
- DEVELOPMENT OF POLICIES ON SUCH ISSUES AS AIDS, AGING AND DUAL DIAGNOSIS SERVICES
- INTEGRATED SERVICES SYSTEM EVALUATION
- COMMUNITY PLACEMENT PLAN/ QUALITY OF LIFE STUDY
- EVALUATION OF OSERS/SUPPORTED EMPLOYMENT PROJECT
- ADVISE ON THE DEVELOPMENT OF A RESIDENTIAL CARE CURRICULUM

FOR FISCAL YEAR 1989-1990 THE COUNCILS WORK PLAN WILL INCLUDE BUT NOT BE LIMITED TO THE FOLLOWING ACTIVITIES:

- REVIEW OF THE SYSTEM (VIA PARTICIPATING IN THE SR 9 PROCESS)
- STUDY OF SUPPORTED EMPLOYMENT
- REVIEW OF THE DEVELOPMENTAL CENTERS ADMISSIONS PROCESS
- MONITORING THE QUALITY ASSURANCE STANDARDS

BASED UPON THE COUNCILS PARTICIPATION AND EXPERIENCE IN THE SYSTEM WE HAVE IDENTIFIED THE FOLLOWING ISSUES THAT REQUIRE FURTHER STUDY:

- THE NEED TO CLARIFY THE ROLE OF THE COUNCIL AND THAT OF OTHER RELEVANT AGENCIES, SUCH AS THE AREA BOARDS. IN THE SYSTEM.

  IT NEEDS TO BE UNDERSTOOD THAT THE COUNCIL IS MANDATED BY BOTH FEDERAL AND STATE LAW AND THAT IT IS NOT A FUNDING ENTITY FOR DIRECT SERVICES BUT A FUNDING ENTITY TO PROVIDE FOR INNOVATIVE PROJECTS LEADING TO SYSTEM CHANGE. ALSO SINCE AREA BOARDS HAVE A DIFFERENT ROLE MANDATED BY THE STATE THAN DOES THE STATE COUNCIL, SHOULD AREA BOARDS NOT RECEIVE GENERAL FUND MONIES TO SUPPORT THEIR STATE MANDATED ACTIVITIES ?

  THE COUNCIL IS EVOLVING INTO A MORE COMPREHENSIVE PLANNING AGENCY LOOKING AT SYSTEMIC ISSUES (VERSUS LOCAL ISSUES) AND PLANNING FOR INNOVATION.

  OUR MONITORING/INVESTIGATORY RESPONSIBILITIES ARE VIEWED AS A VEHICLE TO BE USED TO SUPPORT OUR PLANNING ACTIVITIES. AN EXAMPLE WOULD BE THE MONITORING OF RESIDENTIAL CARE FACILITIES. WE MONITOR. REVIEW, EVALUATE THE FACILITIES, LOOK AT THE INFORMATION AND THEN SAY HERES THE DATA NOW LETS LOOK AT WHAT THE IDEAL SHOULD BE.

  - FUNCTIONAL VERSUS CATEGORICAL DEFINITION
    LAST YEAR THE ISSUE OF WHETHER THE FEDERAL DEFINITION SHOULD BE ADOPTED WAS THE TOPIC OF A LEGISLATIVE HEARING. THE PROBLEMS AND ISSUES RESULTING FROM THE UTILIZATION OF A CATEGORICAL DEFINITION STILL EXISTS. INDEPTH RESEARCH AS TO HOW A FUNCTIONAL DEFINITION CAN BE INCORPORATED INTO THE LANTERMAN ACT NEEDS TO OCCUR.

  - ADEQUATE FINANCING
    RESIDENTIAL SERVICES RATE COMPONENTS SHOULD ENSURE A GREATER QUALITY OF SERVICE. FOR EXAMPLE DIRECT CARE STAFF ALLOWANCES SHOULD APPROXIMATE THE SAME AS IN STATE DEVELOPMENTAL CENTERS.

  - ALTERNATIVE SYSTEM FINANCING
    IN THIS ERA OF LIMITED RESOURCES, THERE IS A NEED TO EXPLORE A VARIETY OF FUNDING MECHANISMS FOR THE SERVICE SYSTEM INCLUDING PRIVATE FUNDING. WHICH FUNDING MECHANISM IS BEST USED FOR WHICH PURPOSES, WHAT PORTIONS OF THE SERVICE SYSTEM COULD BEST BE SUPPORTED BY PRIVATE SECTOR RATHER THAN PUBLIC SECTOR FUNDS. IN LIGHT OF THE EMPHASIS PLACED UPON SECURING AND MAXIMIZING FEDERAL DOLLARS WHENEVER POSSIBLE. THE ISSUE OF SUPPLANTING VERSUS SUPPLEMENTATION OF EXISTING PROGRAMS NEEDS TO BE ADDRESSED.

- RESOURCE DEVELOPMENT
  THIS ISSUE RELATES TO PLANNING FOR NEW PROGRAMS AS WELL AS MORE EFFICIENT ALLOCATION OF EXISTING RESOURCES. THE MAJOR CONCERNS IN THIS AREA IS THE NEED FOR FLEXIBILITY IN DESIGNING COMMUNITY SERVICES TO PROVIDE FOR MORE INTEGRATION AND INDEPENDENCE (WHICH MAY COST MORE IN TERMS OF STAFFING AND OPERATIONS OVER THE SHORT TERM, BUT WILL HAVE LONG-RANGE BENEFITS TO THE INDIVIDUAL AND THE SYSTEM). AND THE INCENTIVE FOR INTENSIVE NEEDS ASSESSMENT AND PLANNING WHEN THERE ARE VERY LIMITED FUNDS AVAILABLE FOR NEW PROGRAM AND SYSTEM GROWTH. INCENTIVES NEED TO BE DEVELOPED TO RECRUIT AND MAINTAIN PHYSICAL THERAPISTS. DENTISTS, MEDICAL DOCTORS, ETC TO PROVIDE NECESSARY SERVICES.

- CRISIS PLANNING
  THIS ISSUE NEEDS TO BE LOOKED AT TWO LEVELS:
  1) THE INDIVIDUAL WHO HAS PERIODS OF BEHAVIOR MANAGEMENT/ HEALTH CRISES AND THE NEED TO AVOID MORE RESTRICTIVE PLACEMENT BY DEVELOPING CREATIVE WAYS TO AVERT THE CRISIS BEFORE IT BECOMES UNMANAGEABLE. THIS IS A PROGRAM DESIGN AND DEVELOPMENT ISSUE, WHICH REQUIRES SOME SYSTEMIC CONTINGENCY PLANNING.WE ARE NOW EXPERIMENTING WITH CRISIS RESIDENTIAL FACILITIES,CRISIS TEAMS WHICH OPERATE ON-CALL, AND IN-HOME INTERVENTION.
  2) MANAGEMENT CRISIS IN COMMUNITY PROGRAMS WHICH COULD BE VOIDED BY TECHNICAL ASSISTANCE, MORE PROVIDER TRAINING, AND EARLY INTERVENTION BY LOCAL MONITORING AGENCIES. FOR EXAMPLE, THE ESTABLISHMENT OF A SERVICE BUREAU MODEL THAT COULD BE USED STATEWIDE AND THAT WOULD PROVIDE ASSISTANCE TO PROVIDERS OF SERVICES. THE BUREAU WOULD BE A VOLUNTEER ORGANIZATION COMPOSED OF INDIVIDUALS WHO HAVE EXPERTISE IN AREAS SUCH AS ACCOUNTING, PERSONNEL MANAGEMENT, LAW WTCH THAT COULD SERVE AS A LOCAL RESOURCE TO SERVICE PROVIDERS.

- REVIEW OF THE RIGHTS ASSURANCE SYSTEM
  SENATOR PRESLEY HAS REQUESTED THAT SR9 TAKE A LOOK AT THIS ISSUE. THE COUNCIL CONCURS THAT THERE IS A NEED FOR INDEPENDENT ADVOCACY ASSISTANCE AND TRAINING FOR BOTH FAMILIES AND CONSUMERS. WE PROVIDED TO THE SENATOR SEVERAL RECOMMENDATIONS THAT HE COULD CONSIDER. THEY INCLUDE BUT ARE NOT LIMITED TO THE FOLLOWING:

- PLACEMENT OF CLIENTS RIGHTS ADVOCATES IN PAI OR AREA BOARDS VERSUS THE REGIONAL CENTER.
- PLACEMENT OF OMBUDSMAN IN REGIONAL CENTERS THAT WOULD FUNCTION AS PATIENT LIAISON VERSUS LEGAL ADVOCATES.

- REQUIRING REGIONAL CENTERS TO NOTIFY A CLIENTS RIGHTS ADVOCATE OF ALL CHANGES IN A CLIENTS PROGRAM PLAN.
- CONVENING OF ADVOCACY TRAINING FOR FAMILY MEMBERS AND PRIMARY CONSUMERS: INFORMATION OF THEIR RIGHTS AND HOW TO ACCESS THE RIGHTS ASSURANCE SYSTEM WOULD BE PROVIDED.

- REVIEW OF THE REGIONAL CENTER SYSTEM

  ITS BECOME CLEAR THAT THERE IS DISSATISFACTION WITH THE EXISTING REGIONAL CENTER SYSTEM. SEVERAL ISSUES NEED TO BE ADDRESSED. IS THE SYSTEM OUTMODED INLIGHT OF THE INCREASED POPULATION IT IS SERVING? ARE PROVISIONS OF THE LANTERMAN ACT FOLLOWED (PROGRAM REVIEW, QUALITY ASSURANCE)? WHAT ARE THE CONSTRAINTS CURRENTLY FACING REGIONAL CENTERS? ARE THERE TARGET GROUPS ELIGIBLE FOR SERVICE (SUCH AS PRADER WILLI SYNDROME/AIDS BABIES) THAT ARE NOT RECEIVING SERVICES AND WHY NOT. ARE ELIGIBILITY DETERMINATIONS MADE IN A CONSISTENT MANNER STATEWIDE? ARE THERE SERVICES THAT SHOULD BE PROVIDED BY THE CENTERS THAT ARE CURRENTLY NOT AVAILABLE?

AS WAS MENTIONED EARLIER. STATE COUNCILS HAVE BEEN FEDERALLY MANDATED TO CONDUCT A COMPREHENSIVE REVIEW OF THE EXTENT, SCOPE, AND EFFECTIVENESS OF, AND ELIGIBILITY FOR , SERVICES PROVIDED TO PEOPLE WITH DEVELOPMENTAL DISABILITIES. THE STATE COUNCIL INITIATED A ONE-YEAR CONTRACT WITH THE BERKELEY PLANNING ASSOCIATES TO DO THIS STUDY. THE COUNCIL IS TO REPORT ITS FINDINGS TO THE GOVERNOR BY JANUARY 1, 1990. IN ADDITION, THE RESULTS OF THE STUDY WILL BE COMPILED WITH OTHER STATES IN THE FORM OF A NATIONAL REPORT TO BE SUBMITTED TO CONGRESS. THIS REPORT WILL DESCRIBE THE CURRENT STATE OF THE NATION WITH REGARD TO SERVICES AVAILABLE TO PEOPLE WITH DEVELOPMENTAL DISABILITIES. ADDITIONALLY, IT WILL SERVE AS A GUIDE FOR STATE AND FEDERAL POLICY-MAKERS TO IMPROVE AND ENHANCE THE LIVES OF PERSONS WITH DEVELOPMENTAL DISABILITIES THROUGH FUTURE POLICY DEVELOPMENT.

A DRAFT REPORT HAS BEEN DEVELOPED BY BERKELEY PLANNING ASSOCIATES DELINEATING SOME OF ITS RESEARCH FINDINGS. THE REPORT WILL GO OUT FOR PUBLIC COMMENT THIS SUMMER. IT IS ANTICIPATED THAT THE REPORT WILL BE SUBMITTED TO THE COUNCIL FOR ACCEPTANCE SOMETIME LATER THIS YEAR. AT THAT TIME WE WOULD LIKE TO SHARE THE REPORT WITH THE SUBCOMMITTEE AND THE SENATE OFFICE OF RESEARCH.

I WOULD LIKE TO SHARE SOME PRELIMINARY FINDINGS THAT HAVE IMPORTANT POLICY IMPLICATIONS.

- SHORTAGE OF RESIDENTIAL SERVICES

  THERE IS A NEED FOR NEW RESIDENTIAL RESOURCES NOT TARGETED FOR PERSONS LEAVING DEVELOPMENTAL CENTERS. FACTORS LEADING TO THE INCREASED DEMAND FOR RESIDENTIAL SERVICES ARE: INCREASES

IN CALIFORNIA POPULATION DUE TO BOTH BIRTHS AND MIGRATION: THE OVERALL AGING OF THE POPULATION (INCLUDING CLIENTS AND THEIR PARENTS). AND THE EFFECTS OF MEDICAL TECHNOLOGY IN SAVING LIVES. TWO GROUPS IN PARTICULAR ARE IN NEED OF THESE SERVICES: THOSE THAT ENTER THE SYSTEM FOR THE FIRST TIME. INCLUDING NEWBORNS. IMMIGRANTS. AND PERSONS PREVIOUSLY CARED FOR PRIVATELY AND THOSE THAT ARE NOW PART OF THE SYSTEM BUT REQUIRE NEW OUT-OF-HOME RESIDENTIAL CARE, INCLUDING PERSONS THAT ARE NOW RESIDING IN THEIR PARENTS' HOMES. AND THOSE IN OTHER KINDS OF RESIDENTIAL ARRANGEMENTS.
DDS HAS TAKEN STEPS TO ADDRESS THIS SHORTAGE SUCH AS TARGETING PDF FUNDS TOWARD RESIDENTIAL SERVICES. IMPLEMENTING COMMUNITY PLACEMENT PLAN ETC. HOWEVER THESE STEPS ARE PRIMARILY DESIGNED TO CREATE NEW RESOURCES FOR PERSONS LEAVING DEVELOPMENTAL CENTERS.

- NEED FOR MORE INDEPENDENT LIVING SERVICES

CURRENTLY THE STATE SPENDS VERY LITTLE ON INDEPENDENT LIVING SERVICES: ABOUT 9.5 MILLION OR 3.6% OF TOTAL REGIONAL CENTER PURCHASE OF SERVICES. NO STANDARDS OR GUIDELINES EXIST FOR THE PROVISION OF THESE SERVICES. INDEPENDENT LIVING HAS NOT BEEN CONSIDERED BY THE STATE AS A VIABLE ALTERNATIVE TO MITIGATE THE RESIDENTIAL SERVICES SHORTAGE. IT IS ESTIMATED THAT OVER 20000 PERSONS ARE CAPABLE OF SOME FORM OF INDEPENDENT LIVING. MORE RESEARCH SHOULD BE DONE TO DETERMINE WHICH KINDS OF INDEPENDENT LIVING SERVICES ARE MOST EFFECTIVE FOR VARIOUS GROUPS OF CLIENTS.

- CLIENTS WITH A DUAL DIAGNOSIS OF DEVELOPMENTAL DISABILITY AND MENTAL ILLNESS FACE A NUMBER OF PROBLEMS IN THE MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES SERVICE SYSTEM.

IN MANY INSTANCES ONE OF THOSE DIAGNOSES DISQUALIFIES THE CLIENT FROM SERVICES ON THE BASIS OF THE OTHER I.E. PROGRAMS FOR THE MENTALLY ILL DO NOT GENERALLY SERVE PERSONS WITH DEVELOPMENTAL DISABILITIES AND VICE-VERSA.
THERE IS NO CONSENSUS ON THE PART OF THE STATE PROGRAMS ABOUT WHICH AGENCY IS RESPONSIBLE FOR TREATMENT OF THE DUALLY DIAGNOSED CLIENT.

OTHER SPECIFIC PROBLEMS INCLUDE:

- THERE ARE LITTLE OR NO COMMUNITY PLACEMENT OPTIONS FOR THESE PERSONS: THERE ARE VERY LIMITED OPTIONS FOR DAY PROGRAMS.

- LACK OF TRAINING OF MENTAL HEALTH PROFESSIONALS REGARDING TREATMENT ISSUES FOR THIS POPULATION. AS A RESULT. DEVELOPMENTALLY DISABLED CLIENTS WITH MEDICATIONS SPECIFIC TO A DISABILITY (SUCH AS SEIZURE MEDICATIONS) MAY BE GIVEN OTHER

MEDICATIONS THAT ARE NOT RECOMMENDED FOR USE BY PEOPLE WITH DEVELOPMENTAL DISABILITIES.

- THE LACK OF SERVICES AND COORDINATION IS ESPECIALLY TROUBLING BECAUSE THIS GROUP IS LEAST LIKELY TO BE ABLE TO ADVOCATE FOR THEMSELVES. WHILE MODEL APPROACHES EXIST, LACK OF FUNDING HAS PREVENTED THEM FROM BEING PLACED THROUGHOUT THE STATE.

- CIVIL RIGHTS

THREE KEY ISSUES IN SECURING CIVIL RIGHTS WERE IDENTIFIED:

- THE NEED FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES TO DEVELOP EFFECTIVE SELF-ADVOCACY AND GROUP-ADVOCACY SKILLS;
- THE NEED FOR ACCESS TO PROFESSIONAL ADVOCATES IN CASES WHERE ADDITIONAL PROTECTION OF RIGHTS IS WARRANTED, ESPECIALLY WHERE THE LEGAL SYSTEM IS INVOLVED AND CLIENTS OFTEN HAVE TO WAIT TO BEGIN AN APPEAL PROCESSES UNTIL A PROFESSIONAL ADVOCATE IS AVAILABLE TO ASSIST THEM.
- THE RIGHT TO HAVE AND RAISE ONES OWN CHILDREN AND THE NEED FOR TRAINING AND SUPPORT SERVICES TO MINIMIZE THE NEED FOR REMOVING CHILDREN FROM THEIR DEVELOPMENTALLY DISABLED PARENTS.

- FAMILY SUPPORT

A MAJOR PREMISE OF THE DEVELOPMENTAL DISABILITIES SERVICE SYSTEM IS THAT CHILDREN WITH DEVELOPMENTAL DISABILITIES SHOULD BE GIVEN THE OPPORTUNITY TO REMAIN IN THEIR PARENTAL HOMES UNTIL AT LEAST AGE 18, AS IS TRUE OF THE MAJORITY OF NON-DISABLED CHILDREN. DDS ESTIMATES THAT THE NUMBER OF REGIONAL CENTER CLIENTS LIVING IN THEIR OWN HOMES WILL INCREASE FROM 48000 PRESENTLY TO 62000 BY FY 1992-93. ALL OF THESE REPRESENT FAMILIES WITH A POTENTIAL NEED FOR SUPPORT SERVICES IN ORDER TO MAINTAIN A HEALTHY AND SAFE HOME ENVIRONMENT FOR THEIR CHILDREN WITH DEVELOPMENTAL DISABILITIES. THE NUMBERS ARE EVEN LARGER IF ONE CONSIDERS THE NEEDS OF FAMILIES WITH CHILDREN WHO MEET THE FEDERAL DEFINITION.

CURRENTLY A TOTAL OF 159000 EXCEPTIONAL NEEDS CHILDREN HAVE EMPLOYED MOTHERS. ABOUT ONE QUARTER OF THESE CHILDREN ARE AGE FIVE OR YOUNGER. AT LEAST 80000 OF THE EMPLOYED MOTHERS OF EXCEPTIONAL NEEDS CHILDREN NEED CHILD CARE AT ANY GIVEN TIME. THE CURRENT LEVEL OF DIRECT STATE SUPPORT COVERS FEWER THAN 1000 OF THE EXCEPTIONAL NEEDS CHILDREN REQUIRING CHILD CARE SERVICES.

ISSUES REGARDING CHILD CARE INCLUDE THE FOLLOWING:

- FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES WHO ARE NOT INCLUDED IN THE STATE DEFINITION, ACCESS TO CASE MANAGEMENT SERVICES IS PARTICULARLY LIMITED.

- LACK OF DAY CARE PROVIDERS WHO ARE WILLING TO SERVE CHILDREN WITH SPECIAL NEEDS.
- LACK OF APPROPRIATE TRAINING OF DAY CARE PROVIDERS REGARDING CHILDREN WITH DEVELOPMENTAL DISABILITIES.
- CHILDREN WITH DISABILITIES OR EXCEPTIONAL NEEDS ARE CURRENTLY UNDER-REPRESENTED IN BOTH STATE SUPPORTED AND PRIVATELY FUNDED CHILD CARE THROUGHOUT CALIFORNIA. CHILD CARE SLOTS ARE LIMITED AND LENGTHY WAITING LISTS ARE COMMON. LACK OF CHILD CARE FOR AN EXCEPTIONAL NEEDS CHILD CAN PREVENT A PARENT FROM SEEKING EMPLOYMENT.

- RESPITE CARE SERVICES ARE NOT AVAILABLE TO FAMILIES WITH CHILDREN WHO DO NOT MEET THE REGIONAL CENTER ELIGIBILITY CRITERIA; ESPECIALLY THOSE FAMILIES WITH CHILDREN WHO ARE MEDICALLY FRAGILE OR TECHNOLOGY DEPENDENT. THIS HAS BEEN IDENTIFIED AS A MAJOR SERVICE GAP FOR MAY FAMILIES WITH CHILDREN WHO MEET THE FEDERAL DEFINITION OF DEVELOPMENTAL DISABILITIES.

LAST BUT NOT LEAST, THE STUDY FOUND, THAT ACROSS ALL TYPES OF INDIVIDUAL AND FAMILY SUPPORT NEEDS, THE BIGGEST ISSUE IS ONE OF INSUFFICIENT RESOURCES. IN EVERY PROGRAM THERE EXISTS FINANCIAL BARRIERS TO SERVING ALL POTENTIALLY ELIGIBLE PERSONS IN NEED OR TO PROVIDING THEM WITH THE FULL RANGE AND EXTENT OF SERVICES NEEDED.

I THANK YOU FOR THE OPPORTUNITY TO SHARE THIS INFORMATION WITH YOU, THE LEGISLATURE. THE COUNCIL LOOKS FORWARD TO ONGOING PARTICIPATION IN THE SR9 STUDY.

SR 9: AN OVERVIEW OF THE STUDY OF THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICES ACT

JOINT HEARING OF
THE SENATE SUBCOMMITTEE ON
MENTAL HEALTH, DEVELOPMENTAL DISABILITIES AND GENETICS DISEASES;
THE SUBCOMMITTEE ON THE RIGHTS OF THE DISABLED; AND
THE ASSEMBLY SUBCOMMITTEE ON
MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES

June 16, 1989
State Capitol, Sacramento, California

I am Dr. Raymond M. Peterson, Executive Director of the San Diego Regional Center for the Developmentally Disabled, a position that I have held since 1969. I am testifying on behalf of the Association for Regional Agencies (ARCA) and have been asked to provide a historic perspective of the Regional Center System as it developed within the Lanterman Act.

In 1963 a Study Commission on Mental Retardation was established and presented in 1965 a report to the Governor and the Legislature entitled "The Undeveloped Resource . . A Plan for the Mentally Retarded in California". This report recommended the establishment of Regional Diagnostic and Counseling Centers throughout California. This proposal was in accord with the recommendation of the Assembly Ways and Means Interim Subcommittee on Mental Health Services in a report the same year, entitled "A Redefinition of State Responsibility for California's Mentally Retarded". After receipt of these reports the Legislature acted in 1965 to change the state government's responsibility for providing mental retardation services in California. Assembly Bill 691 (Waldie) of the 1965 regular session, created the Regional Diagnostic Centers for the

Mentally Retarded and initiated a new approach for caring for persons with mental retardation. A commitment was made to develop a state-assisted, community-oriented system of services in lieu of constructing additional state hospital facilities. Implementation of the legislation followed with two pilot Regional Centers opened in 1966 in Los Angeles to serve Los Angeles county, and in San Francisco to serve five Bay area counties (Alameda, Contra Costa, Marin, San Francisco and San Mateo). Funds for an additional four Centers were included in the 1968/69 State Budget for centers to be located in San Diego, Sacramento, San Jose and Fresno.

In 1968 the Assembly authorized an interim study of the role and responsibilities of the state hospitals and of community programs for the care of persons who are mentally retarded. After a six month study by the Assembly Office of Research and staff of the Assembly Ways and Means Committee the legislature received a report in March 1969 entitled "A Proposal to Reorganize California's Fragmented System of Services for the Mentally Retarded". Seven problems were identified as existing in the system of services for the mentally retarded: 1) the lack of a single agency in most areas of the state vested with the responsibility and with funds and authority to assure the provision of needed services; 2) a lack of funds for the purchase of services; 3) a lack of essential services in many parts of the state; 4) an excessive reliance on the state hospital system; 5) a lack of effective coordination and planning at regional and state levels; 6) a wide disparity in fees imposed on parents of retarded children, depending on where the child is receiving service and 7) California is not taking full advantage of all sources of federal funds available for services. Many of the proposed solutions in this report were passed into law as a part of AB 225 known as the Lanterman Mental Retardation Services Act of 1969.

In 1971 The Lanterman Mental Retardation Services Act was amended to include other developmental disabilities, such as cerebral palsy, epilepsy, and autism and divided the state into thirteen planning areas. Legislation in 1973 and in 1977 updated the Act as now found in Welfare and Institutions Code, Division 4.5, known and cited as the Lanterman Developmental Disabilities Services Act. In addition to serving persons suspected or known to have a developmental disability, eligibility for Regional Center services has been expanded to include any person believed to have a high risk of parenting a developmentally disabled infant, and in 1982 was expanded to include infants at risk of becoming developmentally disabled.

California's Regional Center system serves persons with developmental disabilities under a legislative mandate as defined in Welfare and Institutions Code, Section 4501 et seq., "The State of California accepts a responsibility for its developmentally disabled citizens and an obligation to them which it must discharge. Affecting hundreds of thousands of children and adults directly, and having an important impact on the lives of their families, neighbors and whole communities, developmental disabilities presents social, medical, economic and legal problems of extreme importance. The complexities of providing services to developmentally disabled persons require the coordinated services of many state departments and community agencies to ensure that no gaps occur in communication or provision of services. Services should be planned and provided as part of a continuum. Services should be available to enable persons with developmental disabilities to approximate the pattern of everyday living available to nondisabled people of the same age."

Furthermore, Welfare and Institutions Code, Section 4502 declares that "Persons with developmental disabilities have the same legal rights and responsibilities guaranteed all other individuals by the Federal Consititution and laws and the Constitution and laws of the State of California." The Regional Centers serve as a focal point within the community, through which a person with a developmental disability and his or her family can obtain services and/or be referred to community resources in the fields of health, welfare and education. The Regional Centers' philosophy is that each person should have an opportunity to participate in everyday living experiences that permit development to their fullest potential with access to the facilities and services best suited to them throughout their lifetime.

The Legislature has determined that the service provided to individuals and their families by Regional Centers is of such a special and unique nature that it cannot be satisfactorily provided by state agencies. Therefore, the Regional Centers are operated and administrated by private nonprofit community agencies with a Board of Directors representing the local community determining local policies and priorities. A minimum of one-third of the members of the Board must be primary consumers or their parents or legal guardians.

The Lanterman Developmental Disabilities Services Act defines the manner of contracting, the composition of the governing boards, and Regional Center responsibilities, including intake, assessment, and development of the Individual Program Plan (IPP). Regional Centers provide case coordination, evaluation, consultation and counseling, however provide no other direct client services. Services for Regional Center clients may be purchased from appropriate community providers as identified in the Regional Center clients' Individual Program Plan. Advocacy, public awareness, resource development are major responsibilities of the Regional Centers.

The Regional Center System and the population served have changed significantly since 1966, and the initial pilot projects in Los Angeles and the San Francisco Bay area. Prior to the implementation of the Regional Center concept, a family's first contact with professional help usually came as a result of a crisis situation often when a child was not allowed to enroll in a public school or when the parents could no longer provide the care that their child needed. The Lanterman Act provides timelines for assessment so that there are no waiting lists for persons entering the system. The California Supreme Court ruled in 1985 that eligible clients cannot be placed on waiting lists for funding services listed on the IPP if the service is appropriate and available and is not the responsibility of a generic agency.

There are now 21 Regional Centers serving residents in all of the 58 counties in California. Seven Regional Centers serve Los Angeles County and two Regional Centers now serve residents in the five Bay area counties. The Regional Centers serve nearly 100,000 persons each month with an active community caseload as of June 6, 1989 of 86,338. On June 14, 1989 there were 6,714 persons in State Developmental Centers compared to a population of 13,355 in June 1968. Developmental Center populations have changed throughout the years, with an increasing percentage of residents with severe disabilities.

Regional centers, individually and through ARCA, are working to address challenges of the present and the future. Many of the challenges are due to growing demands for services and limited resources. We are dedicated to meeting the needs of Regional Center clients and assuring quality of care, while continuing to foster independence and community integration. The Regional Centers are serving increasing numbers of children and adults with complex medical and behavioral problems. Community resources and funding for these services have not kept pace with the need. The technology-dependent child, the infant infected with the AIDS virus, and the infant who has been exposed to street drugs in utero are additional problems that are being addressed.

We appreciate the opportunity to participate in these hearings today and look forward to continuing to work with you in this study of the Lanterman Act to improve and strengthen the service delivery system for persons with developmental disabilities in California.

ASSOCIATION OF REGIONAL CENTER AGENCIES
428 J Street, Suite 410
Sacramento, California 95814
916.446.7961

ARCA

REGIONAL CENTERS:

ALTA CALIFORNIA
Sacramento

CENTRAL VALLEY
Fresno

DEVELOPMENTAL DISABILITIES
Orange

EAST BAY
Oakland

EASTERN LOS ANGELES
Los Angeles

FAR NORTHERN
Redding

GOLDEN GATE
San Francisco

HARBOR
Torrance

INLAND
San Bernardino

KERN
Bakersfield

LANTERMAN
Los Angeles

NORTH BAY
Napa

NORTH LOS ANGELES COUNTY
Panorama City

REDWOOD COAST
Eureka

SAN ANDREAS
Campbell

SAN DIEGO
San Diego/Imperial

SAN GABRIEL/POMONA
West Covina

SOUTH CENTRAL LOS ANGELES
Los Angeles

TRI-COUNTIES
Santa Barbara

VALLEY MOUNTAIN
Stockton

WESTSIDE
Culver City

TESTIMONY OF THE ASSOCIATION OF REGIONAL CENTER AGENCIES

TO THE

JOINT HEARING OF THE
SENATE SUBCOMMITTEE ON MENTAL HEALTH, DEVELOPMENTAL DISABILITIES AND GENETIC DISEASES;
THE SUBCOMMITTEE ON THE RIGHTS OF THE DISABLED AND THE
ASSEMBLY SUBCOMMITTEE ON MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES

JUNE 16, 1989

BY

JIM MCDERMOTT
PRESIDENT, BOARD OF DIRECTORS

LANTERMAN REGIONAL CENTER
LOS ANGELES, CA

GOOD AFTERNOON, HONORABLE SENATOR AND ASSEMBLYMEMBERS, HEARING PARTICIPANTS. MY NAME IS JIM MC DERMOTT. I AM THE PRESIDENT OF THE LANTERMAN REGIONAL CENTER IN LOS ANGELES, BOARD MEMBER DELEGATE OF THE ASSOCIATION OF REGIONAL CENTER AGENCIES (ARCA), AND A MEMBER OF THE ARCA STRATEGIC PLANNING COMMITTEE. THAT COMMITTEE HAS BEEN ASSIGNED THE TASK OF COORDINATING THE RESPONSE OF THE ASSOCIATION TO THESE HEARINGS.

WE WISH TO THANK YOU FOR YOUR LEADERSHIP IN REVIEWING THE LANTERMAN ACT AND ITS IMPLEMENTATION. AS YOU HAVE HEARD FROM DR. PETERSON, WE SUPPORT THIS TIMELY REVIEW AND ARE PREPARED TO BE FULL PARTICIPANTS IN YOUR EVALUATION.

AS YOU REQUESTED, DR. PETERSON HAS PROVIDED A HISTORICAL OVERVIEW OF THE LANTERMAN ACT AS IT RELATED TO THE REGIONAL CENTER PORTION OF THE SYSTEM. MY ROLE IS TO SUGGEST SOME REOCCURRING ISSUES THAT THIS COMMITTEE MAY WISH TO CONSIDER IN YOUR REVIEW.

I WOULD THINK THAT ASSEMBLYMEMBER LANTERMAN, WHEN HE DEVELOPED THE REGIONAL CENTER CONCEPT, NEVER IMAGINED THAT WITHIN 20 YEARS, THE SYSTEM WOULD BE SERVING MORE THAN 90,000 CLIENTS, AND THE STATE WOULD BE INVESTING A HALF BILLION DOLLARS ANNUALLY FOR THEIR CARE.

IT WOULD HAVE BEEN HARD TO IMAGINE THE AFFECTS OF TOXIC POLLUTION AND ITS CONTRIBUTION TO BIRTH DEFECTS, OR TECHNOLOGY DEPENDENT INFANTS WHO ARE LIVING LONGER THAN ANYONE COULD HAVE IMAGINED BUT WHO FREQUENTLY NEED SPECIALIZED CARE, OR BABIES WITH AIDS, OR INFANTS WITH FETAL ALCOHOL SYNDROME OR THE CRACK BABIES AND DRUG AND SUBSTANCE ABUSE DEPENDENT BABIES. WITHOUT PRENATAL CARE AVAILABLE TO WOMEN OF ALL INCOMES, WITHOUT EDUCATION TO PROSPECTIVE PARENTS AS TO HOW TO REDUCE THE RISK OF PARENTING A CHILD WITH DISABILITIES, THE NUMBER OF CLIENTS ELIGIBLE FOR THE REGIONAL CENTER SYSTEM WILL CONTINUE TO GROW. AND YOU AS LEGISLATORS WILL BE LOOKED AT TO DEVELOP THE PUBLIC POLICY PRIORITIES WHICH WILL DETERMINE HOW THE STATE WILL RESPOND TO THESE SPECIAL CITIZENS.

THE REGIONAL CENTER SYSTEM, WITH SOLID LEADERSHIP FROM THE STATE, CAN AND WILL RESPOND, WITH YOUR CONTINUED SUPPORT. WE SEE THIS HEARING AS PREPARATION FOR THAT FUTURE RESPONSE.

TWENTY-FIVE YEARS AGO THE STATE OF CALIFORNIA MADE A BASIC COMMITMENT TO SERVING THE DEVELOPMENTALLY DISABLED AND THEIR FAMILIES THROUGH A VOLUNTARY SERVICE SYSTEM. THIS IDEA IS BASED ON TWO PREMISES:

1. THE DEVELOPMENTALLY DISABLED WILL BE SERVED BEST BY AIMING FOR THE GOAL OF INTEGRATING THEM INTO SOCIETY.

2. THE BEST MEANS OF ACCOMPLISHING THIS GOAL IS THROUGH A RANGE OF SERVICES WHETHER COMMUNITY OR INSTITUTIONALLY BASED, THAT ARE DESIGNED TO MEET THE INDIVIDUAL, UNIQUE NEEDS.

THE ISSUES THAT THESE HEARINGS MUST ADDRESS ARE TWO FOLD:

1. IS THIS VISION AND COMMITMENT, SO FORCEFULLY ADVOCATED BY FRANK LANTERMAN, STILL VALID TODAY? AND IF SO,

2. IS THE PRESENT SYSTEM, BOTH AT THE STATE AND COMMUNITY LEVEL, SUCCESSFUL IN MAKING THAT VISION A REALITY?

AS WE JOIN YOU IN THIS REVIEW, WE HAVE BEEN ASKING OURSELVES MANY QUESTIONS. WE ANTICIPATE THAT THE ANSWERS TO THOSE QUESTIONS WILL COME FROM THE PUBLIC DEBATE OF THESE HEARINGS.

WHAT SHOULD THE ROLE OF THE REGIONAL CENTER BE? CLINICAL EVALUATOR? BROKER OF SERVICES? ADVOCATE FOR THE CLIENT? ADVOCATE FOR THE FAMILY? CASE MANAGEMENT OR CARE -TAKER? GUARDIAN OF PUBLIC FUNDS? LEADER IN DEVELOPING INNOVATIVE SERVICES? MOTIVATOR OF THE STATE TO SUPPORT THE CLIENTS NEEDS?

CAN WE AVOID THE BUREAUCRATIZATION OF THE REGIONAL CENTERS? CAN WE CONVINCE A FRUGAL ADMINISTRATION THAT LARGER REGIONAL CENTERS ARE NOT NECESSARILY BETTER REGIONAL CENTERS?

CAN WE INSURE THAT REGIONAL CENTERS REPRESENT THEIR COMMUNITIES? IN THEIR BOARD OF DIRECTORS? STAFF? AND THE POLICIES THEY SET? CAN WE PROVIDE THAT REGIONAL CENTER POLICIES REFLECT THE COMMUNITIES STANDARDS?

CAN WE SUPPORT CONSUMERS IN THEIR EFFORTS TO HAVE MEANINGFUL INPUT INTO THEIR SERVICE SYSTEM?

CAN WE AS REGIONAL CENTERS CONFRONT OUR OWN INTERNAL WEAKNESSES BEFORE FRUSTRATION LEADS TO A LEGISLATIVE SOLUTION THAT MAY BE MORE ONEROUS AND RESTRICTIVE THAN THE PROBLEM WOULD NECESSITATE?

WE RECOGNIZE THAT THIS LEGISLATURE IS RIGHTFULLY CONCERNED ABOUT THE FUTURE COSTS THAT CAN BE PROJECTED FOR THIS SYSTEM. BUT RATHER THAN ACKNOWLEDGE THE STATE'S MYOPIA TO THE ENVIRONMENTAL AND SOCIETAL FACTORS THAT WE BELIEVE CONTRIBUTE TO THE INCREASE IN THE NUMBER OF CLIENTS WE SERVE, INSTEAD, WE IN THE SERVICE SYSTEM ARE MADE TO FEEL AS IF IT IS OUR FAULT THAT WE CANNOT SERVE MORE COMPLEX AND NEEDY CLIENTS ON LESS MONEY. <u>AND</u> IT IS LESS MONEY PER CLIENT WHEN YOU ACCOUNT FOR THE INFLATIONARY FACTORS OF THE ACTUAL WORTH OF THOSE DOLLARS.

WILL A MEANINGFUL COMMITMENT BE MADE TO FUND THE SYSTEM ADEQUATELY, PROVIDING A DECENT WAGE TO THE DIRECT CARE GIVERS AND SUPPORT AND TRAINING TO ASSIST IN RETAINING QUALIFIED WORKERS?

CAN WE AS THE REGIONAL CENTER SYSTEM CONFRONT AND DESTROY THE PERCEPTION THAT REGIONAL CENTERS ARE EXTRAVAGANT IN THEIR EXPENDITURES OF OPERATIONS OR PURCHASE OF SERVICE FUNDING? CAN WE HELP YOU UNDERSTAND THE CONTRADICTION OF AN OPEN-ENDED ENTITLEMENT PROGRAM AND LIMITED STATE FUNDING FOR THOSE ENTITLEMENTS? CAN REGIONAL CENTERS LIVE WITHIN THEIR PURCHASE OF SERVICES BUDGET? IS THE ALLOCATION OF THAT BUDGET APPROPRIATE AND ADEQUATE? ARE PROJECTIONS OF COSTS BASED ON HISTORICAL

DATA OR DOES THE STATE PASSIVELY MANIPULATE THE IMPLEMENTATION OF THE LANTERMAN ACT BY THE LESS THAN ADEQUATE APPROPRIATIONS OF FUNDS? IS THIS A VIOLATION OF THE ARC DECISION?

WHAT SHOULD EMPLOYEES IN OUR SYSTEM EARN? SHOULD REGIONAL CENTER EMPLOYEES EARN AS MUCH AS STATE DEVELOPMENTAL CENTER EMPLOYEES? MOST DO NOT. SHOULD DIRECT CARE STAFF WITH SIMILAR QUALIFICATIONS AND RESPONSIBILITIES EARN AS MUCH AS REGIONAL CENTER STAFF? MOST DO NOT. AS IN OTHER INDUSTRIES, SHOULD THE STANDARD OF REIMBURSEMENT BE SET BY THE MARKET VALUE OF THOSE SKILLS, EXPERTISE AND RESPONSIBILITY IN THAT COMMUNITIES' "OPEN EMPLOYMENT MARKET"? THAT IS WHERE WE COMPETE FOR STAFF.

REGIONAL CENTERS ARE FUNDED FOR STAFF SALARIES ACCORDING TO THE "CORE STAFFING FORMULA". THIS FORMULA HAS BECOME NOTHING MORE THAN AN ALLOCATION METHODOLOGY AND HAS LITTLE RELATIONSHIP TO WHAT IS NEEDED TO PROVIDE THE SERVICES OF THE REGIONAL CENTER. CAN WE DEVELOP A MEANINGFUL FORMULA OR ANOTHER TOOL TO PROVIDE ADEQUATE STAFF THAT REFLECT ACTUAL WORKLOAD RESPONSIBILITIES OF THE REGIONAL CENTER AND WHICH WILL EXPAND AS THOSE RESPONSIBILITIES AND TASKS EXPAND?

SHOULD REGIONAL CENTERS CONTINUE TO PROVIDE SERVICES WITHOUT REGARD TO THE INCOME ELIGIBILITY OF THE FAMILY? CAN THERE BE A CONSISTENT MEANS TEST FOR ALL SOCIAL SERVICES IN THE STATE? SHOULD FEDERAL DOLLARS BE USED TO SUPPLANT STATE DOLLARS FOR SERVICES? SHOULD FEDERAL DOLLARS BE USED FOR STATE ENTITLEMENTS OR TO ENHANCE THE SERVICE SYSTEM? HAVE WE IDENTIFIED THE REAL COSTS OF FEDERAL FUNDS, TO THE STATE, AND TO THE CLIENTS?

SHOULD REGIONAL CENTERS BE RUN AS STATE AGENCIES? ARE THE NEEDS OF THE CLIENT MORE LIKELY TO BE MET BY STATE EMPLOYEES FOLLOWING STATE STANDARDS? SHOULD EVERY REGIONAL CENTER HAVE CONSISTENT POLICIES FOR THE PURCHASING OF SERVICES OR IS IT APPROPRIATE, AS WITH MUNICIPALITIES, THAT STANDARDS AND ORDINANCES ARE SET TO RESPOND TO THE NEEDS OF THAT COMMUNITY?

WE ARE VERY CONCERNED WITH THE QUALITY OF SERVICES FUNDED BY THE REGIONAL CENTER. WE RECOGNIZE THE ENORMOUS INVESTMENT THAT IS NECESSARY TO MONITOR AND GUARANTEE A HIGH QUALITY OF LIFE FOR OUR CLIENTS. WILL THE STATE MAKE A COMMITMENT TO THE RESOURCES NECESSARY TO DEVELOP AND ADEQUATELY FUND PROGRAMS, PROVIDING FUNDS FOR MEANINGFUL TECHNICAL ASSISTANCE AND PROGRAM DEVELOPMENT,

COMPETITIVE WAGES AND A FAIR PROFIT MARGIN FOR THE INVESTMENTS MADE?

WE KNOW THAT POOR QUALITY PROGRAMS EXIST. WE ALSO KNOW THAT THE INCREASED FUNDS AVAILABLE IN PAST YEARS TO THE REGIONAL CENTER SYSTEM ONLY WERE ADEQUATE TO FUND THE "GROWTH" IN OUR SYSTEM AND WERE NOT ADEQUATE TO EVEN BEGIN TO FUND NEW RESOURCE DEVELOPMENT FOR CLIENTS ALREADY IN THE SYSTEM. WITHOUT THE ABILITY TO DEVELOP BETTER PROGRAMS AND OR PROVIDE ASSISTANCE TO PROVIDERS OF MARGINAL CARE, WE WILL NOT BE ABLE TO CORRECT THE INADEQUACIES OF THE DIRECT CARE SYSTEM.

WHY ARE VENDORS SO UNDERPAID? WHY DO WE FUND THEM JUST ENOUGH TO EXIST? JUST ENOUGH NOT TO QUIT AND THEN KEEP DANGLING A PROMISE OF BETTER TIMES AHEAD, TIMES WHERE FUNDING NEVER QUITE KEEPS UP WITH INFLATION. WE HAVE HEARD THAT THE POLICY IS TO KEEP PROVIDERS "QUIET BUT NOT HAPPY". CAN WE TOLERATE SUCH A POLICY WHEN THE LIVES OF VULNERABLE PEOPLE ARE AT STAKE?

WHAT ARE THE TRUE COSTS OF THOSE SERVICES BE AND WILL THE STATE COMMIT TO THOSE COSTS? HAVE WE DEVELOPED A SYSTEM THAT IS "LEAST RESTRICTIVE" FOR OUR CLIENTS?

ARE WE FOSTERING THEIR DEPENDENCE ON US IN INAPPROPRIATE WAYS? HAVE WE HELPED THEM BECOME INDEPENDENT AND LEAD PRODUCTIVE MEANINGFUL LIVES? ARE WE ABLE TO LISTEN TO CLIENTS, APPRECIATE THEIR ABILITIES? AND SUPPORT THEIR CHOICES? OR DO WE FALL PREY TO PATERNALISTIC ATTITUDES THAT INHIBIT PEOPLE'S GROWTH?

HAVE WE MADE A COMMITMENT TO SUPPORTING FAMILIES WHO CHOOSE TO KEEP THEIR SON OR DAUGHTER WITH A DEVELOPMENTAL DISABILITY AT HOME? WHEN WE VIEW THE AMOUNT OF RESOURCES THAT ARE USED IN COMMUNITY PLACEMENTS AND THE MUCH FEWER DOLLARS THAT ARE SPENT TO MAINTAIN THE FAMILY, WE ARE CONCERNED WITH THE PRIORITIES.

HOW SHOULD THE ADVOCACY SYSTEM THAT MAINTAINS THE CHECKS AND BALANCES OF THE SERVICE SYSTEM BE STRUCTURED? WHAT ARE THE COMPONENTS OF THAT SYSTEM AND WHAT ROLE DOES EACH PROGRAM PLAY TO GUARANTEE THAT THE LEGAL RIGHTS OF PERSONS WITH DEVELOPMENTAL DISABILITIES ARE NOT DENIED? HOW EFFECTIVE IS THE FEDERALLY FUNDED ADVOCACY SYSTEM? DOES IT HAVE THE AUTONOMY TO CARRY OUT ITS MISSION IN THE CURRENT ENVIRONMENT? WILL THE STRUCTURE BE EFFECTIVE IN THE FUTURE? WILL THE CURRENT STRUCTURE OF ALL OF OUR ADVOCACY COMPONENTS BE EFFECTIVE AS OUR CASELOADS DOUBLE IN THE NEXT TEN YEARS? HOW WILL SYSTEMIC ISSUES BE

ADDRESSED AND WHO WILL REPRESENT THE INTERESTS OF EACH COMPONENT OF OUR SYSTEM? MOST OF ALL, WHO WILL HAVE THE RESPONSIBILITY TO ENSURE THAT THE COMMITMENT OF EACH ADMINISTRATION TO THE CARE AND GROWTH OF PERSONS WITH DEVELOPMENTAL DISABILITIES IS MAINTAINED?

WHAT ROLE SHOULD DDS PLAY? IS THE MANAGEMENT OF DDS EFFECTIVE AT THE STATE AND LOCAL LEVELS? DO THEY HAVE THE UNDERSTANDING, EXPERIENCE, EXPERTISE AND BACKGROUND TO PROVIDE THE LEADERSHIP THAT IS NEEDED FOR THE NEXT TEN YEARS? WHAT IS THE ROLE OF THE STATE LICENSING AGENCIES AS THEY RELATE TO DDS? DO WE NEED COORDINATION BETWEEN THESE AGENCIES OR A MORE SPECIFIC DELEGATION OF RESPONSIBILITY TO ONE AGENCY?

THESE ARE THE BEGINNING QUESTIONS, THAT WE HOPE WILL LEAD US TO THE ISSUES, ISSUES WHICH YOU HAVE MADE A COMMITMENT TO REVIEW.

THE LANTERMAN ACT WAS BORN OUT OF AGGRESSIVE GRASSROOTS ACTIVITY BY PEOPLE WHO LIVED WITH AND SUFFERED IN A TOTALLY INADEQUATE AND CRUEL SYSTEM WHICH WAREHOUSED THE DEVELOPMENTALLY DISABLED. WE STAND READY TO WORK WITH AND THROUGH THE COMMUNITY TO ASSURE THAT THE PROMISE OF THE LANTERMAN ACT IS FULLY ACHIEVED. THANK YOU.

TESTIMONY PROVIDED TO THE SENATE SUBCOMMITTEE ON MENTAL HEALTH, DEVELOPMENTAL DISABILITIES AND GENETIC DISEASES, SUBCOMMITTEE ON THE RIGHTS OF THE DISABLED, AND THE ASSEMBLY SUBCOMMITTEE ON MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES IN RESPONSE TO SENATE RESOLUTION 9

JUNE 16, 1989

My name is Bethel Coffman and I am the parent of a woman with developmental disabilities as well as the Vice-Chairperson of the Organization of Area Boards on Developmental Disabilities and Chairperson of the OAB's Legislative Committee. I am also the Chairperson of Area Board XII on Developmental Disabilities serving Inyo, Mono, Riverside and San Bernadino counties and have been an active volunteer in the developmental services for 25 years. Because my involvement spans these many years, during which more than one Administration has been responsible for the operations of the developmental services system and this system, as well as its governing statutes, has experience many changes, I believe that primary and secondary consumers look forward to the opportunity to participate in this legislative review and commend you for launching this very ambitious effort.

Today, while I am here representing the Organization of Area Boards, not only will this testimony reflect the thoughts of the OAB but many of my own personal concerns as well. By way of background the Area Boards on Developmental Disabilities are mandated by Division 4.5 of the Welfare and Institutions Code to advocate for the legal, civil, and service rights of people with developmental disabilities. Funded by federal Developmental Disabilities Act funds, the Boards serve a broader functional definition of developmental disabilities than is represented by California's categorical definition, a disparity which denies some people with "like needs" access to California's system without justification except to suggest the State cannot afford to serve them. Undoubtedly, an issue which should be debated as part of the SR 9 process. In carrying out their advocacy role, the Boards pursue a variety of activities including monitoring publicly funded agencies; conducting public information programs; facilitating self advocacy groups to enhance the participation of primary consumers in the system's decision making processes; and conducting needs assessments and resource development activities. While these activities respond to the State mandates in the Lanterman Act, because of their federal funding, the Boards are required, via a Memorandum Of Understanding with the State Council on Developmental Disabilities to conduct activities in the Council's selected federal priority areas. For the most part, these two roles do not conflict, however the burden placed upon the Boards to respond to two separate mandating authorities was not envisioned by the Legislature nor adequately funded by the federal government. Because of this, during the SR 9 review, the OAB will be developing recommendations regarding the preferred future role and support mechanism for the Area Boards.

In response to the SR 9 process the OAB, mandated to resolve common problems, improve coordination, exchange information, and provide advice to the Legislature and others for the Area Boards, formed a Task Force charged with assisting the Boards and their communities in responding to and participating in the SR 9 review as well as identifying and addressing issues of statewide significance which need discussed during this process, including the role of Area Boards.

One of the activities of the Task Force has been to offer guidance to the Area Boards in the organization, coordination, and product development of the community workgroups requested by the three legislative committees conducting this review. Because of the vast size, complexity, and diversity of the State, the Task Force found it unreasonable to provide strict guidelines regarding the development of these community workgroups as Area Boards indicated a desire, in some cases, to utilize existing community groups to implement the process requested, however the Task Force has issued guidance to the Boards requesting that whatever community process is utilized it must ensure participation by a broad range of people in the system including but not limited to providers of services; primary and secondary consumers; advocacy groups; city, county and state agencies; federal definition service groups (i.e, regional resource centers); local legislators and legislative aides; regional centers (board and staff); vendor advisory committees; coordinating councils; education agencies; community advisory committees; State Developmental Centers, etc. In addition to ensuring broad representation, the Task Force cautioned that it must be equitable, not dominated by professionals and designed to encourage and enhance primary and secondary (parent) participation. Considerable concern exists regarding the effective involvement of people with developmental disabilities in this process with the conclusion that the Boards need to utilize self advocacy groups and others to achieve this goal in addition to the broader community workgroup process. As an example of this effort, Area Board IV serving Napa, Sonoma, and Solano counties has prepared a summary version of the Lanterman Act for consumers, a copy of which is attached to my written testimony, and is launching an effort to prepare a slide show on the service system. Both these tools are designed to be utilized when the Board visits day programs to explain the system and solicit consumer input into the SR 9 process. Other Boards are planning to use various techniques, designed to be responsive to their unique catchment area, to ensure primary consumer participation.

While the process for community input will vary depending upon the unique needs and desires of each area, the Boards have been requested to develop products which promote uniformity. Specifically short issue papers which describe the concern, provide some background on the issue, and suggest a method to solve the issue. Ideally, these will represent a consensus of the workgroup and provide the Legislature and others with concrete recommendations on which to debate proposed system refinements, if appropriate. With this uniformity, the Task Force hopes to identify common themes of interest and a variety of systemic recommendations to address the issues raised. Ideally, the work of all the community groups which employ this simple format for reporting can be cataloged by issue area to promote easy in understanding of the outstanding issues and multiple visions of how to achieve resolutions to these concerns.

While guidelines from the Task Force are designed to allow flexibility, discussions with the Boards have included suggested group processes which can be employed to identify and narrow the number of issues addressed to a reasonable number and mechanisms to achieve consensus on the recommendations resulting from this process. The Boards clearly identify themselves as facilitator and group participant with no expectations or plan to control the outcome of the process.

Another charge of the Task Force was to identify statewide issues of concern as an adjunct to the local community process. During a brainstorming session, the following issues were identified for further exploration. It should be noted that as an overall guide, the Task Force felt that the system functioning needs to be evaluated against its own goals of promoting independence, integration, and productivity with a outstanding priority of keeping families together in the community. Issues identified included:

a. consumer choice - does it exist and how can it be enhanced?
b. advocacy roles - who does what for whom, when?
c. resource development - who is responsible and where should the focus lay?
d. funding - availability and creativity
e. monitoring - enforcement power to improve system, who is responsible for quality assurance?
f. community placements - is the trend toward the medical model and if so, why?
g. eligibility - why are there inconsistencies throughout the State?
h. individual planning - is it outcome valued?
i. consumer participation - how does the system promote informed participation?
j. family support - is it really available beyond limited respite care and case management?

In beginning to discuss some of these issues, the Task Force realized a need to look at the system design in an attempt to identify roles and who serves them, such as who is the monitor; service broker; advocate; planner; provider; resource developer, etc? In doing this it became apparent that at times many agencies/organizations have overlapping responsibilities originally designed as a check and balance system which may now serve to create confusion and delay in achieving the systems' goals and that while all the parts are critical, clarifying their roles, responsibilities and authorities and removing disincentives for carrying out such would be a positive step toward improving the system. For example, at least four agencies are involved in resource development activities both at the state and local level with decision making at multiple levels within each agency. This scheme has caused confusion and a certain amount of dissention which only serves to shift valuable energy from the original activity. From the Task Force's perspective, it would seem more efficient to clarify at what level each organization has involvement and authority in the process of resource development and to design and implement a system which adhere's to and honors that design. Another example is with regard to the Area Boards, while designed as the system's "COP" (monitor), very little enforcement authority exists to ensure the job gets done, thus the role loses its effectiveness.

This is just a brief summary of the preliminary discussions by the Task Force. While local communities will undoubtedly focus on the needs of people with developmental disabilities to order to achieve the system's goals, the OAB's discussions are focused on a systemic design needed to achieve those goals. It is generally felt that the philosophy and overall construction of the system is sound, however the full potential of the system to achieve its goals has been hampered by the implementation of policies and practices which do not promote or encourage the flexibility envisioned by Frank Lanterman and the many parents who painstakingly fought to develop the system for people with developmental disabilities in California.

I hope this testimony has provided you with an understanding of the Area Boards' response to your request for group facilitation at the local level as well as its activities focused on systemic design and implementation. We look forward to further participation in this process and to presenting bold proposals designed to enhance the system for debate and ultimate implementation as deemed appropriate and necessary.

THE LANTERMAN ACT

(Named after Assemblyman Frank Lanterman from
Southern California. He was a strong advocate
for people with disabilities.)

Before 1960, most people with developmental disabilities in California lived at home or in state hospitals. There were very few programs for consumers in the community. California and the federal government spent very little money on programs for people with disabilities. Most of the money spent was for large segregated programs like state hospitals.

After 1960, services for the disabled started to improve on the federal and state level. On the federal level, President Kennedy advocated for more money and better services for people with mental retardation and other disabilities. He was concerned about people with disabilities because he had a sister who was disabled. Under President Kennedy's administration, millions of dollars were spent on research, training, and services.

In California, during the late 1950's and early 1960's, parents started to complain about the poor quality of care in the state hospitals. Parents took their complaints to their local Assembly and State Senate officials. In 1965, the California Legislature reviewed the state hospitals and the state's role in helping people with developmental disabilities. They found over 13,000 people living in state hospitals and over 2,000 people on waiting lists to get in. After this review, the California Legislature decided to put more money toward the goal of keeping people at home and providing services in the community.

In 1969, the California Legislature passed into law the Lanterman Mental Retardation Services Act. The Lanterman Act helped start a statewide program to provide services to people with mental retardation in community programs.

In 1972, the Lanterman Mental Retardation Services Act was changed to include people with cerebral palsy, autism, epilepsy, and certain types of head injuries. The Lanterman Mental Retardation Services Act then changed to the Lanterman Developmental Disabilities Services Act.

The Lanterman Act was set up to help support people with developmental disabilities so that they would be able to live in their own communities. It also gave consumers the right to services which helped them live more independently in the community.

The Lanterman Act set up three important agencies to help consumers get the services they need: the Regional Center, Area Board, and the State Council.

Regional Centers

What Is A Regional Center? A Regional Center is a place that helps you, the people who have developmental special needs, get services. There are 21 Regional Centers in California. Regional Centers are run by a group of people picked from the community called a "Board". The Board helps the Regional Center decide what is needed to serve you the best. You might be able to be on the Board if you want.

Whom Does A Regional Center Serve? A Regional Center will serve you if you have special needs which can be called a "developmental disability". That means that before you were 18 years old, you may have had trouble learning as fast as others, or you have had seizures (epilepsy), or you have had trouble talking or walking, or you have had a hard time knowing how to act with other people, or you have had cerebral palsy. Adults over 18 can often get help from the Regional Center too. If you aren't sure if you can get services from a Regional Center, call them and ask.

What Can A Regional Center Do For You?

* Help you get a place to live.
* Help you get a place to work and learn during the day.
* Help you learn to be on your own more (like how to cook, how to go to the store, how to take care of your own money, how to use the bus, and many other things).
* Help you in getting around town (transportation) like use of vans and buses.
* Help you in being in charge of your own feelings and knowing how to get what you need.
* Help get special chairs or wheelchairs, or braces or shoes or talking machines, if you need them.
* Help girls and boys under five years old get in preschools.
* Help get someone to babysit or help out, to come and stay at your house, or a child's house, while the people you live with (maybe your parents) go out for the evening or take a vacation.
* Help in meeting new friends and being part of the community.

Area Boards

As California is such a large state, the people in the Legislature decided to develop a program to make sure that people with developmental disabilities are getting the things that they need. The Lanterman Developmental Disabilities Services Act set up 13 Area Boards to help. The kinds of things they do are:

1) Help people speak up for their rights or speak for people who can't speak for themselves;
2) Help people understand about developmental disabilities;
3) Help people start groups who will speak up for people with developmental disabilities;
4) Look at programs that work with people who are developmentally disabled and make sure they are doing what they are supposed to do;

Area Boards (continued)

5) Find out what people need all over the state;
6) Make sure that everyone is working together;
7) Help get programs started that meet people's needs and are good programs.

State Council on Developmental Disabilities

The State Council has a responsibility to plan and coordinate resources to protect the legal, civil, and service rights of persons with developmental disabilities. The Council is made up of consumers, parents and state agency administrators.

RIGHTS

All people who have developmental disabilities have these rights:*

1. You have a right to learn things that will help you do your best, things like cooking, or how to live in an apartment, or how to work.
2. You have a right to have people treat you with care.
3. You have a right to be by yourself when you want to be.
4. You have a right to go to classes and learn things like reading and writing.
5. You have a right to be with people who do not have handicaps.
6. You have a right to see a doctor when you need to see one, and without waiting a long time.
7. You have a right to go to any church you want to, or go to a synagogue, or stay home and not go to a church or synagogue.
8. You have a right to go places, and to be with people.
9. You have a right to exercise and have fun.
10. You cannot be tied down, or locked in a room, unless you are doing something that might hurt another person or yourself.
11. You only have to take as much medicine as you really need.
12. People cannot do experiments on you unless you want them to, and people do not have the right to do experiments that might hurt you.
13. People cannot do things that are bad for you, and they must spend some time with you to make sure you are doing okay.
14. You have all the other rights that non-disabled people in the United States have.

* From "Your Rights and Responsibilities", by People First of California

If you live in a group home or a state hospital, you also have the following rights:

1. You have a right to wear your own clothes.
2. You have a right to have visitors everyday.
3. You have a right to have a safe place to keep your personal belongings.

RIGHTS (continued)

4. You have a right to have spending money (P & I money).

5. You have a right to make phone calls and have people call you at home.

6. You have a right to write letters and receive letters that have not been opened. You must be given paper, envelopes, and stamps if you want to write a letter.

RIGHT TO APPEAL

If Regional Center or another agency makes a decision about your services that you disagree with, you have a right to appeal their decision.

When Regional Center or another agency decides to change your services, they must write to you and explain:

1. how your services would change,
2. why they want to change your services,
3. when they plan on making the changes,
4. the law or policy that allows them to make the change,
5. the steps you need to take to appeal their decision, and
6. where you can go to get help to appeal.

If you need help asking for an appeal, the agency must help you fill out the appeal form.

You have a right to have someone help you with your appeal (an advocate).

A meeting will be scheduled to talk about the decision. You have a right to be at that meeting and to have an advocate, a friend or a family member go to the meeting. The meeting must be scheduled at a time and place that you are able to get to.

OBSTACLES TO IMPLEMENTATION OF THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICES ACT

OVERVIEW

THE PROMISE OF THE LANTERMAN ACT

In the Lanterman Developmental Disabilities Services Act, the Legislature made a commitment on behalf of the State of California to its developmentally disabled citizens. It was a commitment to provide sufficient community-based services to prevent or minimize institutionalization of developmentally disabled persons and their dislocation from family and community (§§ 4501, 4509, 4685); a commitment to provide services that would enable developmentally disabled persons to maximize their potential capabilities for independent, productive and normal lives in their home communities (§§ 4501, 4750-4751); and a commitment to prevent and minimize disabilities through early and timely intervention services (§§ 4501, 4644, 4685).

In conjunction with these goals and priorities the Legislature recognized the right of developmentally disabled persons to participate as equal members of society and to receive treatment and services which foster developmental potential, protect personal liberty, and are provided in the least restrictive conditions necessary to achieve the purposes of treatment. (§ 4502.) In short, the Legislature recognized that developmentally disabled people are entitled to enjoy the same legal rights as all other citizens and to achieve the maximum independence possible in their daily living.

The principles and values underlying the rights and obligations contained in the Lanterman Act come from a variety of sources, including: constitutional principles establishing a right to treatment and habilitation services in the least restrictive environment; clinical principles based on studies demonstrating the efficacy of providing services in normalized settings; and economic cost-benefit analyses establishing the direct and indirect fiscal benefits of such services.

THE PAI PERSPECTIVE

Assemblyman Frank Lanterman donated the legislative history of the Act to the University of Southern California Archives. However before the materials were sent to USC he lent them to PAI to review and copy. We continue to rely on that extensive history in representing our clients and in continually interpreting the intent of the ACT and our comments today are based on our interpretation of that history.

For the past ten years PAI has been providing advocacy services to developmentally disabled Californian's including the provision of legal assistance and representation. The conclusions and issues outlined below follow from the experience our organization has had in those ten years. They address frequent and recurring problems that clients encounter. But while they may critically point out failures of the existing service system they are not meant to be interpreted as an indictment of any particular element of that system but rather as a recognition of our collective failure to achieve the vision of the Lanterman Act.

It is important that we enter into this process of critical analysis of the Lanterman Act with the recognition that we have all succeeded in some areas and failed in others. If we are going to expose the truth we must do so in a spirit of openness that facilitates self examination and reflection, in an atmosphere where we can examine critical issues and allows us to point out the consequences of policies land practices without attacking the motivation or good will of any of the players.

PAI in this testimony has focused on specific problem areas resulting from our representation of clients without leaping to recommendations regarding system change and redesign. It is our expectation that the process to follow will ensure that occurs and address possible ways of correcting current problems. While we present these issues from the advocacy perspective this is not to imply that they can simply be resolved by the changing of statutory language. Clearly these problem areas must be examined and serve as a starting point to extrapolate fundamental problems in system design, in current levels of authority and responsibility, in accountability, in how much control to vest in the recipients of service and ultimately in assessing the political and social will, commitment and resources available to improving this service system.

FOR SOME: AN UNFULFILLED PROMISE

The principles, goals and values underlying the Lanterman Act remain valid. They represent the best and most noble values and aspirations of a ideal democratic society that strives to extend full participation and citizenship to all of its members.

The Legislature recognized that to achieve such goals a system of coordinated services are required to "ensure that no gaps occur in communication or provision of services" and that "services should be planned and provided as part of a continuum . . . sufficiently complete to meet the needs of each person with developmental disabilities, regardless of age or degree of handicap, and at each stage of life." (§ 4501.)

The Lanterman Act has clearly improved the lives of thousands of persons with developmental disabilities. For others, however, the continuum of services is not sufficiently complete. Services which are necessary to enable them to live more independent and productive lives as the Legislature intended are not available.

Many developmentally disabled people who are living in the community are not able to maximize their potential capabilities for personal and economic independence and productivity because the specialized programs and services they need -- including training and educational programs focusing on independent living, vocational, and social skills -- are not available.

Others are living in the community or participating in community-based programs, but in settings that are more restrictive and less normalized than necessary -and ironically are provided less protections than in the "restrictive" institutions they left. For example, many more persons could be working in regular, integrated work environments if adequate vocational training or supported work programs existed. They instead find themselves in segregated sheltered workshops. Many individuals who could be living independently or semi-independently if programs were available to provide independent living skills training or ongoing support and assistance in maintaining a household, instead must live in segregated, congregate living situations where there freedom and autonomy is stifled rather than advanced-where they don't get to chose what they eat, or where they go, or who they spend their time with.

Many families face a constant struggle to care for their disabled children at home and are forced to place their children out of home -- in either community care facilities or state institutions -- because of the chronic shortage of family support services. This has occurred despite the fact that the Legislature explicitly placed "a high priority on providing opportunities for children with developmental disabilities to live with their families" and gave "a very high priority to the development and expansion of programs designed to assist families in caring for their children at home." (§ 4685.)

Finally, almost 25 years after the initial legislative commitment to a community-based service system, hundreds, perhaps thousands, of developmentally disabled persons remain in state hospitals who by the admission of everyone, including their families and the interdisciplinary teams that provide professional insight regarding their needs and potential, could live in community settings but for the unavailability of appropriate facilities. According to a November 1988 report issued by the Office of the Legislative Analyst, even the Department of Developmental Services estimates that some 1,600 state-hospital residents have been determined to be appropriate for community placement, yet they remain hospitalized because of insufficient community resources. Judicial Reviews of State Developmental Center Placements: Implementation of the In re Hop Decision at 20.

There is reason believe that these numbers are on the rise:

- Sonoma Developmental Center, for example, is over its maximum capacity and reports substantial increases in hospital admissions of children whom hospital staff believe are not appropriately placed.
- Because of the dearth of community options, the closure of a community facility typically results in the hospitalization of former residents, many of whom have lived their entire lives in the community. (The recent closure of Laurel Hills Developmental Living Center in Sacramento this January is a case in point.)
- Courts have resorted to improvising hospital commitment procedures utilizing over-broad or undefined commitment criteria because the unavailability, rather than inappropriateness, of community placements leaves them with no alternative. (E.g., North Bay Regional Center v. Sherry S. (1989) 207 Cal.App.3d 449.)

SOME SOURCES OF THE PROBLEM

Through our work in advocating on behalf of persons with developmental disabilities for over 10 years, Protection & Advocacy, Inc., has identified a number of recurring and systemic problems in implementation of the Lanterman Act. Some of these problem areas, are detailed below:

One of the most fundamental issues is the problem of unrealistic and inflexible rate setting which simply does not adequately take into account the realities of the marketplace and the service needs of clients. Housing costs and salaries for staff with requisite skills and experience cannot often be met under existing rate structures. As a result, there is a shortage of quality programs and services, particularly for persons with the most specialized service needs.

As a result of the chronic shortage of appropriate programs and gaps in the service continuum, regional center program planning is often based on the availability of services rather than the needs of individual clients as the Legislature intended.

Many of the problems in implementation of the Lanterman Act can be attributed to a lack of innovation and flexibility in the program planning process, often due to rigid and arbitrary policies or practices which do not allow for program planning or allocation of resources based on individual client need. These policies and practices often set inflexible statewide rate ceilings; prevent creative approaches to meeting client needs by, for example, discouraging the establishment of new types of service categories; or preclude the purchase of supplemental or supportive services (e.g., one-to-one aids, in-home health care, specialized respite services, day care) -- even on a temporary or interim basis -- that could prevent placement in more restrictive

settings than otherwise necessary. Regional centers typically have devoted insufficient attention or resources to their program development and advocacy functions. In fairness, the inadequacy of regional center program development activities is, in part, due to the failure of regional center budgets and staffing levels to keep pace with the growing demand for services. The failure to pursue their advocacy function, however, particularly within the regional center service system, stems also from the conflict inherent in the regional centers' dual role of coordinating and providing services on the one hand, and monitoring and advocating for clients' rights in relation to those services on the other. Regardless of the origins of these problems, the result is inadequate services, insufficient protection from abuse and neglect, and the ultimate denial of rights and entitlements.

Finally, for many, the problem increasingly is access to the regional center service system itself. Administrative regulations and regional center intake and assessment practices have resulted in the exclusion from regional center services for many. Most often, these are either persons with both developmental disabilities and identified mental disorders, or non-mentally retarded individuals who, nonetheless, have conditions similar to mental retardation or who have similar service needs to mentally retarded persons.

THE NEED TO REAFFIRM THE COMMITMENT

The reasons why the Lanterman Act's promise has not become a reality for all persons with developmental disabilities are many. None of the obstacles to the Act's full implementation are insurmountable, however, as experiences in California and other states have demonstrated.

The Legislature must reaffirm and provide further clarification of its longstanding commitment to the goal of a community-based service system. Regional centers must be further encouraged to develop innovative and economical methods for meeting individual client needs (§§ 4651, 4652) and they, and responsible State agencies, must be prevented from applying policies and procedures or establishing rate systems which preclude achievement of this end.

In sum, what is required, at a minimum, is a renewed and strengthened legislative commitment to the existing principles, values and mandates of the Lanterman Act. This commitment cannot be totally abstract or theoretical. For many reasons, including advances in medical technology and a long history of successes with the community-based service model (for which the Lanterman Act was a major pioneering influence), the demand for services is greater than ever. If the State of California is to continue to accept "a responsibility for its developmentally disabled citizens and an obligation to them which it must discharge," then it must be willing to commit the financial and human resources necessary to ensure that the promise of the Lanterman Act is not an empty one.

IDENTIFIED OBSTACLES TO IMPLEMENTATION OF THE LANTERMAN ACT

I. ISSUES CONCERNING LIVING IN THE LEAST RESTRICTIVE ENVIRONMENT

The Lanterman Act entitles developmentally disabled persons to individualized services provided in the least restrictive environment and designed to promote clients' normalization, independence and achievement of their maximum potential. Welf. & Inst. Code § 4501, 4502, 4646, 4648; ARC v. DDS, 38 Cal.3d 384 (1985). The Act also places a high priority on providing the services necessary for developmentally disabled children to live with their families, including respite, day care and behavior modification programs. Welf. & Inst. Code § 4685.

In federal fiscal year 1986-87 PAI handled a total of 301 requests for assistance on issues concerning community residential placement. In 1987-88 that number was up to 401 and only six months into 1988-89 was 315. From these statistics and PAI's direct involvement in both individual client representation, and activities related to reviewing the policies and practices of public and private agencies responsible for implementing the Lanterman Act, PAI staff have concluded that this is an area where the implementation of the Lanterman Act falls seriously short of its intent. Among the problems PAI has identified are:

A. Insufficient in-home support to families of developmentally disabled individuals results in inappropriate out-of-home placements.

Many families are unable to maintain their children at home without appropriate in-home support; yet, inappropriately restrictive regional center policies, including limitations on respite hours and after-school programs and blanket refusals to provide day care for working parents who cannot otherwise obtain such care <u>because</u> of their children's disability, all too frequently results in out-of-home placements. In PAI's experience, even when respite hours are called for in client Individual Program Plans (IPPs), they may not be provided because the rates allowed by the Department of Developmental Services (DDS) are inadequate to obtain skilled persons capable of caring for children with behavior problems or medical needs.

One client, recently represented by PAI, required 24-hour a day in-home nursing care, only 16 hours of which were covered by the family's insurance. This meant that the family had to provide constant nursing care themselves, eight hours a day, seven days a week, 365 days a year. While acknowledging that the family was in desperate need of respite and that the child might have to be placed in a hospital if the family were not provided with some relief, the regional center refused the family any respite at all because it had a policy that said respite would not be provided for children on respirators. A hearing officer found that the policy could not be applied because it was inconsistent with the Lanterman Act requirement that services be provided based on individual need.

B. Lack of community residential placements results in inappropriate placement of developmentally disabled persons in state developmental centers(hospitals).

The calls and cases handled by PAI staff repeatedly demonstrate that there are insufficient specialized services facilities and health care facilities to provide homes for persons with challenging behavioral problems or medical needs. For example, one regional center client's IPP has called for community placement <u>for five years</u>, yet no community placement has yet been found for the client.

In almost all of these cases, regional centers have suggested placement at state development centers because there are <u>no available alternatives</u>. At times it has been recommended that families place their adult or minor children in state developmental center improve their chances of obtaining a community placement under the "Community Placement Plan" process. The absurdity in this process, whereby an individual must be inappropriately placed in a state hospital in order to increase his or her chances of being appropriately placed in the community, is obvious and clearly violates the Lanterman Act and the constitutional rights of developmentally disabled persons.

The inappropriate institutionalization of young children is dramatically apparent at Sonoma Developmental Center, which admitted over 30 minors in the last year and a half alone, <u>almost all of whom</u> are believed by hospital staff <u>to be appropriate for community placement</u>.

In a number of instances this year community care and health care facilities have closed or, for other reasons not related to the clients' needs, decided to discharge clients. The result was often institutionalization of the clients because there were no appropriate community placements available. when an 80-bed facility closed in Sacramento this year, approximately 50 adults and children, most of whom had lived their entire lives in the community, were moved to state hospitals throughout the state without any warning, without any due process, and without consent because no other community facilities were available. Most of these people have little hope of returning to the community in the near future.

Related difficulties in obtaining placement confront individuals currently in state developmental centers (hospitals). PAI has represented individuals who were determined by ID Team staff to be appropriate for community placement; were found by a court to no longer meet civil commitment criteria; were ordered released after successfully petitioning by writs of habeas corpus; or were ordered committed to a community facility under Welf. & Inst. Code § 6509. In all of these situations, individuals have nevertheless remained in state developmental centers for long periods due to the lack of appropriate community facilities.

C. Lack of innovative community housing options deny developmentally disabled persons individualized residential services.

There is a continuing unavailability of innovative community housing options designed to meet individual needs, increase independence and provide a choice of living arrangements. The present system of facility design and rates structure results, in practice, in homes for no fewer than six clients. This does not provide many clients with living options they want or the autonomy they would be able to exercise in their own or supervised apartments for example.

The Legislature intended to encourage innovative programs, techniques and staffing arrangements, §§ 4651, 4652. DDS itself has recognized the worth of smaller facilities (Obstacles to Community Placement (1988)), yet such alternatives remain unavailable. PAI has represented a number of clients who need and desire, but have been unable to obtain innovative living options. Among these cases are those involving, for example, developmentally disabled mothers and their children who could remain together if a family foster care living situation were available.

D. DDS policies violate the Lanterman Act and undermine the development and support of community placements.

The Lanterman Act mandates that regional centers assure that a continuum of residential placements exists and that they develop new facilities, or modify services at existing facilities, when necessary to implement individual IPPs. Welf. & Inst. Code § 4501, 4648; ARC v. DDS, 38 Cal.3d 384 (1985). This mandate is often not being fulfilled. The Act also provides that the cost of services is not intended to bar the placement of developmentally disabled persons in appropriate community living arrangements, so long as the cost does not exceed the average monthly cost of services in state developmental centers. Welf. & Inst. Code § 4682. This provision is being disregarded.

DDS in our view controls the number and type of residential facilities which regional centers may develop in ways that are not consistent with the spirit or intent of law. IN setting rates for specialized services facilities, DDS ends up intruding on the IPP process by redetermining clients' needs for particular levels of service. In fact the locus of control and decision making is taken further and further away from the client and his or her needs.

DDS policies have also had the effect of restricting the ability of regional centers to provide additional supportive services (e.g., provision of one-to-one aides) within existing facilities when necessary to enable individuals to remain in the community. In several PAI cases, DDS has refused to authorize a rate adequate to make appropriate services available, even though the requested rate was considerably below the average cost of state developmental center placement. As a result, absent litigation, clients who can appropriately live in the community have remained institutionalized, or are at imminent risk of institutionalization.

For example, one southern California facility was successfully serving 6 severely physically involved residents with a one-to-two staff-client ratio. This staffing pattern was supported by the regional clenter. However, DDS set a rate adequate only for a one-to-three staff ratio. A fair hearing was initiated by PAI on behalf of the clients. The hearing officer ruled that the clients require one-to-two staffing and this service must be funded.

In another case, a specialized service facility gave notice that three autistic men in their mid-twenties would have to be moved by the regional center solely because it wanted to serve children. The regional center could find no appropriate placements for them anywhere in the state, and so developed a proposal for a new facility with a local provider. DDS has refused to authorize payment of the rate the provider requires to open the home, although it is more than $2,000 below the average monthly cost of state hospitals. Unless the rate is approved, the three men will have no where to go except to state hospital, despite the fact that this would not be the least restrictive environment for any of them or the most cost effective option.

II. INDIVIDUAL PROGRAM PLAN ISSUES

The Lanterman Act requires that regional centers develop an Individual Program Plan (IPP) for each regional center client to determine and direct the regional center and other service providers in providing care and treatment to the client. Although the IPP process requires participation of the client and/or the client's parents or authorized decision maker, it takes place in private and depends upon the good faith of regional center staff and strict adherence to the procedures outlined in statute, to operate in the manner the Legislature contemplated in creating the Lanterman Act. When all goes well, it is a collaborative, participatory process resulting in a detailed and accurate description of an individual client's program and service needs. In many instances, however, the process fails to function as it should.

In 1987-88 PAI provided technical assistance and direct representation to 221 individuals on problems related to IPPs. Through this casework and other contact with developmentally disabled persons, their families and advocates, PAI has identified the following recurring problems in relation to the Individual Program Plan development process:

A. IPPs are often inadequate, lacking a complete and appropriate description of clients' problems and service needs.

As the service planning document for each regional center client, the client's IPP must clearly and specifically identify the client's disabilities and the programs and services needed by the client, in order for the client to be served properly. To do this, IPPs need to be based on sound and thorough clinical assessments of the client's disabilities and needs. This is one of the fundamental responsibilities of regional centers. However it is very common for us at PAI to receive all client records and still not be able to determine the clients needs because assessments are non existent or incomplete. We end up trying to convince various service agencies to conduct proper and complete assessments or are forced to contract for the assesssments ourselves just to determine what the client needs. We find in many instances IPP teams proceeding without the very information they need to develop the plan. Consequently, the goals and objectives in many IPPs are not specific, measurable or complete.

The descriptions of services necessary to meet IPP objectives are, likewise, often inadequate. It is not uncommon to see an objective like: "Mary will be placed in a day program," without any additional specification of the client's individual needs or of the characteristics of a day program capable of meeting those needs. As a result, clients often do not receive the services they need.

B. Services documented in IPPs are based upon the availability of the services rather than the needs of clients.

The IPP process, as specified by the Lanterman Act, is intended to produce a true picture of a client's service needs, regardless of the current availability of services. This does not take place in many cases. Instead, the vision of regional center staff are severely limited by what exists and by a systems orientation that does not promote innovation and creativity. Rather the client is forced into the proverbial "Procrustean Bed",i.e. the available bed is identified and the client is forced into it. . if the bed is too small the client is likely to get his or her legs cut off in order to fit. Service needs that currently cannot be met don't show up in the IPP. This lack of documentation results in inadequate efforts to develop needed programs and services, and leaves policy makers and the Legislature with an unrepresentative view of system-wide needs and problems. The system fails to really be driven by client needs as it was intended because of the failure of this process.

C. Regional center purchase of service committees, not IPP teams, make the real decisions concerning service provision.

The Lanterman Act grants IPP teams exclusive authority to determine client needs and authorize the purchase of needed services. Unfortunately, the document developed by the IPP team is often little more than a "wish list" which then must be approved by regional center purchase of service committees. These committees typically base their decisions on fiscal or other administrative concerns rather than individual client need. Committee members are not members of IPP teams and clients have no opportunity to address them. Yet it is they who make the final decisions about the purchase of services, sometimes disregarding the program planning process entirely.

For Example, PAI has represented clients who were making considerable progress in independent living skills programs but were told the service would no longer be provided because of a regional center policy which limited independent living skills training to two years, regardless of whether the client's IPP team had found that the client would continue to benefit from the program.

D. Regional centers provide inadequate written notice about denials or modifications of services.

The Lanterman Act requires that regional centers provide written notice to clients in the event of any change or denial of services. This notice must include the reason for the service change or denial, the relevant statute, regulation or policy on which the regional center made its decision, and information about how to file an appeal.

These notices regularly fail to provide adequate explanation for regional center decisions. It is not uncommon to encounter notices which provide no more explanation than: "We are denying your request for regional center services because we find that you are not developmentally disabled." Such notices do not provide a client with the basis for the decision -- in this instance, why the client was determined not to be developmentally disabled. Without this information, a client can neither determine whether the regional center decision was reasonable nor, in the event the client disagrees with the decision, properly prepare for an appeal.

E. Time limits placed on services circumvent the aid-paid-pending provisions of the Lanterman Act.

In addition to requiring that clients be given adequate notice of any proposed changes in services, the Lanterman Act requires that regional centers continue to pay for services in clients' IPPs pending the outcome of client appeals of such proposed actions. Many regional centers have a practice of placing time limits on the provision of services listed in IPPs which can result in circumventing this requirement and the client not being provided with needed and statutorily required services.

For example, a regional center may indicate on an IPP that a particular service will cease to be provided after six months. At the end of the six months, if there is a dispute about whether the service should be continued and the client files an appeal, the regional center will argue that it need not pay for the service pending the appeal because the service was time-limited. In such circumstances, some regional centers even refuse to provide written notice of termination of the services, on the grounds that the limitation contained in the IPP was adequate notice. Under these circumstances, there is little a client can do but obtain preliminary relief from a court prior to the hearing, which is not an affordable or practical option for most clients.

III. REGIONAL CENTER ELIGIBILITY ISSUES

Many persons who are legally entitled to regional center services are being denied services because of improper eligibility determinations. Eligibility issues are the single greatest source of PAI's work on behalf of developmentally disabled persons served by regional centers. Some of the recurrent problems in this area are:

A. **A general unwillingness to apply the "functional" or fifth category of eligibility under the Lanterman Act, thus resulting in denial of services to persons who qualify for services under this criteria.**

The Lanterman Act definition of who is eligible for regional center services includes both diagnostic and functional categories. The functional category of eligibility includes persons with conditions which are similar to mental retardation or which require services similar to those needed by mentally retarded persons. This category is intended to ensure that persons with such disabilities do not go unserved. The legislative history of the Act is rife with examples that the Legislature intended this service system to meet the needs of people well beyond those with mental retardation.

In numerous cases in which PAI has represented or provided technical assistance to individuals who have been denied services and who have conditions such as attention deficit disorders, Prader-Willi Syndrome, birth injury, brain damage as a result of head trauma and pervasive developmental disorder, the individuals have been found eligible at administrative hearings. Nevertheless, regional centers continue to routinely find persons with these and other conditions similar to mental retardation ineligible for services. The result of these consistently successful hearing decisions has not had the effect of modifying existing policy.

B. **An inappropriate and unjustifiable reliance on IQ scores to determine eligibility.**

It has been PAI's experience that individuals with IQ scores of 70 or higher are often found ineligible by regional centers, regardless of whether these individuals have functional disorders or difficulties that are similar or equivalent to retardation and therefore may be eligible for regional center assistance. In fact, eligibility is often denied even if only one of several IQ test administrations results in an IQ score above 70. Additionally, regional centers rarely perform other types of assessments (e.g., neuropsychological or adaptive skills evaluations) which might identify cognitive and functional impairments that are often not revealed by reliance on IQ tests alone.

In one case, for example, PAI successfully represented a client with Prader-Willi Syndrome who was denied eligibility solely based on an IQ score in the 80's. This client had relatively strong verbal skills which accounted for his ability to perform well on an IQ test. However, this 38-year-old man had functional skills equivalent to those of a 9-year-old. Among other things, he could not follow simple verbal instructions, could not tell time, could not live on his own, and required constant supervision and reminding in relation to self care. In most ways, he functioned like, and had service needs similar to individuals with mental retardation.

C. An overly broad application of the "solely psychiatric" exclusion contained in DDS regulations to deny services to developmentally disabled persons whom the Legislature intended to be served.

This is occurring when persons with "dual diagnoses" (persons who have been identified as being mentally ill as well as developmentally disabled) are erroneously regarded as only having psychiatric problems and so are denied regional center services.

This problem also occurs when the necessary clinical assessments are not performed to determine whether a person has a developmental disability, in addition to a mental disability, and persons are found presumptively ineligible. For example, PAI staff recently represented a client with Tourette Syndrome, a borderline IQ and atypical organic brain syndrome, who appealed a regional center's determination that he was ineligible for services. The regional center's decision was based on its claim that the client's IQ was not in the mentally retarded range and that Tourette Syndrome is a solely psychiatric condition. PAI showed that the client had functional problems like that of a mentally retarded person and needed the same kinds of services, including self help skills, independent living, mobility skills and socialization skills...and that these were exactly the kinds of persons the legislation was intended to serve in addition to the more obvious clients like those with classic mental retardation. On appeal, the client was found to be developmentally disabled and eligible for services.

IV. REGIONAL CENTER INTERAGENCY ISSUES

In-Home Health Care

Another area of major area of concern is the adequate provision of in-home nursing services to technologically dependent developmentally disabled children and adults. These cases illustrate the inability of some of our systems , including private insurers, to change rapidly enough to keep up with improved medical advances in care and technology. In-home services are now available that enable developmentally disabled persons to live independently or at home with their families or caretakers, thus avoiding unnecessary institutionalization in acute care or skilled nursing facilities, as well as greatly reducing the cost of care. Much of this technology was not available or affordable until recently. During the past two years, PAI has seen an increase in requests from developmentally disabled persons and families in cases where necessary in-home care could keep the family together but was not being provided. PAI has identified the following concerns through these and other PAI activities:

A. Lack of adequate case management services to ensure that clients receive necessary in-home care from generic agencies.

The generic sources for in-home nursing care include California Children Services (CCS), Medi-Cal, private insurance plans and health maintenance organizations (HMOs). Each program has different eligibility criteria, application procedures and practices, and appeal/arbitration rights. In many instances, none of these agencies is willing to assume responsibility for providing in-home nursing services to a developmentally disabled person, despite the fact that the individual both needs and is eligible for the services. As a result, many clients remain inappropriately and unnecessarily placed in facilities for months and even years before in-home services are secured.

In PAI's experience many case managers lack the training and resulting expertise regarding in-home alternatives and are not familiar with eligibility criteria and application processes for in-home nursing services available through generic sources. Without informed case management assistance, many developmentally disabled persons and their families are unable to access needed services.

B. Failure by regional centers to advocate for generic services on behalf of their clients.

Regional center clients are told there is nothing regional centers can do for them when they are denied services through generic agencies, such as CCS, private insurance companies or Medi-Cal. However, in accord with their responsibilities under the Lanterman Act, regional centers have an obligation to independently assess the need for services, actively advocate for the provision of appropriate services, assist clients and their families in appeals processes and provide interim services pending the outcome of appeals. Welf. and Inst. Code § 4648(c); 17 C.C.R. §§ 50510, 50550(b).

C. DDS contract language and memoranda to regional centers impermissibly prohibit regional centers from reimbursing parents of regional center clients for share of costs for medical services provided by CCS or Medi-Cal.

As a result of DDS policies, many regional centers continue to refuse to reimburse clients for share of costs associated with medical services provided by Medi-Cal or CCS. This occurs despite regional center responsibility under the Lanterman Act to provide such services to the extent that they are not available from other, generic agencies, and despite a recent DDS fair hearing decision in a PAI case determining that such reimbursement is required.

One case involved a young girl who needed leg braces. Initially the family applied for services through CCS, but because their share of costs was over $1,000 per year the family received no assistance from CCS. Claiming that it was following DDS directives which did not allow reimbursement for share of costs, the regional center denied funding for the initial braces and the refitting which was required two years later because the child had grown. The family was forced to go to a fair hearing against the regional center twice and won on both occasions. The hearing officer held that DDS' position on share of costs violated the Lanterman Act.

STATEMENT OF

CAPITOL PEOPLE FIRST[1]

TO THE JOINT HEARING OF:

THE SENATE SUBCOMMITTEE ON MENTAL HEALTH, DEVELOPMENTAL DISABILITIES AND GENETIC DISEASES

THE SENATE SUBCOMMITTEE ON THE RIGHTS OF THE DISABLED

and

THE ASSEMBLY SUBCOMMITTEE ON MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES

on

"SR9: AN OVERVIEW OF THE STUDY OF THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICES ACT"

STATE CAPITOL JUNE 16, 1989

* * * * * * *

INTRODUCTION

We wish to thank the Committees for this opportunity to express our view of the Developmental Services system and of the Lanterman Act. We have the exhilarating feeling that this time we will be listened to with understanding, and that our recommendations will carry weight.

Capitol People First is a self-advocacy organization of persons with developmental disabilities. Most of us have cognitive disabilities. This means that we are still labeled by most people with the tag "mental retardation". We work with volunteer advisors who are generally non-disabled in the way we are. Our advisors assist us with many things, including communications. This paper, for example, was edited by our advisors from hundreds of hours of conversations, discussions, arguments and even shouting matches, most of which have been preserved on audio tape, and recently, on video tape.

The nature of SELF-ADVOCACY is not necessarily an adversarial process, but it is clear that there would be no need for self-advocacy if there were no conflict between the views of primary consumers and those of the people who run the DD system as well as the views of other well-meaning people who practice <u>advocacy</u> "on our behalf".

It is Capitol People First's fate to be the frequent subject of complaints that we carry negative criticisms of the system too far, and that we have nothing positive to say.

We suggest that such criticisms are misinformed, but we acknowledge that we are angry at injustice toward our brothers and sisters, impatient with mismanagement of services that are supposed to help primary consumers solve their problems of everyday living, and outraged regarding misinformation held and spread by too many professionals <u>about</u> people with disabilities, their competencies and the nature of their possible futures. Such anger may in fact be necessary - and we believe it is - as the beginning of solutions to these problems.

Thousands and thousands of primary consumers of developmental services are outraged and affronted every day of their lives by a system which "knows best" for them, and never asks what <u>they</u> think is best for themselves. These so-called <u>consumers</u> have not only every right, but an <u>obligation</u> to identify the flaws in the system which are barriers to a good quality of life for them.

Once system problems are identified THROUGH THE EYES OF PRIMARY CONSUMERS and/or people who truly are capable of seeing the system and the world through the eyes of consumers, then it becomes the joint responsibility of consumers, professionals, parents, advocates, the Legislature and whoever else is involved in the process of problem-solving and policymaking to make the indicated corrections.

This testimony is a good example of what happens when a genuine partnership develops between primary consumers and people whose disabilities, if any, do not handicap them in communications, and whose perceptions of the issues are conditioned by the consumer point of view.

<u>Problems with Credibility and Communications within California</u>

It has been our perplexing experience that our recommendations and observations have been received generally with greater respect and comprehension in other states and countries than by many governmental units and private agencies in our home state. However, in all honesty, we must note that we probably are invited only to faraway places where people have heard of us and <u>are not afraid of us</u>.

At home, it is often a different story. For example, we made recommendations in 1984 to the State Council on Developmental Disabilities in our report, SURVIVING IN THE SYSTEM: MENTAL RETARDATION AND THE RETARDING ENVIRONMENT. In 1987 and again in 1988 we made recommendations to Area Board III, our home area board, at its invitation, during its needs assessment process.

If you will revisit <u>Surviving in the System...</u>, and if you will review our statement to ABIII, you will see basically the same set of concerns that we are presenting here, although over time we have learned to focus them better.

The reason we dwell on so many of the same issues is that the vast majority of our recommendations have remained unimplemented, most of them unheeded. While we have understandably been disappointed at our difficulty in getting our views taken seriously at home, we believe that there are many reasons for this lack of response.

There is a point of view held by many actors in the developmental services system, the people we generally refer to as the KEEPERS, that consumers really don't have the capacity to know what they want and need. This belief is reinforced by the consequences of keeping consumers <u>in</u> the Retarding Environment, where they too often, but understandably, live <u>down</u> to expectations. This attitude is more prevalent in California than in many others places we have visited and studied.

Then there are the less self-serving, but often equally hurtful premises on which generations of well-meaning people have been "helping" us. Jacobus tenBroek, whom many of you remember as the founder of The National Federation of the Blind, as a teacher at UC Berkeley, and as a writer and thinker on poverty and disability issues, called it the "tyranny of good will". We find this in most places. It seems almost a given in social service systems that we are familiar with.

It is important at this point to make clear that we believe in the ability to achieve independence by the vast majority of persons who carry the label of "developmental disabilities", and in particular those classified as having "cognitive disabilities". By independence we mean substantial control over the fundamental decisions of life: where to live and with whom; what to eat, and when and with whom; what to wear; when to go out and for what purposes. This is, of course, only a partial list for purposes of illustration.

Lamentably, it is our perception that the current administration of the executive branch of California Government does not have a significant commitment to helping consumers live up to their potentials. We are dealt with basically as a burden to the taxpayers, and our <u>existence</u> constitutes the <u>public problem</u> to be dealt with. There is precious little orientation in the current administration to the business of <u>helping us solve our problems of everyday living</u> - and unfortunately this attitude filters from the top down along with the dollars that control system behavior.

This is perhaps the appropriate place to make a critical point to the Committees: **WE DO NOT BELIEVE THAT THE FUNDAMENTAL PROBLEMS WITH THE CALIFORNIA DEVELOPMENTAL SERVICES SYSTEM LIE IN THE LANTERMAN ACT, WHICH STILL STANDS AS A MONUMENT TO FORWARD THINKING. WE PERCEIVE THAT THE PROBLEM IS RATHER ONE OF FINDING WAYS OF FORCING THE ADMINISTRATORS AND SERVICE PROVIDERS IN THE SYSTEM TO OBEY THE LANTERMAN ACT AND RELATED LAWS!**

This is a daring statement, we realize. However, as the Committees proceed with their investigations, we will be happy to assist in identifying specific examples of what we are alleging here. Tragically, they abound. Programs that do not stimulate growth and development are not being devendorized in any systematic way. More than a decade after the Legislature required it, a quality assurance system has yet to be set in place. The demand that consumers be placed in the least restrictive environment is ignored, or, we believe, at times actually subverted. Programs that, in our opinion, meet the intent of the Lanterman Act with respect to assisting consumers and their families to function in the most normal ways, are starved for resources or hounded out of existence. We can assist the Committees to gather evidence on each of these allegations. And there are more. We hope to provide input to the Committees during the entire study process, and will work as closely with your staff as we are able.

SPECIFIC RECOMMENDATIONS

Our belief in the ability of adults with severe disabilities to live independent, integrated and productive lives is not based on a denial of the existence of conditions that impair our functioning to a greater or lesser degree. Rather, we differentiate between physiological or functional disabilities, on the one hand, and on the other, the handicaps placed on us by the erroneous beliefs of society and/or the service systems that are designed allegedly to serve our needs to live with our disabilities.

It is therefore in the spirit of our firm belief in and total dedication to the principle that services to people with developmental disabilities can be emancipating both to consumers and to the public in general that we offer the following specific recommendations for consideration by the Committee.

1. INDEPENDENCE AND INTEGRATION: FAMILIES AND CHILDREN

The membership of Capitol People First is composed largely of disabled adults whose families received little or no help with them when they were children. The type of assistance offered/provided was generally to institutionalize disabled children, or if the parents insisted on keeping them at home, segregated programs and services for them. It has been less than 15 years, since the passage of PL94-142, that talk of integrated education in the community has taken a meaningful turn. Services to families in the their own homes is still more talk than action, and the idea of permitting families to control the nature of those services (generally through control of the funds expended on such services) seems to be a puzzling concept for many Californians.

The childhood experiences of most of our members were less than happy. Because of that, we sometimes forget that there is a new generation coming along who need not be put through the pain nor subjected to the scarring experiences of the Retarding Environment. When we think about it, however, we realize that the CHILDREN must be the system's number one priority.

a. Families must be kept together, and the assistance they need for this should be given to them - <u>in their own homes</u>.

b. All disabled children should be integrated in school and into the community at the earliest opportunity.

c. Making this set of issues priority number one also means a massive emphasis on prevention of developmental disabilities. In fairness to the system, this has been a priority, but much more can and should be done. We believe we know how to free up some of the resources needed for this and related vital activities such as early intervention, complete integration of disabled children in school from the very beginning, and other fundamental activities designed to reduce the duration and degree of dependency of persons with disabilities to an absolute minimum.

2. INDEPENDENCE AND INTEGRATION: INDEPENDENT LIVING FOR ADULTS

<u>Background</u>

Recommendation 1. above does not mean that we write ourselves off - <u>we</u> being the adults who have been subjected to and handicapped by the Retarding Environment. We accept that the children have first priority, but believe that proper services to <u>us</u> can create a WIN/WIN situation for consumers and taxpayers, ultimately releasing resources to put in places where they can do the most good.

In the 1980's, stimulated by the success of the Independent Living movements of other groups with severe disabilities in demonstrating that control of one's own life, in a home of one's own choosing, was not an idle dream, a small group of people labeled as mentally retarded began working with dedicated parents, professionals, and volunteers to determine if the goals of <u>independence</u>, <u>integration</u> and <u>productivity</u> could be achieved on a significant scale within the developmental services system.

The objective was to show that a reasonable degree of belief in oneself, bolstered by the willingness of society to extend financial and moral supports in a variety of ways, could enable INDEPENDENT LIVING for people who previously would have been lifelong dependents of society.

That dependency otherwise entails institutionalization in nursing homes, state hospitals, or maintenance in non-medical group facilities with high staff/client ratios, etc., at huge cost to society not only in dollars spent on care, but also in the loss of productivity of the persons so isolated from the real world.

Unfortunately, this movement by people labeled as retarded to achieve genuine independence began coincident with a sweeping reduction in government commitment to publicly assisted human service programs, especially new ones. So today, for example, in California, of the one billion dollar budget administered by the State Department of Developmental Services, about half still goes to maintain state hospitals for 8% of the served population, while 2% of the same budget finds its way (perhaps) to services to support independent living by the roughly 6-8% of system clients who are living in unsupervised arrangements.

We need to make it clear that we are not discussing inadequacies with respect to the independent living training program segment of the developmental disabilities system, which continues to demonstrate the efficacy of its services. What we are concerned with is allowing clients who are living on their own to experience the full impact of independent living by promoting the development of significant enhancements to the services they now receive once they have begun to live unsupervised lives.

Nor are we discussing the possibilities only for "high-functioning" consumers. Included among the clients of the developmental disabilities system are many living with multiple disabilities, and about 90% of such cases include cognitive impairments. The vast majority of these clients are maintained in high-cost, restrictive institutions - state hospitals, nursing homes, intermediate care facilities. A handful of these people with multiple, severe disabilities have found (or fought) their way into Independent Living programs, and are struggling, generally successfully when they get the right supports, to achieve a stable, integrated life in the community. Capitol People First is proud to claim a significant number of such persons among our members.

Earlier we spoke of a **WIN/WIN** reallocation of resources with in the system. We must be careful here that we do not appear to endorse the removal of resources from the system. Quite the contrary. We have been among the most vocal critics of the administration as it has inappropriately (and possibly illegally) removed resources from the DD system through alleged attempts (frequently failed, at great cost to the quality and continuity of services - cf. SB50 of just this spring) at replacement of state funds with federal funds.

But if the system can be moved in the direction of the long-standing federal goals of **INDEPENDENCE, INTEGRATION, AND PRODUCTIVITY**, goals underlying the original Lanterman Act as well, then fiscal and program priorities can be put into a rational framework that will serve all needs much, much better and with significantly more fiscal efficiency.

The proposal is simple. Its execution can be an interesting challenge in the face of resistant administrators. But the potential results could be dramatic beyond the belief of most current observers of the developmental services system.

a. Wholesale movement to least restrictive environments

We believe that many thousands of adult primary consumers now living in out-of-home group placements (there are currently more than 60,000 in this category in California) can be taught to live with no supervision, or very minimal supervision in the form of visiting support services. We have seen people with the same social/functional characteristics as consumers who have learned to live on their own being kept under strict supervision in state hospitals (euphemistically called developmental centers), nursing homes, and board and care homes. The costs of such "care" run from 4 to 10 times what is currently spent on consumers who live in their own homes, in control of their own lives.

We believe that spending half the DDS budget to maintain state hospitals for 8% of the served population, and less than 2% on services to support independence is a totally inept and unacceptable allocation of resources. It reflects a violation of the spirit - and, we believe, the letter - of the Lanterman Act, which clearly and unequivocally calls for the development of least restrictive placements for clients of the DD system.

In 1985, DDS issued a draft proposal of a long range (5 year) plan. That plan called for, among other things, the development of 10,000 independent living placements by 1990, and a reduction of the state hospital population by about 50% over the same period. We urge the Committee to study that document, and to extract from the Department the reasons it receded from its original ideas, why such progressive ideas can't or shouldn't be implemented starting at once, and how much a system based on the 1985 ideas would be costing relative to the costs of running the system as it continues to be run.

b. Community integration requirements

We do not argue that California communities are already well-prepared for a large influx of persons with disabilities. We recognize that the facts generally are otherwise. But many of the areas of unpreparedness relate to failures of government to respond to the needs of many populations, not just the disabled. Affordable, accessible housing is scarce. Public transportation is poor at best, and abominable at worst. The refusal of large numbers of health professionals and institutions to accept Medi-Cal is a scandal of major proportions. In general, the poor, the elderly, and the disabled are disadvantaged by these lapses of public responsibility.

Ironically, the failure to deal with these issues results in the creation of "gulags" for the disadvantaged - in the community, in the form of such things as public housing, which is once again in the news as the subject of continuing "sleaze" management at high levels of government - and out of the community, in the form of astronomically costly to merely outrageously expensive institutional placements, totally inappropriate for persons who are not acutely ill.

If such "gulags" were abolished - and we refer to such institutions as nursing homes and other warehouses for the elderly who with proper support could maintain independence, as well as to institutions for persons with developmental and other disabilities - enormous amounts of money would be freed to expand and maintain community supports for independent living. We detail some of those supports below. We have been investigating and conceptualizing with other interested individuals and groups a variety of means of enhancing the service system from outside as well as from inside the system.

If it can be demonstrated that these enhancements can and do assist the system to introduce clients into and maintain clients in the least restrictive environment, policymakers should consider actual vendorization of some of these enhancements, and assisting in other ways those which are appropriate to the voluntary sector to operate on a stable, ongoing basis.

A brief example of the service enhancements follows, using a general conceptual framework of <u>Personal Assistance for Independent Living</u> developed in conjunction with World Institute on Disability:[2]

> ~ Maximizing client self-direction and self-reliance as recruiter and employer of an attendant. While there are significant similarities in the problem when the client has only a physical disability and when the client has a cognitive disability as well, more often than not the differences in the intensity and even nature of the problem are dramatic. Time and again we have seen the extreme dependency and vulnerability which accompanies the need for such service. Low-paid, inadequately trained personal service attendants too

often replace the institutions as oppressive, self-serving forces in the lives of persons who under _ideal_ circumstances have a difficult time speaking up for themselves.

Thus, determining what additional training of involved parties and what additional external supports to achieve the desired ends may be necessary when the client has multiple disabilities including intellectual impairments is of an INCREASINGLY HIGH PRIORITY as the issue of gaining and/or maintaining independent living becomes a central concern.

~ Circles of Support. There have recently come to our attention a Canadian experiment known as "_Joshua Committees_," and similar support-network building efforts in Connecticut and Colorado. These are support circles of citizen advocates who commit themselves to becoming a _family of neighbors_ to an individual to help her/him truly integrate into the community. Assistance provided may include helping meet unusual transportation needs, introduction to a variety of integrated social situations (and hand-holding where such seems appropriate in the ice-breaking stages), specialized teaching where the vendorized service system is unequipped or unwilling to supply it, assisting the client to find innovative housing - i.e. a living place well-adapted to the person's needs, both physical and social - and so forth. (Note that this concept is _entirely_ distinct from the better-known _peer_ support groups.)

The apparent advantages of this technique include the number of dedicated friends and teachers suddenly (and indefinitely) available to a disabled person who is struggling to gain or maintain a foothold in independent living, the client's variety of experiences with a large array of facilitative assistance, the mutual support and insulation from burn-out the group members provide each other, and the rapidity with which such intensive community involvement may help the client with "catching up" to the real world.

~ Services to reduce need (duration, intensity) for other services. Examples: friendly health monitoring in the absence of visiting nurse services to avoid acute care hospitalization; simple friendship to avert the sense of isolation that often leads to emotional breakdowns.

~ The volunteer advisory staff of Capitol People First has pioneered a sophisticated communications assistance program which we call simply <u>facilitation</u>. Essentially, we assist people with cognitive disabilities to access information on which to make informed choices, and also to achieve a more effective expressive communications system. This subject is explored in several concept papers developed by Capitol People First which are available on request.[3]

~ Capitol People First has also pioneered a peer counselor program, utilizing the services of a developmental disabilities system client who has shed institutionalized and "retarded" behaviors, established her/himself as an integrated, independent member of the community. These successful peers can assist other clients with problem-solving as well as serving as a positive role model for people struggling to achieve or maintain their own independence. Again, discussion papers on this subject are available from Capitol People First.

3. PRODUCTIVITY

The issue of productivity has several dimensions which we believe can be properly considered by the Committees in their study. The Committees will be well-advised to take a multi-faceted look at the system's approach to work and its alleged equivalents, day programs for "non-competitive" consumers.

a. <u>Supported Employment</u>

We have been particularly gratified to observe the Department of Rehabilitation and the OSERS Consortium discovering that it can "cream" from the DD population the way it does every other disability group. With the advent of the Supported Employment paradigm, people with developmental disabilities, especially those with cognitive disabilities, who were heretofore consigned to sheltered workshops or other segregated day programs, have been assisted into competitive integrated jobs. The Legislature needs to verify this perception, and to keep the pressure on Rehabilitation to continue creaming through the Supported Employment program or in any way necessary to achieve results the results that are now obviously possible.

We believe, however, that the Legislature should be especially wary of "enclaves". The data suggest that enclaves generally do not promote integration, do not provide decent wages, and may be a subterfuge for moving the Retarding Environment and continuing sub-minimum wage payments into the so-called real workplace.

Finally, on the subject of Supported Employment: One of the selling points of the program has been that it will provide real jobs for people with severe disabilities. We have seen films of such achievements, but we have yet to see one of our own severely disabled members assisted into such a job - other than as a telephone solicitor for dubious products.

We recommend to the Committees that they establish criteria for determining who is a severely disabled person eligible for Supported Employment services, and then do a census of job placements of such people. In the process, you may wish to examine the financing methods used by the program to develop job opportunities. We believe you may find significant structural disincentives to assisting severely disabled people into the regular job market built into the fiscal management of Supported Employment in California.

b. Eliminating sheltered workshops and segregated day programs for persons with developmental disabilities

Surviving in the System..., a document produced in 1984, states our still unchanged position on segregation in all forms. We have been, and continue to be, unalterably opposed to the placement of people with disabilities in euphemistically-named warehouses which are either medical model settings (state hospitals, nursing homes), or babysitting facilities such as most group homes, sheltered workshops, and "day programs." If the Committees wish, we can lead them to representative sites of each of these categories virtually anywhere in the state - one visit is worth 10,000 horror stories on paper.

We are happy to share with the Committees a statement on the practical disadvantages of segregation that we developed in recent years:

> Why segregation is counterproductive.
>
> We're all aware of the moral and constitutional issues implicit in the segregation of "labeled" people. What follow are some practical and operational observations relating to the argument that segregated programs are wrong because they're ineffective.

a. Segregation is a structural inhibition to normalization.

(1) In itself, segregation promotes maladaptation through reinforcement of learned deviant behaviors.

(2) In segregated settings, there is an absence of normalizing, maturation-stimulating role models.

(3) The very nature of segregation creates restriction of exposure to and experience of a normal variety of environments retards socialization and understanding, hence informed choice, of options.

b. Segregation of people with disabilities fosters vulnerability through teaching them to rely on and respond without question to an authority figure - the KEEPER.

c. Segregation does nothing to counter the misperceptions of the non-disabled public - cf. Wolfensberger "devaluation" theory.

LEGISLATIVE RECOMMENDATION

Whereas in most areas, we believe that forcing administrative obedience to the Lanterman Act is the appropriate first step toward determining needs for substantive program legislation, the case of sheltered workshops and their ilk is an exception. We believe that the Legislature should adopt a phase-out plan for discontinuing public support of such archaic facilities and programs. People who are able to work competitively should be helped to find and keep jobs - using the supported employment model or any other model that is appropriate and effective.

For people who clearly are not competitive in the private labor market, a variety of options - none involving forced segregation - need to be developed. This is not the time or place to outline such options - Capitol People First will be happy to work with the Committees after they have had an opportunity to observe first-hand what we are critiquing here.

c. Non-economic productivity

World-wide, there has emerged in recent decades, among advanced thinkers in the fields of disabilities and economics, the understanding that paid work is not the only form of productivity.

Some members of the Capitol People First Board of Directors have generally opted not to pursue low-wage, dead-end jobs simply to prove to the world that they can WORK. For this, they have come in for their share of criticism. "To be truly effective politically," say these critics, "you must demonstrate that you share in the American dream. Otherwise people won't take you seriously." We believe that this represents a sadly limited view of the "American Dream".

Connie Martinez, our Vice-President, is an excellent example of the contrast between paid and non-paid productivity. Connie has held the following jobs in the past ten years or so: hanger-sorter at Good-Will Industries or its functional equivalent - she can't exactly remember the name of the place; table-mopper in a cafeteria; public policymaker. The first two jobs were paid - sorting hangers at rate of 17 cents an hour, busing tables at the then-prevailing minimum wage. A consequence of the latter job was that she lost her Medi-Cal coverage.

Now she is a member of the State Council on Developmental Disabilities, a member of the executive committee of the President's Committee on Employment of People with Disabilities, a board-member designee of the new Coalition of Regional Center Clients, a member of the President's Task Force on Recruitment of Americans with Disabilities for Public Service, a member of the Congressional Task Force on the Rights and Responsibilities of Americans with Disabilities. None of these positions remunerate her, other than covering expenses (and not even that in some instances).

Of the three options for productivity she has been presented during her life, it is no great mystery why she prefers public service, even if unpaid. To call her unproductive and a bad role model for other consumers, as some of her detractors have done, is to demonstrate a serious lack of comprehension of productivity and priorities.

Likewise, the entire Capitol People First Board, whether or not otherwise employed, has dedicated itself to disability awareness training in and through public schools, generally in conjunction with the Hand-in-Hand project of the San Juan School District, supported by the State Department of Education. The importance of this activity cannot be over-emphasized, and yet it is not seen as a "job" by most observers.

Our CPF President, Sandra Jensen, is a woman who was born with Down syndrome. Notwithstanding the prognosis by the doctor who delivered her, she is able to live on her own, in her own apartment. She has educated President Bush - when he was Vice-President - to disability issues. She reads and writes. She can use American sign language to communicate with persons who are deaf. In recent years, she has declared that her Down Syndrome has given way to Up Syndrome. To know Ms. Jensen is to feel better about the world and about oneself - a not insignificant contribution to us all, and one that may be regarded appropriately as a form of productivity.

We dwell on this issue because it is one of perspective. Not to cherish the valid contributions to society of people with disabilities simply because they are not remunerated can be itself a gross form of discrimination. Be clear that we are not denigrating paid employment - quite the contrary - but we <u>are</u> arguing that such is not the full or adequate measure of a person's value.

CONCLUSION

CAPITOL PEOPLE FIRST salutes the California Legislature, and in particular the Committees jointly holding today's hearing, for the massive commitment represented by SR9. We will be pleased and proud to be called on to assist in any way we can, and if so asked, we pledge our unstinting cooperation in this endeavor.

CAPITOL PEOPLE FIRST to SR9 HEARINGS, 6/16/89 NOTES: page 1

[1] CAPITOL PEOPLE FIRST is a non-profit 501(c)(3) organization of persons with mental retardation and other developmental disabilities, based in Sacramento, CA. It is dedicated to self-advocacy and to helping primary consumers of developmental disabilities system services assume greater control over their own lives. We believe that the greatest degree of success in self-advocacy comes through constructive action in demonstrating to the world what needs to be done and what can be done to achieve normal living opportunities for disabled persons.

Capitol People First's current board of directors and advisors are the same team that produced Surviving in the System: Mental Retardation and the Retarding Environment under contract to the California State Council on Developmental Disabilities. This report is believed to be the first needs assessment and set of policy recommendations to the developmental disabilities system ever composed substantially by mentally retarded primary consumers of developmental services.

Since publication of Surviving in the System, of which more than a thousand copies have been requested and distributed world-wide, Capitol People First has become increasingly active in developing nontraditional models for helping persons with mental retardation overcome the "retarding environment" and achieve new competencies for living their lives with the minimum of dependency.

The key to this lies in enabling disabled people to live, learn, work and play in integrated environments, where non-disabled people will be their associates and role models. Where such integration has in fact taken place, it can be observed that the disabled participants themselves soon become role models for other persons with disabilities. This observation and its implications, as well as the convictions and commitments that it inspires, are the basis for the active involvement of Capitol People First in projects intended to educate change change the service system and significantly impact public attitudes. Among these projects are the training of people with mental retardation as peer counselors in the developmental disabilities service system, and developing living situations for severely disabled people in which they maintain genuine control over the services they need.

For further information, please contact:

CAPITOL PEOPLE FIRST
6835 Wavecrest Way
Sacramento, CA 95831
(916)424-0121

[2] **THE WORLD INSTITUTE ON DISABILITY** is a private non-profit 501(c)(3) corporation which brings the perspective of people with disabilities to the study of public policy. In the five years since its inception, WID has become widely known in the disability movement and the service system for the quality of its research and public education efforts.

WID is currently carrying our a federal project that focuses on the California Developmental Disabilities System. This project asks persons with developmental disabilities, their families, and professionals, to help refine a quality of life scale that can be used to assess the effectiveness of services for the population with developmental disabilities. In this project WID is working closely with Capitol People First, as well as with the California Developmental Disabilities Council, the Organization of Area Boards, the Northern Los Angeles Regional Center, Protection and Advocacy, The California Association of Rehabilitation Facilities, the California Coalition of Independent Living, the Ways and Means Committee of the California Assembly, and the University of California, Los Angeles and Irvine.

[3] In this particular regard, we feel we must bring to the attention of the Committees the matter of our sister and Vice-President Connie Martinez, and the difficulties she has experienced with the State Council on Developmental Disabilities. We support her in her struggle for treatment as an equal, and we support other primary consumers involved with the State Council who also have had difficulties with Council staff and/or with Council policies.

We know that the members and staff of the Committee are familiar to a greater or lesser degree with Connie's problems, and this is not the place to review them - Connie is perfectly capable of that on her own. But because Capitol People First has been so intimately connected with the development of "facilitation" for the consumers who are in increasing numbers being appointed to policymaking bodies, we feel we cannot allow the current situation with Connie and the Council to go unremarked. At the same time, we believe it is proper and relevant to care for consumers on the Council or its committees, because it is in direct contradiction to the current policy on facilitation.

Unless the Council votes other than is expected today at its regular meeting (today is Friday, June 16, 1989), Connie will be denied independent facilitation in her role as a Council member. Two former employees of the Council were invited to bid on the facilitation contract that the Council has been letting for the past three years, and both of them underbid the person who has facilitated Connie all that time. Connie has refused the services of the people who submitted the lower bids, on grounds that are not of importance here, except as they reflect the Council's unwillingness or alleged inability to permit consumer members to have independent facilitation. If the

Council should plead inability under the law to accommodate Connie's demands for independent facilitation, as is indicated in several communications from James Bellotti, the Council's Executive Director (which Connie has shared with us and we believe will be happy to share with the Committees), Capitol People First will be pleased to work with the Legislature to remedy this problem.

With respect to the issue of attendant care for persons with disabilities serving on the State DD Council, we raise a similar concern as to the wisdom or propriety of the avowed Council policy. Prior to the April meeting of the Subcommittee on Consumer Involvement, Diana Kenderian, a member of the Subcommittee from Fresno, a person who can travel without an attendant but needs attendant services on site at Subcommittee meetings, requested the Council to find an attendant for her in Pomona, the location of the SCI meeting, which is several hundred miles from Fresno.

Ms. Kenderian received a letter from Harvey Bush, Chair of the State Council on Developmental Disabilities, dated April 12 (two days before the Pomona meeting), which said in relevant part:

> "...When accepting appointment to the Council, its Committees or Subcommittee (sic), the appointee must take into consideration the responsibilities that go along with such a position. One particular responsibility is that of making arrangements for one's own attendant care if it is a requisite for participation. On the other hand, it is the responsibility of the Council to provide the finances necessary for that attendant care. In short, the appointee is responsible for locating and arranging appropriate services, while the Council, and by extension its staff, is responsible for paying for that service. I feel that it would also be appropriate for Council staff to provide suggestions to the appointee, potential resources for services... (sic)"

In other words, the Council's policy on attendant services for members is the precise opposite of its policy on facilitation. In both specific situations which have elicted the "policy" positions of the Council, the consumers in question have been put at a significant disadvantage. We must, under the circumstances, draw the conclusion that the Council's policies with respect to Personal Assistance services to disabled Council members, while apparently inconsistent, are in fact consistent in such a way that consumers are invariably on the losing end.

arc

ASSOCIATION FOR RETARDED CITIZENS – CALIFORNIA
1510 J Street, Suite 180, Sacramento, California 95814, (916) 441-3322

Joan S. Taugher
President

Frederic W.J.G. Hougardy
Executive Director

Statement of Association for Retarded Citizens - California for the June 16, 1989 hearing of the Senate Subcommittee on Mental Health, Developmental Disabilities and Genetic Diseases, the Subcommittee on the Rights of the Disabled, and the Assembly Subcommittee on Mental Health and Developmental Disabilities on "SR 9": AN OVERVIEW OF THE STUDY OF THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICES ACT."

I am Joan Taugher, the President of the Association for Retarded Citizens-California. I am also the sister of a man with mental retardation, who has lived with me and my husband for the past 31 years.

The ARC thanks the Legislature for undertaking this study of the administration of the Lanterman Developmental Disabilities Services Act. The ARC was founded in 1950 by parents and friends who realized the need to advocate for the general welfare of persons with mental retardation. In the past two plus decades, the Legislature has established a record of action on behalf of defining the state's role in providing for children and adults with mental retardation and other developmental disabilities.

In 1966, the Legislature appropriated funds for two pilot regional centers. Three years later, the Legislature passed the Lanterman Mental Retardation Act of 1969, which established 21 centers statewide. In 1975-76, the Legislature undertook a reappraisal of services for persons with mental retardation and the result was the 1976 Lanterman Developmental Services Act. As with all major developmental disabilities legislation, the 1976 legislation was overwhelmingly supported and passed by the Legislature and the developmental disabilities community. In all of the Legislature's action, the ARC has helped in shaping the policy debate and participating in drafting the resultant Legislation.

The ARC has been concerned for a number of years about the failure of the Lanterman Act to be fully implemented and the resultant negative consequence for children and adults with mental retardation and their families. Rather than each year bringing movement towards full implementation , we see slippage and erosion. We are dismayed and frustrated that two plus decades later, the Legislature must address why the Lanterman Act is not implemented.

As your committee notice states, a comprehensive study of the Lanterman Developmental Disabilities Services Act is an unprecedented and monumental task being undertaken by the Legislature and the Legislature is committed to doing a thorough and meaningful job. At the February annual meeting of our membership, the ARC delegate body passed a resolution on SR 9 urging the Legislative committees to keep the Lanterman Act and the findings of the Supreme Court in the 1985 ARC-California ruling, with respect to the Act foremost in your deliberations.

The ARC remains fully committed to the values, philosophy and goals of the Lanterman Act for individuals with mental retardation and other developmental disabilities.

The ARC remains committed to the 1985 ARC-California vs. Department of Developmental Services California Supreme Court ruling. The Court declared that the Lanterman Act clearly defines the right of the developmentally disabled person to be provided with services and the corresponding obligation of the state to provide them. The ruling also said that it is through the IPP procedure that a developmentally disabled person receives, as an entitlement, services that enable him to live a more independent and productive life in the community.

We offer you the following comments and observations as you and the developmental disabilities community undertake this very important study.

What does ARC want? The ARC wants the Lanterman Act fully implemented for persons with mental retardation and their families.

How does the ARC believe you should undertake this study? The ARC believes that the study must keep as its primary focus, the individual and his/her needs and the extent to which his/her needs are met. Where services fall short, you must determine why responsible agencies are failing to take all necessary steps to see that the clients' needs are met.

The study of the administration of the Lanterman Act must examine all the elements in the Act. All the provisions are interconnected in the creation of advocacy and service systems to help consumers and families throughout their lifetime. While the availability and quality of services is better than it has ever been, parents don't have to look far to see failings in the service and advocacy systems. We give you five examples. They are not the exception to the range of what happens to people with developmental disabilities in the course of how publicly funded agencies conduct themselves.

* In Sacramento, this past January, with no advance notice to clients and families, 87 children and adults with developmental disabilities were thrown out of their Sacramento nursing facility, Laurel Hills Developmental Living Center, as a result of facility problems with the Internal Revenue Service (IRS). Shocked parents and guardians received phone calls that morning from Alta Regional Center telling them to pick up their family member or they would probably be transported to state developmental centers. (Some parents saw it on TV!)

* In a major series in January, the Los Angeles Times detailed case after case of abuse, neglect and sometimes death in a series on problems in the community care system for persons with developmental disabilities.

* In November 1988, Westside Regional Center announced cuts in client services in response to a projected budget shortfall. Thus, only four years after ARC parents battled all the way to the Supreme Court on behalf of their sons and daughters, a regional center, which exists only to be the advocate for consumers and families, directly flaunted the Supreme Court and announced cuts in service. The ARC had to threaten Westside with legal action before Westside rescinded its announced cuts.

* This year the Association of Regional Centers Agencies sponsors legislation SB 50 to deal with a shortfall in the regional center operations budget. The statewide purchase of service budget shortfall is not even addressed in the legislation.

* Inland Regional Center includes language in client IPPs to the effect that funding for needed services will be according to Board approved funding policy and within budgetary constraints. In response to ARC's inquiry, Protection and Advocacy determined that the language does violate the intent of the Lanterman Act and the 1985 ARC-California Supreme Court ruling.

If the Lanterman Act were being followed in lett0er and intent, the Los Angeles Times could not write a series on neglect and abuse in community care, 87 clients in the Laurel Hills Developmental Center would not have been abruptly displaced and lastly and most importantly, the ARC would not have had to threaten to sue a regional center over its plans to balance its purchase of service budget on the backs of vulnerable and dependent persons and their families.

In simple terms, the Lanterman Act established the ground rules by which various publicly funded agencies are to see that children and adults with mental retardation have their needs identified and services appropriate to those needs provided. Too many publicly funded entities which are statutorily responsible for advocating and protecting vulnerable and dependent individuals, are not doing their jobs as called for in the Lanterman Act and other state law.

The ARC wants you, our elected officials, to hold the regional centers, the Departments of Developmental Services and Social Services, and a host of other existing bodies, responsible and accountable for their performance.

As I said in my opening comments, I speak to you as a sister of a man with mental retardation and as the President of the ARC. I am one of the persons who can say that my family member is having his needs met through the existing service system. On the other hand, I know first hand of too many families who are not able to advocate for their family member and who are not able to secure necessary quality services. I am a member of the ARC because ARC members know that abuse and neglect does exist and that many persons with mental retardation have no family to be their advocate and to be concerned for their welfare.

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June 16, 1989

Joint Hearing of
The Senate Subcommittee on Mental Health, Developmental
Disabilities and Genetic Diseases;
The Subcommittee on the Rights of the Disabled;
The Assembly Subcommittee on Mental Health and
Developmental Disabilities

SR 9: AN OVERVIEW OF THE STUDY OF THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICE ACT

Mr. Chairman, Members of the Committee, Ladies and Gentlemen:

It is indeed an honor and privilege to appear before you today as you commence a significant, comprehensive joint investigative study of all aspects of the administration of the Lanterman Act service system.

I am Joshua White, President of the California Association of Residential Care Homes. CARCH is an organization which was formed specifically to promote, obtain, support and safeguard the best interests of the residential care field. It was organized in 1967, and since its inception, we have endeavored to work with legislative and administative offices of the County, State and Federal government on issues addressing the residential care home industry.

I have with me, Elizabeth Halahan, Vice President of CARCH, and also owner of a community residential care facility serving developmentally disabled persons. Ms. Halahan, a noted expert in the DD field, will be giving testimony next.

This is a most significant hearing, the first of its kind in a long time. A detailed, comprehensive review of this system is long overdue, for our industry has been engaged in a struggle for many years, trying to maintain quality care. We are committed to the original goals of Lanterman. We are committed to providing quality care to residents who are placed with us, and as we grow and develop, we are continuing to improve the quality of care and represent our membership in a most professional manner. Our staff is professionally trained and prepared to work with you and the Committee's staff during the conduct of this study.

We are pleased that the Committee will be encouraging the formation of small working groups throughout the state. CARCH is ready to assist the Committee. As a statewide organization, we have represented in our membership, persons from throughout the state from a diverse population and you will find that our association is available and is in contact with and part of grass roots organizations which can assist the Committee as it goes about the task of setting priorities and discussing alternative recommendations.

The implementation of the Lanterman Act is, obviously, of great concern to all of us in this industry, from care givers, to consumers, to families, and state profit and non profit organizations. We look at the Lanterman Act from a perspective of four questions:

with the lack of adequate funding for home suport for families, the limitations of respite care and the lack of assurances from the federal government that the program applications will be funded as submitted.

We are confident that the launching of this study and the series of hearings to garner testimony throughout the state will provide many other areas of great concern to all of us. Tho other concerns of our organization are as follows:

ONE: The matter of fiscal constraint is a major problem. Let the record show that providers of care are suffering from an underfunding that approaches 30%. As we review the recent report from Price Waternouse, we are concerned that this audit primarily concerned itself with the audit of available funds for providers, not the unmet needs. We are sure you will find that a reasonable adjustment in the rate situation is necessary just to keep up and stay alive.

TWO: It should be noted that the bifurcation of the funding of this program creates enormous problems, particularly when you realize that the non-medical funding comes 100% from the general state fund and the present shortfall or deficit places us in a disadvantageous position for it violates the original intent of Lanterman by creating a segregated system.

In summary, the unbridled cost expansion without cost considerations tends to freeze and brutalize us and the entire system. Persons testifying today will be providing you with information about what is not working and what the bariers to the implementation to the Lanterman Act are. I am sure that much evidence will be presented as to the causes. We merely wish to point out that the Waterloo issue of our organization is very upsetting, but we firmly believe that in the very beginning, the estimate of care was understated. We need to learn how to revise the base rate. We need to learn how to appropriately slot the array of need, and we need to learn how to estimate that need, for in our system, people are slotted into categories which makes it very difficult to take care of people to need total care as well as people who require less care.

Finally, Mr. Chairman, we are delighted to know that your Committee plans to study all aspects of the administration of the Lanterman Act, and we would hope that that comprehensive look will also look at the way in which money is transmitted to the care givers. We would like to focus our energies on providing and maintaining the care of high quality and ensure that the services we provide are the best quality, rather than having to focus so much, as we have in recent years, on cost restraints. Many of us in the provider industry feel embattled and somewhat repressed because of these restraints. We are prepared to answer any questions that the Committee will ask, and are looking forward to working with you during the conduct of this study.

June 16, 1989

Joint Hearing of
The Senate Subcommittee on Mental Health, Developmental
Disabilities and Genetic Diseases;
The Subcommittee on the Rights of the Disabled;
The Assembly Subcommittee on Mental Health and
Developmental Disabilities

SR 9: AN OVERVIEW OF THE STUDY OF THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICE ACT

Mr. Chairman, Members of the Committee, Ladies and Gentlemen:

Thank you for your invitation to share with you in this exchange of information during this investigative process of the Lanterman Act system.

I am Elizabeth Halahan, Vice Presdient of the California Association of Residential Care Homes. I come here not only as this fine organization's Vice President, but as a person representative of the service providers for the developmentally disabled in California, as well as an instructor for other service providers coming from Los Angeles, Riverside, and Orange County.

It is exciting to know that the system will be thoroughly looked at for its validity to properly administer the concepts of the Lanterman Act itself. For it is with total agreement by most of the Reg. Center people, providers, consumers, but especially their parents, that the intention of the Lanterman Act can stand purely on its own merits without additional creative legislation or regulation. It's these same parents and consumers who worked so vigorously twenty years ago to help inact the Lanterman Act that truly understand the inadequate administration of the Act.

The Lanterman Act stands as one of the finest pieces of legislation ever drafted, combining humanism with a working method for service delivery. As a member of the California Association of Residential Care Homes, and a service provider at-large we will do everything we can to assist you in your investigative process to enhance all aspects of this Act. Thereare a myriad of issues which this study will cover. Some of the most critical, which I will comment on briefly, are:

1) PRICE-WATERHOUSE AUDIT

Recently, I attended a meeting here in Sacramento for disclosure of the results of the Price/Waterhouse audit. It was stated that in this particular study there were no geographical differences in the cost of housing. It astounded me to hear that statement since you have only to pick up newpapers from across the state and the average person will discover costs vary from area to area. Also, the audit realized that board and care service providers were fitting their expenditures to the amount of income received, but that non-profit organizations had truer costs as did specialized services. Could that be, perhaps, because specialized services deals with a budget design of actual costs with monies then coming in accordingly, and the non-profit organizations must develop other sources of income to offset deficiencies of the state funding.

2) STAFFING/BUDGET

It is the hope of the service providers that when the state agencies are formulating budgets they remember the unmet needs of the clients we are responsible for. That when regional centers have contracts with services providers for twenty-four hour supervision that they allocate at least minimum wage plus a minimum of 18% for workmen's compensation and employer taxes to cover each twenty-four hour cycle because the work demand is there not only by contract but by need of the clients. And that, ladies and gentlemen, is only one budget item.

3) INAPPROPRIATE PLACEMENT

We have consumers inappropropriately placed in either workshops or the work supported programs that are bored, with increased behaviors, that are not being challenged. They are experienced mall walkers or sight-seer's of parks. When parents or service providers try to seek changes, they are told nothing can be done, that once an individual is in a rehabilitation funded programs. it is very difficult to transfer to a regional center funded program or vis versa. We have seen clients removed from programs they were successful in because of the difference in the funding agencies. It wasn't important that the client was doing well with little or no behaviors even though he was errantly placed there. One agency will not give in when another can pick up the bill. What happened to the idea of fulfilling client needs in this instance.

4) REGIONAL CENTER AND INTRA-AGENCY RELATIONSHIPS

We have seen client consumers, parents and service providers caught in the cross fire in intra-regional center servicing and funding. The agency of residence not wanting to fund when a client is transferred out of the district, or not providing necessary services. With respect to work supported programs, how would you feel if your youngster was scheduled to work four hours a day, five days a week, and he or she received $10 for three weeks work? And, upon investigation you find the individual was credited with twice the time for leisure activities, and four times the time for community activities, with no pay.

This was after the client, parent, service provider was advised the program was to consist of four hours of productive work to be remunerated for. There are excellent programs available, but there are just as many not living up to their commitment to the worker. Here, again, however these programs are underfunded.

5) TITLE 17

Title 17 regulations and rate study. In talking with individuals from the various areas in the state, questions and statements are raised such as these:

1. The criteria set is almost in line with those of the ICF programs. Why, the majority are non-medical facilities.
2. The small six bed home is becoming a mini bureacracy with the level of paperwork demanded. They are becoming the institution that the client was taken out of. The safe castle "home" atmosphere is being lost.
3. With lack of funds, which creates staff shortage, there will be less quality time spent with the residents.
4. With the "paper push" every level is so busy qualifying their existence, that the facts and figures say what others want to see or hear, not necessarily what is.

I had been advised that a group of individuals had approached a particular legislator to seek his assistance in getting additional funds for services to the disabled person. His reply was this: "Your departments budget is sufficiently funded, you just need to change the system so that the funds can be appropriated from the top to the front lines where they are needed. The outline for servicing the disabled is already there, it just needs full implementation."

There were figures circulated not too long ago that revealed during 1987-88 75,000 deinstitutionalized developmentally disabled persons were provided services for $410,000, while 6,800 institutionalized persons received services for $468,000. The building in which those folks reside may have changed, but when did the idea of the program change?

6) CLIENT RIGHTS ISSUE

Orange county has not yet joined the ranks of the ARM program. But for those areas that have, the lament is the same but more intense. The wheel has been reinvented but with much more paper work. The owner/administrators feel disassociated from their residents. Rather than giving direct care, or having that ability to "read" the unsaid of the developmentally disabled person to head off behavior propblems, they are obligated by regulation to stay caught in a mirage of paperwork. And, what happens to clients rights when the client decided he/she doesn't care to be "programmed" that particular day or in that particular program? When does that consideration take place? When a person works however many hours a given day, where does their wishes and desires come in as to how they will spend the rest of their day before retiring?

Thank you very much for allowing me the privilege to share with you this afternoon.

Elizabeth Halahan, Vice President
California Association of Residential Care Homes, Inc.

Senator Dan McCorquodale
Chair Senate Sub-Committee on Mental Health,
Developmental Disabilities and Genetic Diseases.

Senator Milton Marks
Chair Senate Sub-Committee on the Rights
of the Disabled.

Assembly Member Richard Palanco
Chair Assembly Sub-Committee on Mental Health
and Developmental Disabilities.

CASHPCR regards the decision of the Legislature to review the implementation of the Lanterman Disabilities Services Act as positive, constructive and timely. The decision to combine the resources of legislative members and staff in a joint integrated approach is most sensible. CASHPCR pledges to support the grass roots effort with factual input at the public hearings. In addition we will assist the study staff in identifying and quantifying relevant issues.

As a preliminary step CASHPCR has identified 8 areas of vital interest. These are:

1. The placement process.
2. Integration of a single system of care at Home, in the Community or Developmental Center, with equity in quality.
3. State owned, State operated community facilities.
4. A career development path for all employees in the system.
5. An objective accreditation system for all system functions.
6. Accountability and responsibility identification within the entire system.
7. Analysis of direct and indirect costs.
8. Preservation of all current entitlements.

THE PLACEMENT PROCESS

The goal of CASHPCR is to insure that all placements in the system are the result of a parent/professional analysis of the client, recorded in an Interdisciplinary Team and driven by criteria of where individuals will prosper and develop to their fullest potential, vis a vis the capabilities of placement options to develop this potential, both in the short range and long range time period.

Currently the placement process is illogical and driven by obscure legal barriers and unsubstantiated philosophical beliefs. The process has been accurately described by Mr. John Chase, in his letter to Senator McCorquodale of June, 1989 which is quoted herein:

> "The California Developmental Centers are defined by law as and otherwise presumed a restrictive environment. This situation has always bothered us as it raises barriers to placement and treatment in a developmental center that have no legal counterpart in admission to a so-called community-care facility. A Regional Center can place a client in any community-care facility it chooses, where he or she may reside indefinitely without legal review and with minimal monitoring. On the other hand if a regional center determines through its interdisciplinary process, no matter how correctly, that a client would be best served in a developmental center, enormous legal obstacles to that placement will be certainly encountered. In this latter situation, a full court hearing or trial may be required in which an adult client's parents can be excluded, and where opposing attorneys square off in a adversarial proceeding; one for placement, the other against. And with bi-annual legal reviews required of every resident of a developmental center, this same burdensome and unpleasant process can be repeated every two years. There is, moreover, a growing inclination be the courts to raise this barrier even higher. The reasons for this counter-productive practice seem to have their origin in the misbegotten notion that a modern treatment facility for developmentally disabled people is analogous to either a prison or 19th century insane asylum. This perception was always illusory, and whatever faint similarity might once have supported the analogy is decades out of date. It is, therefore, certainly obsolete and at worst that it is denying life-sustaining care to needy people. One unfortunate consequence of these obstacles to developmental center care is that severely to profoundly impaired mentally retarded people are often placed in unsuitable community-care facilities simply because of the red tape, delays and uncertainty involved in negotiating a placement in a state developmental center. And unfortunately the same discouraging process can recur every two years when a developmental center placement is subject to clinical and court review.

SYSTEM INTEGRATION

The single system integrated concept with quality of care being the overriding driver will reduce the adversarial relationship which has resulted in inappropriate placements based on fear. Developmental Centers have been tarred with perceptions of institutions of 50 or 60 years ago. Community facilities are viewed with fear because of a nebulous system of quality assurance and monitoring. Clients maintained at home have been deprived of adequate development programs because of parental distrust of conditions in both the community and Developmental Centers. There are superb community programs and facilities with dedicated staff, California has seven Developmental Centers which rate in quality of care with the finest in the United States.

There should be no difference in client security and opportunity regardless of where the placement is effected. Placement should be a dynamic event and not regarded as a life time sentence. There is significant migration today within the system. Facilities fail and clients are moved, Developmental Centers reach capacity and clients are moved, Clients can no longer be maintained in the family home and must move. Programs are judged inappropriate for desired outcomes and clients move. This will always happen. Hopefully an integrated system, where quality is the main objective, will minimize this movement. Quality is costly but in the long run quality has always proven to yield a high return on investment.

STATE OWNED, STATE OPERATED COMMUNITY FACILITIES

Eleven states now operate a certain percentage of their community facilities. I have attached a summary of their experiences which lists the rationale for the state accepting this responsibility, the relative cost vs private operation, and the anticipated growth of the approach.

The numbers of facilities range from 1 in Maine to 355 in New York. In the summary it is interesting to see that the need for acceptance of direct responsibility by the State was the primary reason for investing in this approach.

CASHPCR strongly recommends that California pursue this option on a trial basis. If for no other reason it will provide the reserve capacity that is now lacking within the existing system. Developmental Centers are near or a full capacity. Community facilities are closing or threatening to close at an alarming rate. Across the board Quality Assurance has not been attained.

CAREER DEVELOPMENT

The highest single item of cost in the D.D. system is personnel. Any successful personnel management system recognizes that people must be given the opportunity to grow. This opportunity must be visible to employees and must be supported by programs and criteria which are quantifiable and attainable.

The reward to management of such a system is a productive, informed staff. As growth occurs corresponding rewards in terms of responsibility, salary and fringe benefits, are the by product accruing to the employee.

State employees enjoy an excellent personnel management system. Unfortunately the community employees do not have a recognizable system which encourages growth. The consequences are high turnover, low morale and productivity. Isolated excellent personnel management systems do exist, and the result is what I referred to as "superb community facilities". However the average employee finds it almost impossible to define his growth path and command a livable salary within the community industry. This is a problem which must be addressed if the D.D. system is to succeed in California.

ACCREDIDATION

The keystone of credibility for the D.D. system will be the adoption of an objective system of monitoring which is unbiased and which monitors against realistic standards proposed by D.D. system advocates. The Accredidation Council for Developmental Disabilities is the type of system which insures credibility in the eyes of the parents, consumers, and the administration. California's Developmental Centers have been the subject of this type of monitoring for several years. In this time parents have seen the growth of quality, employee motivation and system acceptance. It is time to extend this system to all functions. E.G. Regional Centers, Community Facilities, Programs and Home Care support. We as parents believe we have a quality system in the Developmental Centers because of the ACDD surveys. In addition, Governor Deukmajian has mandated this procedure to convince him that the system function he is directly responsible for is working.

ACCOUNTABILITY AND RESPONSIBILITY

Todays system is a maze of techniques designed to avoid responsibility and accountability I mentioned that the Governor is the direct line for fixing responsibility for functions that are State operated. Unfortunately the community system with its protective shield developed by Private Enterprise can elude responsibility in the most frustrating manner. Abuses cause investigations, findings, rulings, delays in corrective action and ultimately forgiveness of the original transgression.

INDIRECT/DIRECT COST ANALYSIS

This may be the toughest challenge. to assure that Tax dollars supporting the system are bringing the maximum benefit to the D.D. clients. Again this is an area where hard numbers are difficult to come by. But perceptions exist that many dollars could be more effectively spent to directly benefit the client These perceptions run the gamut of high rents, ostentatious offices, swollen salaries of executives, duplicative boards, council committees, so called off site study sessions, excessive travel, ad infinitum. On the direct cost side the opposite perception exists. Employees at minimum wages and little or no training opportunities. This is an area where the Legislative Analyst, Little Hoover Commission or similar function could render a great contribution to identify inappropriate expenditures of funds and maximize direct care benefits.

8. PRESERVATION OF CURRENT ENTITLEMENTS

The most significant difference between the D.D. system and the Mental Health system is in the area of entitlements. You as legislators have established the entitlements of the D.D. system. These have been recognized by the Supreme Court as inviolate unless the legislature changes them. These entitlements have had a significant number of years to prove their true value. It is essential that any revision of the Lanterman Act preserve them.

CONCLUSION

The D.D. system has adopted a syllabus of key words which attempt to define the ideal environment Many of these key words were generated in abnormal laboratory settings where ideal conditions of funding, staff, surrounding and time, were not constrained. Under these ideal settings conclusions were reached which have been accepted today as the norm. Many of these conclusions however have not been supported by data in less than optimum conditions. A home like environment in a high crime, poverty stricken area can not be attainable and will never be considered "least restrictive". Six severe behavior clients in a single residence may never achieve the goal of normalization. Accordingly in reaching your conclusions on the effectiveness of the D.D. program the practical aspects of 20th century must be reconciled with the idealistic research and laboratory expectations.

CAPT California Association of Psychiatric Technicians

TESTIMONY OF
Dan L. Western, CAPT Legislative Consultant
before the
Senate Subcommittee on the Rights of The Disabled
June 16, 1989

Our organization represents the 5,200 Psychiatric Technicians who provide direct client care services in the state's seven Developmental Centers. The main concerns I wish to discuss today are the changing environment within the centers and state budget funding practices which have a direct impact on client care.

Over the last few years, the role of the centers has been to prepare clients for community placement, to house those clients who are beyond the ability of the community programs, and to serve as a safety net to catch those clients who spill out of community programs that have failed.

As we look at the client population of the centers, we see a steady increase in clients who have the greatest of disabilities. Disabilities that, in many cases, are far beyond the scope of community programs. Many have behavior problems in addition to other disabilities. Some have been committed by the courts in relation to crimes, and many are violent.

At the same time that the complexity of the disability and the incidence of violent behavior are increasing, the state administration has seen fit to squeeze back the staffing and services. This is putting the staff at greater risk of making mistakes and incurring injuries. And the centers themselves risk losing their accreditation by ACDD. Porterville has already lost its accreditation altogether. Agnews has failed to have its accreditation renewed, but they have one year to correct the deficiencies.

The Agnews ACDD Report stated that, "It was most apparent that the agency did not have sufficient direct contact staff working with individuals in many areas." A second comment is, "many staff, both supervisory and direct contact, acknowledged that they were working on overtime during the survey." This is a sad but common practice -- ordering extra staff to be present for show when the accreditation survey team comes around.

2400 - 22nd Street, Suite 110 • Sacramento, CA 95818 • (916) 454-1707

The Department of Developmental Services has testified that federal licensure requirements are approaching ACDD standards. When a center fails accreditation, there is a strong possibility that it could also fail the federal standards. If this were to happen, it would jeopardize hundreds of millions of federal dollars that now flow into the California program.

Some of the issues that are creating the problems in the delivery of client care come straight out of the state budget process. Although each center's executive director is responsible for client care at the local level, there are five levels of review between the executive director and the Legislature. These include the Deputy Director of all centers, the Director of Developmental Services, the Secretary of Health and Welfare, the Department of Finance, and the Governor. At each point, a bite is taken out of the center's original budget request for staffing and other needs. The end result is that funds in the proposed budget that goes to the Legislature are often less than enough to cover a center's obligations. The department's only option to free up this money is to hold positions vacant that would otherwise be filled. And that results in a direct reduction in client services.

Since this is done while the administration is developing the proposed budget, the legislators usually don't know it is occurring. As an example, the proposed budget failed to provide enough of an increase in what is called the "coverage factor." This is to cover for the time employees are away from regular duties for vacation and other earned time off, leaves, in-service training, and other demands placed upon the staff due to licensure or accreditation.

For example, state licensing requires developmental center nursing staff to be "adequately trained." To meet this mandate, DDS provides an average of 43 hours of training per nursing staff member every year in such things as CPR, first aid and record-keeping. Therefore, additional staff must be hired to cover this time. However, the budget provides staffing to cover for only 3 of the 43 hours. The developmental center staffing budget must absorb the rest. That cost is $4.85 million requiring a 1.4 percent salary savings. And that means holding 144 positions open.

Another example is when DDS contracted out janitorial and laundry services to private companies a few years ago. An agreement with CSEA required that those employees would not be laid off. Since then, most have been absorbed into other jobs with their own funding. But nearly 200 are still on the payroll without specific funding. To pay this $2.67 million cost, eight-tenths of one percent of additional salary savings is necessary. That means 82 more vacant positions.

My last example in hidden service reductions includes contractual obligations. State law requires that, to the extent feasible, school-age children in developmental centers must be educated in local schools. The law requires DDS to reimburse the counties for the cost of schooling DDS clients. But the state budget is $4.4 million short of paying for this cost. Therefore, it comes out of developmental center staffing by adding 1.3 percent to salary savings, meaning 134 more vacant jobs.

These hidden reductions due amount to 3.5 percent. This translates to $11.9 million and 360 positions that must be held open. But that's not all.

In addition to the hidden salary savings, there is the "official" salary savings that shows up in the Governor's budget. A. Alan Post, the respected Legislative Analyst for 24 years, has told us that when the salary savings process began in the 1950's, it was never intended to be used as a tool to simply reduce a department's budget. It was designed to account for the small amount of money saved during normal turnover of staff. It should seek out its natural level which is between 3 and 4 percent. In contrast, this coming year's Governor's budget has a salary savings of 7.2 percent for developmental centers. The difference is a reduction in staff and services.

So when the hidden salary savings is added to the official salary savings together, it amounts to 10.7 percent or 1,100 positions that DDS must hold open. This is a direct reduction in client services.

In closing, I offer the following recommendations:

1. All direct patient care staff should be budgeted at 100% of staffing standards.

2. Staffing standards should be updated, by law, every three years.

3. If the salary savings method is imposed, it should seek its natural level and not be forced higher just to save money.

4. Contractual obligations should be fully funded and not be paid from staffing funds.

5. At budget hearings, there should be an understanding that all programs are 100% funded in the Governor's budget. The departments should be required to report if they must hold positions open to pay for obligations that are not specifically funded in the budget.

CALARF
CALIFORNIA ASSOCIATION OF REHABILITATION FACILITIES

SENATOR HOTEL BUILDING • 1121 L STREET • SUITE 309 • SACRAMENTO, CALIFORNIA 95814 • (916) 441-5844

Date: June 16, 1989

To: Senator Dan McCorquodale
Senator Milton Marks
Assembly Member Richard Polanco

From: Christine Daly
Chairperson
CALARF Committee on SR9/ACR 521/A.B.1151

Thank you for inviting the California Association of Rehabilitation Facilities, CALARF, to provide testimony at this "kick off" Hearing for the Study of the Lanterman Developmental Disabilities Service Act.

CALARF represents over 100 service providers who operate habilitation and day program service for over 20,000 individuals with developmental special needs. We have a tremendous amount of experience with the developmental disabilities service system and have a great deal to contribute regarding the implementation of the Lanterman Act over the past 12 years.

The recent success of the CALARF et al. class action lawsuit underscores the fact that the law which the Legislature and Governor put into statue has not been fully implemented.

SR9 provides an excellent and timely forum for study of the system. We appreciate the fact that you have chosen to study how the Lanterman Act has been implemented from the Department of Developmental Services down through the provision of direct services and are not embarking on an academic study of the language of the Act.

CALARF has formed a committee for the expressed purpose of working with the Senate and Assembly Subcommittees to ensure that facilities serving persons with developmental special needs can provide you with meaningful testimony regarding their experience with the implementation of the Lanterman Act and ideas for improvements in areas where there may be deficits. I have attached a copy of our committee roster. As you can see the committee has statewide representation which should help to pinpoint systemwide problems.

We respectfully request that you work to prevent major amendments to the Lanterman Act during the time of this study. The time lines for the study are reasonable. If the study leads you to draft legislation we believe it will be legislation which will be based on the broadest possible gathering of information and addresses statewide system implementation needs.

CALARF members are working hard to leave our old baggage at the door and are committed to improving the future for individuals with developmental special needs.

Our Association looks forward to working with you throughout the time required to complete this project.

Thank you.

PUBLIC HEARING - SENATE RESOLUTION 9
Sacramento, California
June 16, 1989

TESTIMONY PRESENTED BEFORE THE SENATE SUBCOMMITTEE ON MENTAL HEALTH, DEVELOPMENTAL DISABILITIES AND GENETIC DISEASES; the SENATE SUBCOMMITTEE ON THE RIGHTS OF THE DISABLED; and the ASSEMBLY SUBCOMMITTEE ON MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES.

MEMBERS OF THE HEARING COMMITTEE, STAFF CONSULTANTS, LADIES & GENTLEMEN:

I AM LONNIE NOLTA AND I WILL BE MAKING COMMENTS ON BEHALF OF THE UNITED CEREBRAL PALSY ASSOCIATION OF CALIFORNIA AND FOR THE CALIFORNIA ASSOCIATION OF RESIDENTIAL RESOURCES. UNFORTUNATELY, THE INDIVIDUALS WHO WERE SCHEDULED TO PRESENT TESTIMONY ARE UNABLE TO BE HERE TODAY DUE TO PROGRAM OPERATION NEEDS IN HOME COMMUNITIES. IN CONSIDERATION OF THE TIME LIMITATIONS, I WILL WEAVE THE CONCERNS OF BOTH ORGANIZATIONS TOGETHER AND ATTEMPT NOT TO REPEAT COMMON CONCERNS.

BOTH ORGANIZATIONS ARE CURRENTLY IN THE PROCESS OF REVIEWING THE SERVICE DELIVERY SYSTEM WITHIN LOCAL GEOGRAPHIC AREAS WITH THE INVOLVEMENT OF PRIMARY CONSUMERS, FAMILIES, ASSOCIATED SERVICE PROVIDERS AND INTERESTED COMMUNITY CONSTITUENTS. AT THIS POINT, MOST LOCAL GROUPS HAVE IDENTIFIED NUMEROUS BARRIERS WITHIN THE SERVICE SYSTEM. THEY ARE ALSO LOOKING AT PROGRAMS AND SERVICE RESOURCES WHICH HAVE A SIGNIFICANT POSITIVE IMPACT ON PEOPLES LIVES AND WHICH SOULD BE AVAILABLE THROUGHOUT THE STATE. THESE ORGANIZATIONS ARE NOW BEGINNING THE PROCESS OF IDENTIFICATION OF ALTERATIVES AND SOLUTIONS TO ADDRESS SOME OF THE MAJOR BARRIERS. IT IS ANTICIPATED THAT THIS PROCESS WILL CONTINUE INTO THE FALL. FOLLOWING A FULL REVIEW OF LOCAL AND SYSTEMIC ISSUES, THESE ORGANIZATIONS WILL PROVIDE A REPORT WITH RECOMMENDATIONS FOR YOUR REVIEW AND CONSIDERATION.

WE COMMEND THE LEGISLATURE FOR TAKING THE TIME TO DO THIS INDEPTH REVIEW OF THE IMPLEMENTATION OF THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICES ACT. FOR A SYSTEM WHICH WAS ORIGINALLY DESIGNED FOR 16,000 PERSONS WITH SPECIAL, LATER AMENDED TO INCLUDE A BROADER SCOPE OF HUMAN SERVICE NEEDS AND CURRENTLY SERVING ABOUT 90,000 PEOPLE, IT HAS OUTGROWN MANY OF THE INITIAL ADMINISTRATIVE CONCEPTS FOR APPROPRIATE, EFFICIENT SERVICE DELIVERY. NEEDS HAVE INCREASED AND CHANGED, AND SO HAS THE "STATE OF THE ART". IT IS NOW TIME FOR REFINEMENT AND EXPANSION INTO A MORE PROGRESSIVE, EFFECTIVE SERVICE SYSTEM DESIGN.

WE BELIEVE THAT THE CURRENT LANGUAGE CONTAINED IN THE LANTERMAN ACT IS EXCELLENT ... IT PROVIDES GREAT FLEXIBIITY IN BOTH THE TYPE AND DELIVERY OF SERVICE RESOURCES WHICH SHOULD AND CAN BE PROVIDED. UNFORTUNATELY, MUCH OF THE ACT HAS NEVER BEEN IMPLEMENTED OR IN SOME CASES IT HAS BEEN MISUSED BY DIFFERENT ADMINISTRATIVE POWERS IN AN EFFORT TO CONTROL COSTS RATHER THAN TO CEATIVELY MEET THE NEEDS OF CONSUMERS.

SOME OF THE IDENTIFIED BARRIERS/CONCERNS ARE AS FOLLOWS:

* SERVICE ELIGIBILITY.

MANY PERSONS (ADULTS AND CHILDREN) WITH CEREBRAL PALSY HAVE HAD GREAT DIFFICULTY IN OBTAINING SERVICES THROUGH THE REGIONAL CENTER SYSTEM. ADULTS HAVE FOUND IT NECESSARY TO REPEATEDLY APPEAL SERVICE DENIAL BEFORE FINALLY BEING ACCEPTED; FAMILIES WITH YOUNG CHILDREN HAVE BEEN SHIFTED BET BETWEEN RESOURCE SERVICES SUCH AS THE REGIONAL CENTER, CALIFORNIA CHILDRENS SERVICES, AND MEDICAL. THIS PROCESS OFTEN TAKES MONTHS BEFORE THE CHILD FINALLY RECEIVES A NEEDED SERVICE. DURING THIS PAST YEAR, ONE REGIONAL CENTER ATTEMPTED TO PASS A POLICY WHICH WOULD HAVE DENIED SERVICE TO ANYONE WITH CEREBRAL PALSY WHO WAS NOT IDENTIFIED WITH THE CONDITION PRIOR TO THE AGE OF THREE YEARS! CLEARLY, NOT IN CONFORMATY WITH THE MANDATE OF THE LANTERMAN ACT. THE ACTION WAS OPPOSED AND LATER DROPPED.

* EARLY IDENTIFICATION, INTERVENTION, AND PREVENTION.

AGAIN, EVEN WHEN PARENTS ARE SEEKING ASSISTANCE, IT OFTEN TAKES MONTHS FOR THE FAMILIES TO OBTAIN SERVICES AND IN MANY CASES MUST BE REFERRED TO PROTECTION & ADVOCACY FOR ASSISTANCE. GENERALLY, MOST THE THESE CASES DO FINALLY RECEIVE SERVICE, HOWEVER, ONLY AFTER ADDITIONAL STRESS HAS BEEN PLACED ON THE FAMILY AND IN SOME INSTANCES, RESULTING IN MORE COMPLICATED HEALTH CONDITIONS FOR THE CHILD.

* LACK OF IN-HOME FAMILY SUPPORT SERVICES.

IN GENERAL, RESPITE CARE IS THE ONLY AVAILABLE SERVICE AND IN MOST AREAS OF THE STATE THE REGIONAL CENTER HAS CAPPED THE NUMBER OF HOURS PER MONTH. SOME FAMILIES WITH FRAGILE INFANTS/CHILDREN ARE RECEIVING LIMITED IN-HOME NURSING. UNFORTUNATELY, THE CURRENT LOW RATE OF REIMBURSEMENT FOR NURSING SERVICES BY BOTH REGIONAL CENTERS AND MEDICAL HAS FORCED SOME FAMILIES TO PLACE CHILDREN IN OUT-OF-HOME RESIDENTIAL PROGRAMS -- TEARING APART THE FAMILY UNIT AND RESULTING IN HIGHER COSTS TO THE STATE. THE DEPARTMENT OF HEALTH SERVICES HAS NOT SUPPORTED THE IMPLEMENTATION OF THE COMMONLY KNOWN FEDERAL "KATIE BECKETT" INCOME DEEMING WAIVER PROGRAM WHICH UNDER SPECIFIC CONDITIONS, WOULD ALLOW THE CHILD TO BE CONSIDERED FINANCIALLY INDEPENDENT FORM THE FAMILY AND AUTOMATICALLY QUALIFY THE CHILD FOR MEDICAL.

* LACK OF ADULT INDEPENDENT LIVING SUPPORT SERVICES.

REFERENCE IS MADE TO CURRENT PROBLEMS INDIVIDUALS HAVE IN OBTAINING APPROPRIATE, DEPENDABLE ATTENDENT CARE AND/OR IN-HOME SUPPORTIVE SERVICES NEEDED TO MAINTAIN INDEPENDENT LIVING. BOTH THE FUNDS AND HOURS ARE TOO RESTRICTED. THE WAGES ARE MUCH TOO LOW WHICH OFTEN RESULTS IN UNSKILLED, SHORT-TERM WORKERS.

INDEPENDENT LIVING SKILL TRAINING AND SUPPORT SERVICE PROGRAMS FUNDED THROUGH THE REGIONAL CENTERS ARE VERY LIMITED IN MOST PARTS OF THE STATE. FOR MANY FOLKS TRYING TO LIVE INDEPENDENTLY, THERE IS A NEED FOR ASSISTANCE WITH MONEY MANAGEMENT, SHOPPING, AND OTHER DAILY LIVING SKILLS.

* LACK OF AGENCY COORDINATION.

LITTLE PROGRESS HAS BEEN MADE TO ENSURE COORDINATION OF THE SERVICE DELIVERY SYSTEM BETWEEN STATE AND/OR LOCAL RESOURCE AGENCIES. FOR INSTANCE, NO REALLY STRONG ALLIANCE AND COMMITMENT TO CONTINUETY IN SERVICE DELIVERY HAS BEEN EFFECTED BETWEEN THE DEPARTMENTS OF HEALTH SERVICES, REHABILITATION AND DEVELOPMENTAL SERVICES REGARDING A POLICY FOR SHARED COSTS IN THE PURCHASE OR MAINTENANCE OF ASSISTIVE DEVICES.

* BARRIERS IN DAY PROGRAM SERVICES AND ALTERNATIVE RESIDENTIAL SETTINGS.

THE CONSUMER:STAFFING RATIO MUST BE INCREASED TO PROVIDE ADEQUATE SERVICE LEVEL, WITH A HIGHER RATE OF REIMBURSEMENT TO ENCOURAGE QUALIFIED STAFF TO ENTER AND STAY IN THESE PROGRAM WHICH SERVE SOME OF OUR MOST SEVERELY INVOLVED CITIZENS.

* INSUFFICIENT LOCAL ADVOCACY FOR INDIVIDUALS AND FAMILIES.

THE LIMITED STAFF OF PROTECTION & ADVOCACY IS SPREAD MUCH TOO THIN - SOMETIMES IT TAKES WEEKS JUST TO WORK WITH AN ATTORNEY. THEY HAVE DONE AN OUTSTANDING JOB BUT ARE IN NEED OF ADDITIONAL STAFF AND MORE LOCAL COMMUNITY OFFICES. THE AREA BOARDS HAVE ALSO BEEN EXTREMELY SUCCESSFUL IN ADDRESSING MANY ISSUES ON BEHALF OF INDIVIDUALS, HOWEVER, THEY CONTINUE TO BE UNDER STAFFED AND UNDER FUNDED. IN ADDITION, THERE ARE GROWING CONCERNS WITH THE POTENTIAL FOR "CONFLICT OF INTEREST" AMONG REGIONAL CENTER CLIENTS RIGHTS ADVOCATES REGARDING APPEALS AGAINST A REGIONAL CENTER.

THERE IS CONCERN THAT THE DEPARTMENT OF DEVELOPMENTAL SERVICES DOES NOT APPEAR TO ADVOCATE ON BEHALF OF CONSUMERSNEEDS -- CITIZEN AND ORGANIZATION ADVOCACY SEEMS TO BE THE ONLY EFFECTIVE MEANS OF TO OBTAIN BUDGET AUGMENTATIONS OR LEGISLATION TO PROTECT SERVICES. THERE ARE ALSO CONCERNS THAT THE ONLY WAY SOME CONSUMERS ARE ABLE TO OBTAIN SERVICES IS THROUGH LEGAL ACTION OR THE THREAT THEREOF ... THAT SERVICE PROVIDERS ARE FORCED TO LITIGATE INORDER TO GET CRITICALLY NEEDED RATE ADJUSTMENTS TO MAINTAIN PROGRAMS/SERVICES.

* LOSS OF LOCAL PROGRAMS AND SERVICES.

WE HAVE SEEN MANY EXCELLENT SERVICES DISCONTINUED OVER THE YEARS. PROGRAMS ARE STARTED, NOT PROPERLY FUNDED, AND FADE FROM VIEW -- OTHER PROGRAMS ARE STARTED TO FILL THE GAPS -- AND MANY OF THEM SLIDE FROM SIGHT. THERE APPEARS TO BE LITTLE COORDINATION BETWEEN THE DEPARTMENT OF DEVELOPMENTAL SERVICES, THE DEPARTMENT OF HEALTH, AND THE DEPARTMENT OF SOCIAL SERVICES IN THE LICENSING ARENA. WE HAVE LOST A NUMBER OF PROGRAMS DUE TO CLOSURE BY LICENSING, SOMETIMES THEY SHOULD BE, BUT, WE ALSO HAVE LOST GOOD FACILITIES. MORE FACILITIES ARE FALLING SHORT OF LICENSING REQUIREMENTS DUE TO LACK OF FUNDS TO PROPERLY STAFF, MAINTAIN BUILDINGS, PAY FOR SKYROCKETING INSURANCE, OR TO PAY APPROPRIATE WAGES AND BENEFITS TO ENCOURAGE THE HIRING OF SKILLED WORKERS. WE NOW PLAY "MUSICAL PROGRAMS" WITH ROTATING STAFF -- AND MORE TRAGIC, "CONSUMER HOPSCOTCH" FROM ONE PROGRAM TO ANOTHER.

* LOSS OF "HOPE" -- ARE THERE OPPORTUNITIES TO CHANGE OUR COURSE.

OVER THE YEARS, WE HAVE BUILT MUCH ON THE EARLY DREAMS OF FAMLIES WHO WERE LOOKING FORWARD TO SECURE, STABLE, HIGH QUALITY RESOURCES FOR SONS AND DAUGHTERS ... THE DREAM OF A LIFE-LONG CONTINUUM OF SUPPORTIVE SERVICES. WE HAVE SEEN PRIMARY CONSUMERS BEGINNING TO MOVE INTO EFFECTIVE SELF-ADVOCACY. WE HAVE SEEN THE WORKERS IN THE SYSTEM GAIN GREATER FAITH IN THE ABILITIES OF PERSONS WITH SPECIAL NEEDS. WE ARE MOVING INTO AN ERA WHICH CAN AND SHOULD BRING REFINEMENT IN THE IMPLEMENTATION OF THE SYSTEM. WE BELIEVE THAT THIS TASK CAN BE ACCOMPLISHED WITH THE HELP OF CONSUMERS, FAMILIES, AND THE PROFESSIONALS IN THE FIELD. WE BELIEVE THAT THIS REVIEW WILL IDENTIFY AND BRING FORTH NEW IDEAS, ALTERNATIVE WAYS TO ENHANCE THE LIVES, SECURITY, AND DIGNITY OF PERSONS WITH DEVELOPMENTAL DISABILITIES.

WE STRONGLY SUPPORT THE SENATE RESOLUTION 9 HEARING PROCESS AND ARE COMMITTED TO ASSIST. WE ALSO FEEL THAT THE VARIOUS STATE DEPARTMENTS SHOULD BE WORKING TOGETHER, WITH ALL OF US, IN AN EFFORT TO STRENGTHEN THE RESOURCE SYSTEM. WE ALSO BELIEVE THAT ALL MEMBERS OF THE LEGISLATURE SHOULD RESPECT AND AID IN THIS PROCESS, THUS, WE WOULD URGE THAT ALL LEGISLATION WHICH COULD RESULT IN MAJOR CHANGES TO THIS SYSTEM BE REFERRED TO THE COMMITTEES REPRESENTED IN THIS REVIEW SO THAT ADEQUATE TIME AND CONSIDERATION CAN BE GIVEN TO THE CONTENT.

THIS IS A TIME FOR ENHANCEMENT, SOME CHANGE, AND FOR WISE DECISIONS!

LOTTE E. MOISE
30401 SHERWOOD ROAD • FORT BRAGG, CALIFORNIA 95437
707 964-2948

Senate Resolution 9 Testimony

June 16, 1989 - Sacramento

THE BETRAYAL OF BARBARA

to betray: To fail or desert in a moment of need.

She was born in California with a disability called mental retardation. She also happened to be born thirty-five years ago at a time of great hope and promise - a time when parents began to go to bat for their (then) children's right to live at home - in dignity. Raised in Mendocino County, she was loved, supported and respected by friends, neighbors and family, and has grown to be a neat young woman - warm, trusting, sensitive and loyally friendly. She constantly exceeds our expectations with slow but steady growth.

BUT - there is a great big BUT that surfaces in the development of this story toward what ought to have a "happily-ever-after ending." For her disability has somehow robbed her of the right to self-determination - the possibility of assuming control of her own life. She is a Regional Center "client" and as such has about as much control as a pawn on a chessboard.

Barbara moved away from Fort Bragg in 1972 - at her own urging - when her older sister and brother were in college and she too "wanted to go somewhere!"The years since then have been a perfect illustration of the lack of stability and permanence of community programs here in the Golden State of California. Inspite of the Lanterman Act - our enabling legislation which is the envy of other states - we have betrayed Barbara's trust over and over again.

I deliberately use the editorial "we" because by indirection I, like many parent pioneers, have become part of the system. I helped create the Lanterman Legislation. I chartered Area Board I and Redwood Coast Regional Center, selected and employed its first director and chief counselor, helped launch Citizen Advocacy and a northcoast residential program called The Continuum, and was in on the groundfloor of Protection & Advocacy - only to find myself powerless and out of control of my daughter's life. One part of me - the "professional parent" part - has become co-opted by the system that has too often failed my daughter. The other part - the mother part - has stood by with knots in my stomach and flutters of fear in my heart, as Regional Center kept Barbara helplessly and hopelessly unsettled and "homeless" - living out of a suitcase while waiting for a placement.

1984 was the worst year. Three moves: the first due to cuts in independent living skills training in her happy group home - then a temporary move to another group home which was intended to be a transition to apartment living for which she was NOT a candidate and NOT ready. All this time waiting for a placement in a licensed carehome which wanted Barbara, while a CEDR test flip-flopped from mild to severe to moderate, and each time took weeks to be returned from Sacramento. The caretaker could not afford to take Barbara at the "mild" rate and finally filled the opening with someone else while Barbara waited disconsolately with her wordly possessions still in boxes.

The next possibly appropriate residential program became "inaccessible" to her by virtue (and was that ever a misnomer) of a new board policy of her Regional Center. They would not vendor the newly created 7th and 8th beds in the home, unless they fulfilled certain "unique unmet needs" for Regional Center clients. Barbara's urgent personal need for stability and security did not count. Our family's wishes mattered not. We were again on hold, visiting possible alternative places. We (Barbara's sister and I) then went to Fair Hearing, and eventually accomplished her placement in the home under consideration, but at one point we were told half jokingly, half threateningly. "Well, you know we COULD place Barbara in ..... (a town in another county - totally unfamiliar to her, hours further away from me, and impossible for Greyhound use for her). Talk about family dislocation.

There have been three moves in the four years since then - two of them once more dramatic dislocations - the last one a happy situation IF the people's energies are not eroded by the difficulties of making ends meets.

Put yourself into Barbara's shoes. Her self-esteem and confidence (two hard-won qualities when you are disabled) had been eroded. At one point the residential shuffle threatened her close and loving relationship with her boyfriend who had been a significant person in her life for several years. At work her performance plummeted. She internalized the situation and said things like: "They want me out of here, Mom!" Find me a new home, Lotte." "They want more money for me." And while Regional Center blithely and blindly followed their rules, regs, and rates - rigidly like good little bureaucrats - Barbara's emotional strength was being sapped, and her sister Karen and I stood by with heavy hearts.

I tried to reassure her by telling her of the many poor people who sleep in tents, broken down buildings, or under bridges. "You will never be without a home," I said. "Karen and I will see to that." A few days later she phoned her sister. She wondered how she might meet some of the poor people that Lotte is talking about. "I would like to invite one or two of them to my birthday party in December." In the face of a year of blatant betrayal by our system Barbara still hopes and trusts...

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BUT - there is a great big BUT that surfaces in the development of this story toward what ought to have a "happily-living-ever-after ending." For her disability has somehow robbed her of the right to self-determination - the possibility of assuming control over her own life. She is a Regional Center "client" and as such has about as much control as a pawn on a chessboard.

For Barbara the year 1984 has been a perfect illustration of this condition, here in the Golden State of California. "We" have betrayed her trust, and I use the editorial "we" because by indirection I, like many parent pioneers, have become a part of this system. I helped create the Lanterman Legislation. I chartered an Area Board and a Regional Center, selected and employed staff persons, launched advocacy and residential programs and now find myself powerless and out of control. A part of me has become co-opted by the system that is failing my own daughter. The other part - the mother part - has stood by with knots in my stomach and flutters of fear in my heart, as Regional Center has kept Barbara helplessly and hopelessly unsettled and "homeless" since the service reductions of the winter of '83.

She had been living happily and harmoniously in a small group home in Sonoma County for several years. Close to her sister, close to public bus lines to the work activity center, able to travel home by Greyhound on weekends, she learned new skills, made real friends, and considered Sonoma County her "home away from home." It was the way it should be for a young adult.

Last year's program cuts meant an end to the specialized services for Barbara in this home, and from then until now she has literally NOT known where to hang her hat - where she belongs - where she will be living. A placement in another group home - one which moves residents to apartment living - proved to be too demanding, and at a staff meeting this spring it was determined that she would have to move again - this time to a small family care home. Such a small home was available near by. They wanted Barbara and made her feel welcome during a trial visit. The caretaker however could only accept her if Regional Center paid the residential rate for moderate level of care. It seemed a logical assumption that Barbara needed a moderate level of care since she was unable to keep up with the preparatory program for apartment living.

This is when the CDER, The Client Developmental Evaluation Report, raised its ugly head. The CDER is used to help Regional Centers plan client services and determine residential rates. It is administered, scored and interpreted in strange and arbitrary ways.

Barbara's CDER was completed THREE DIFFERENT TIMES this summer. Each time the report was filled out as if in a vacuum, without proper interviews or consultation with those who can best judge her abilities, i.e. work supervisor, residential counselor, sister or mother. The results swung wildly from "minimum" level of care the first time - to "intensive" level of care the second time - back to "minimum" the third time. In the meantime my daughter Karen and I had helped Barbara organize and pack her worldly belongings, and she was within three days of moving to her new home, when the caretaker decided that she could not afford to wait any longer, and filled the vacancy with another person at "moderate" residential rate. Barbara was left sitting on her boxes - living out of a suitcase - feeling unwanted once again. The CDER has since been done one more time and we await results.

All of this happened this summer. It is now winter, and Barbara is still in her second placement - still living out of that suitcase - while we have run into yet another bureaucratic snag of major proportions. Another group home - another possibly appropriate residential program - has welcomed Barbara after a trial visit, but this placement has become "inaccessible" to her by virtue (and is that ever a misnomer) of her Regional Center's board policy. This spacious rural home has recently upped its licensed capacity from 6 to 8. The Regional Center's policy will not vendor beds # 7 and # 8 unless they fulfill certain "unique unmet needs" for Regional Center placement. Barbara's desperate personal need for stability and security do not count. Our family's wishes matter not. She can only go there as a private placement by paying the supplemental Regional Center rate over and above her own SSI. Ironically her SSI check constitutes 80% of Regional Center's residential rate!

Since we cannot consider this option, we are again on hold, and waiting for Regional Center to present us with an alternative referral for consideration.

Even more ironic is the fact that I, champion for the principle of normalization for a dozen years, and advocate for small community homes, am being hindered and blocked in the placement process of my daughter, by a rigidly interpreted policy which is a perversion of this principle. The number six is here being endowed with magic qualities, while all other philosophical, psychological and practical considerations - such as quality of care, training and attitude of caretakers and staff, involvement in and access to community activities, dislocation from familiar neighborhoods, and interruption of fragile precious personal friendships are thrown to the winds.

Put yourself into Barbara's shoes. Her self-esteem and confidence (two hard-won qualities when you are disabled) have been eroded. The residential shuffle is threatening her close and loving relationship with her boyfriend, who lives near by, and who has been a significant person in her life for many years. At work her performance has plummeted. She says: "They want me out of here, Mom!" "Find me a new home, Lotte." "They want more money for me." And while Regional Center blithely and blindly follow their rules, regs and rates - rigidly like good little bureaucrats - Barbara's emotional strength is being sapped, and her sister Karen and I stand by with heavy hearts.

Last week I tried to reassure Barbara by telling her of the many poor people who sleep in tents, broken down buildings, or under bridges. "You will never be without a home," I said. "Karen and I will see to that." Yesterday she phoned her sister. She wondered how she might meet some of those homeless people that Lotte is talking about. She would like to invite one or two of them to her birthday party in December! In the face of a year of blatant betrayal by our system Barbara still hopes and trusts...

Lotte Moise 11/84

P.S. 11/30/84 - Barbara finally moved today. It took a Fair Hearing Appeal and intensive family advocacy to make it happen. What about those who stand alone?

Testimony of:
Linda Leahy
1551 5th Street
Sacramento, CA 95814
(916)442-6895

In 1982 the Northbay Regional Center of Sonoma County, refused my daughter Colleen service based on the fact that they found her to have average intelligence, and also they only accepted people already on SSI.

In 1987 the Redwood Coast Regional Center of Mendocino County refused my daughter service based on the decision of the prior Regional Center's decision, and that they found her to have average intelligence. We appealed and lost.

In 1988 the Alta Regional Center of Sacramento County refused my daughter service based on the decision's of the two prior Regional Center's decisions and the fact that even though she was diagnosed as having Cerebral Palsey, it was not substantial enough in their opinion to warrant their help. We are fighting this decision now.

Colleen Leahy has been disabled since birth. She has Cerebral Palsey, Autism, Severe Asthma, and severe learning disabilities. She was in special education classes all through grammer, junior high, and high schools. She was also in special education class in Junior college. She is now on SSI. By every definition in the California Code she is qualified as deveopmentally disabled. Getting her into a Regional Center has been impossible, and is severely preventing her from community services that can only be administered through them or their referral.

F. Burns Vick, Jr. – J. D.

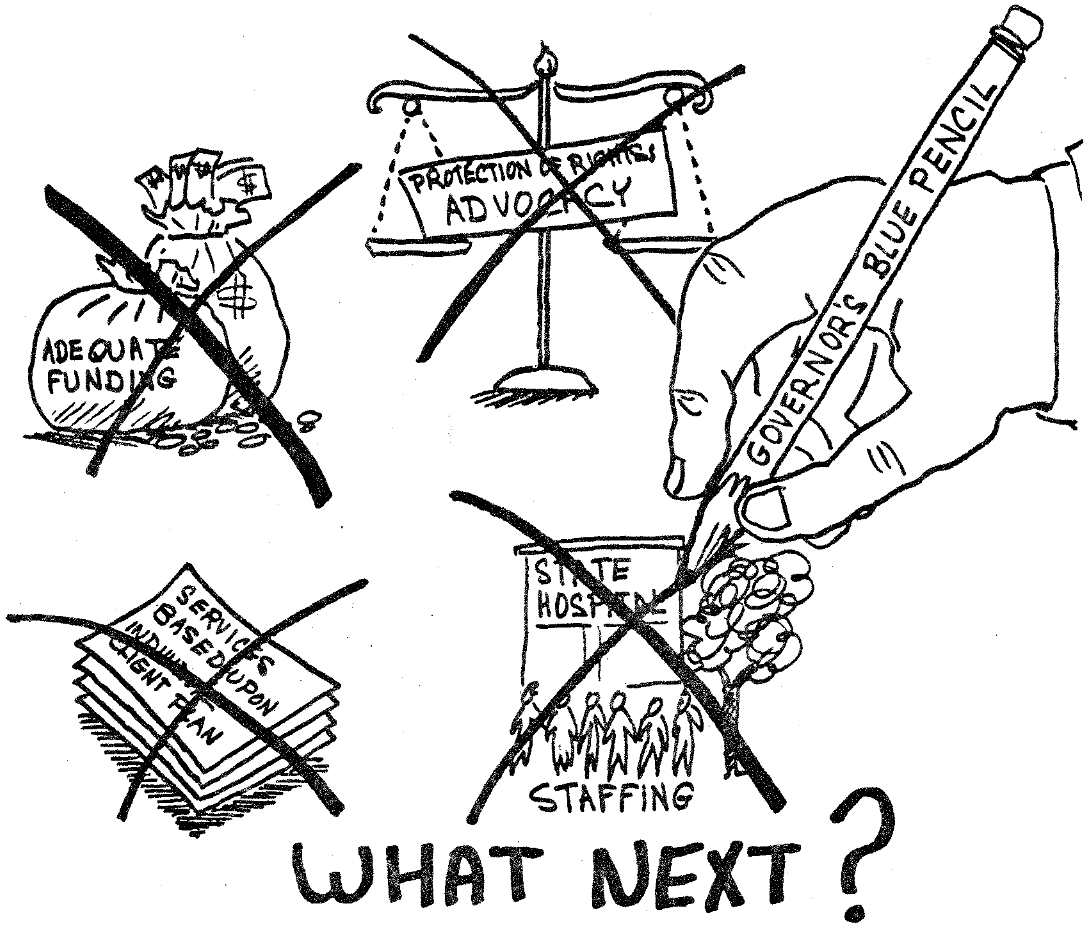
Vick & Associates
1020 Eleventh Street, Suite 210
Sacramento, California 95814
Phone: (916) 442-7239

Challenge of the 1990's: Restoring the Balance and Fully Implementing the Promise of the Lanterman Developmental Disabilities Services Act

S.R. 9 - A.C.R. 52 Hearings

Testimony: June 16, 1989

F. BURNS VICK, Jr. - J.D.
Public Policy Consultant
Sacramento



QUALIFICATIONS AND EXPERIENCE OF PRESENTER

I wish extraordinary luck to Senators McCorquodale and Marks, Assemblyman Polanco, and their legislative staff, with this monumental undertaking, which will be shaped by the final versions of Senate Resolution 9 and Assembly Concurrent Resolution 52.

Each of you on this hearing panel and most here today know I am Burns Vick, a public policy consultant, lobbyist and attorney who has specialized throughout my professional life in disability rights and service entitlement advocacy. Since November of 1976 -- for better or worse -- my fingerprints have been on a substantial number of public policy and funding decisions in California's developmental services and related fields.

I began as the Director of Legislation and Staff Attorney for the California Association for the Retarded (C.A.R.), now the Association for Retarded Citizens - California (ARC-C). In July of 1981, I diversified my clientele by becoming a private, policy consultant and contract lobbyist. My focus has been consistently and selectively to represent consumer-directed interests fostered by nonprofit corporations having statewide impact.

All of my clients have prided themselves as service providers and advocates for progressive public policies and funding for Californians who need public funding for programs and services and who, in many cases, are considered vulnerable because of functional limitations as a result of age, disability, mental health and other special needs.

My remarks today are not sculpted to represent the interest of any particular client or organizational viewpoint. At my request, I am testifying as an individual. My opinions come out of my professional expertise as a public interest technician in these fields plus my personal commitment to protect the integrity of the Lanterman Act and other progressive public policies.

THE CHALLENGE FOR THE 1990's.

The heart of S.R. 9 concludes a need to "study all aspects of the administration of the Lanterman Act service system". A.C.R. 52 offers similar language but has more specificity about the agenda for review and recommendations.

My initial approach for this first hearing was to provide a "laundry list" of specific provisions of existing law which have not been properly and/or completely implemented to date. At the request of these legislative committees, I will be available to do so depending on final decisions in each House about the scope of and methdology utilized to implement S.B. 9 and A.C.R. 52.

However, upon reflection, I decided to focus on three troublesome phenomenon which I believe prevent our great State from meeting the promise of the Lanterman Act. As developmental services and other human services advocates plan for the 1990's, I hope they will turn their attention to several underlying problem areas. As a beginning contribution for a better future, I have included several recommendations with each general problem area identified.

I trust each of you agree -- even if only privately -- with the political reality represented by the cartoon on the cover page of my testimony. This partisan, blue-pencil prerogative -- the threat and/or actual use of -- is the fundamental reason for the current subversion of the delicate balance of competing interests and forces affected by the implementation of our Lanterman Act.

Hence, I find a disappointing verdict for the 1980's even though still in progress... one of an abysmal failure to implement the letter and spirit of these laws.

MY CONCLUSIONS ARE THAT THERE HAS BEEN:

(1) NO REAL COMMITMENT TO NOR POSITIVE LEADERSHIP DEMONSTRATED BY CALIFORNIA'S ADMINISTRATIVE BRANCH DURING THE 1980'S TOWARD THE GOAL OF FULL AND PROPER IMPLEMENTATION OF THE EXISTING LANTERMAN ACT.

(2) A FAILURE BY KEY POLICY-MAKERS AT ALL LEVELS OF GOVERNMENT TO GENERATE SUFFICIENT REVENUE OR TO MAKE SIGNIFICANT CHANGES IN CURRENT FUNDING METHODOLOGIES IN ORDER TO GUARANTEE REAL CHOICES AND OPTIONS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES TO LIVE AND FUNCTION IN THE LEAST RESTRICTIVE ENVIRONMENTS IN ALL ASPECTS OF THEIR LIVES.

(3) A CONCERTED EFFORT BY THE ADMINISTRATIVE BRANCH OF THE GOVERNMENT IN THE 1980'S TO PREVENT THE MOST KNOWLEDGEABLE, BEST-QUALIFIED AND TRULY REPRESENTATIVE CITIZENS FROM SERVING ON KEY POLICY-MAKING AND ADVISORY BODIES IN THE DEVELOPMENTAL SERVICES AND RELATED FIELDS.

Now for points to address these areas of concern and substantiate my conclusions. Recommendations follow.

INAPPROPRIATE BUDGETING PROCESS

California's budgeting process in developmental services continues to be bifurcated between the use of public funds for residents of developmental centers and clients of regional centers residing in their home settings or in out-of-home placements other than developmental centers.

This situation arises not only from historical utilization patterns and extensive capital outlay investments but from the fact that there are major fiscal disincentives for the State under the federal Medicaid program. Numerous treatises and dusty studies review the specifics of this issue and make recommendations for changes at the federal and state levels.

Understandably, the State has as a highest priority to garner additional federal financial participation for all publicly-funded programs and services. This results in a built-in bias in favor of out-of-home residential placements in developmental centers, Skilled Nursing Facilities and Intermediate Care Facilities because of current Medicaid laws and regulations.

Possible Medicaid "waivers" -- which would permit real options and choices for primary consumers and families -- are "few and far between". Also, California has been "Johnny come lately" historically in submitting waiver requests and challenging rejections by the federal government.

REGIONAL CENTER PURCHASE OF SERVICE POLICIES BIASED IN FAVOR OF INSTITUTIONAL, RESIDENTIAL AND DAY PROGRAMS

Because of historical funding and allocation patterns, there is a clear bias for out-of-home residential placement subsidies and traditional day programs. Fortunately, because of relatively new federal "supported employment" policies and the leadership of the California Association of Rehabilitation Facilities (CAL-ARF), part of that stagnated picture is changing.

Rather than review the regional center funding methodology exhaustively, I want to focus today on a major fiscal disincentive within "the bigger picture". Specifically, I reject the current the arbitrary capitation methodology which has evolved for programs and services in the "Other Services" category. This methodology "flies in the face" of Lanterman Act provisions related to regional center responsibilities and the IPP as specified in W&I Code Section 4640 *et seq* and the California Supreme Court decision in the entitlement litigation brought by the Association for Retarded Citizens - California (ARC-C).

You will recall, this category supports creative and progressive options, which give real choices to primary consumers and their families: independent living skills training, respite care and creative options which could assist families maintain infants and children in home settings.

This negative trend will be reversed only when the Administration chooses to initiate an infusion of funds in this category and/or change their allocation tactic of "levelling downward" under the guise of seeking "equity" in the allocation process among and between the twenty-one regional centers.

In short, through increased allocations, DDS should reward its regional center contractors for developing and implementing individual program plans (IPP's) which truly meet the needs of the clients by offering creative options and choices.

I remind each of you that "budget control language" specifying the process to be used for determining the extent to which regional centers are living within their budgets DOES specify as an option that DDS can go to the Legislature and request additional funds. Instead of using this provision, the Administrative branch in the 1980's has chosen to engage in activities designed to "squeeze down" the regional centers rather than take the initiative to seek additional funds for full and proper implementation of IPP's.

RECOMMENDATIONS TO ADDRESS PROBLEMS PRESENTED IN CONCLUSIONS #1 & #2:

(1) Senators McCorquodale and Marks have been the staunchest advocates for progressive developmental services policies. One or both should get appointed to the Senate Budget & Fiscal Review and/or Senate Appropriations Committee in order have greater latitude to effect fiscal policy changes.

(2) The Administrative branch should be nudged aggressively to implement Article 4, "Supportive Services for Persons Living at Home" [W&I Code Sections 4685 et seq.] as the highest priority for new funding. This will entail active legislative oversight through policy and fiscal commitees.

(3) The Legislature should ensure complete implementation of the Final Recommendations submitted by The Interagency Task Force on Early Intervention Services. These were submitted on January 1, 1988, pursuant to A.B. 114, Statutes of 1985, Chapter 26.

(4) The Legislature should review the status of implementation of "California's 1986-87 Goals and Objectives to Ensure Stability and Quality in Programs and Services for Developmentaly Disabled Persons" as submitted by Senator Marks on October 23, 1986, after his hearing.

(5) The Administrative branch should be required to implement provisions of Chapter 12, "Community Living Continuums" [W&I Code Section 4830 et seq], which were developed as consensus recommendations after extensive hearings and recommendations involving consumers, providers and advocates throughout California.

Finally, comments about my third conclusion related to the effort of the administrative branch to prevent the most knowledgeable, best-qualified and truly representative citizens from serving on key, policy-making and advisory bodies. Your hearings substantiated actions involving the Governor's office down through certain state agencies and departments.

Fortunately, I can make this short because your legislative committees developed an extensive record on the subject in 1988. Your focus was gubernatorial appointees on the State Council on Developmental Disabilities and Protection & Advocacy, Inc.

This substantiated the problem and should have cleared the way for serious debate on creative legislative proposals in 1989. However, the consensus was to "wait for the S.R. 9 hearings".

So in the interest of time, I direct your attention to policy changes suggested in A.B. 2256, introduced by Assemblyman Terry Friedman. He was moved to introduce an Assembly measure by the intensity of support and sincerity of commitment demonstrated by consumers, family members, professionals and advocates who testified in Los Angeles and Sacramento during your 1988 hearings. This two-year bill can be a vehicle in the future.

We all know Mr. Friedman as an unwavering supporter of adequate public funding in the developmental and other human services fields. He is particularly concerned about the development of a truly independent system of legal and systemic advocacy and assistance for consumers and families.

The first major goal of the legislation is to identify policy changes which would ensure maximum and meaningful consumer involvement in policy-making, service planning and advocacy services in this field. The second is to support a process which will result in an viable plan for all types of advocacy in California.

Amendments to A.C.R. 52 acknowledge the need to review "the roles and functions of the regional center and developmental center clients' rights advocates and their future utilization in the advocacy system for the service delivery system for persons with developmental disabilities". This aspect has been of concern for years to critics of the current use of these advocates. To quote ARC-C policy, restructuring could result in greater "overall effectiveness and accountability of the Regional Center system".

RECOMMENDATIONS TO ADDRESS PROBLEMS PRESENTED IN CONCLUSION #3:

(1) Bring in a new Administration which is not threatened by differences of opinion and which does not have as a primary agenda trying to "control" and/or discredit the voices of consumers and providers of services.

(2) Establish an independent entity to make recommendations to the next Governor on political appointments to ensure there will be well-qualified, truly representative individuals who will not have partisan, political agendas.

Regional Center Clients' Action League

PRESENTATION BY DAVID SOKOLOFF

ACTING CHAIRMAN - REGIONAL CENTER CLIENTS' ACTION LEAGUE

SENATE HEARINGS ON SR 9 - REVIEW OF THE LANTERMAN ACT

JUNE 16, 1989

INTRODUCTION:

My name is David Sokoloff, I am a past President of the Marin Association for Retarded Citizens, a past President of the California State Association for Retarded Citizens, and a past Chairman of the State council on Developmental Disabilities. I appear before you today as the acting Chairman of the Regional Center Client's Action League.

PRESENTATION:

Speaking on behalf of the Action League I welcome this new legislative enquiry into the problems of the system. For during the last twenty-five years almost all the important progressive changes in California's system of services have resulted from consumer and legislative initiative. The Action League promises to work with your Committee to find constructive ways to improve the service system.

My purpose today is to tell you about the Action League and to share with you some general observations about the obstacles and opportunities before us. The Action League will offer specific proposals for system reforms for your consideration at your Committee's hearings later this year.

The **Regional Center Clients' Action League** is a non-profit action organization currently being organized all across the state. We are at this moment working with our attorneys to set up the formal organization. Our purpose is to expand the role of the consumers in shaping the service systems that affect our lives.

We plan to enroll 100,000 members - clients of Regional Centers, their families and friends. Our members are connected and related to three-quarter of a million voters. We will represent the full spectrum of developmental disabilities and include people with different service needs and different philosophies. We will focus on only a few issues of major concern to our members, and we will complement the work of other consumer oriented organizations and collaborate with them.

We will influence policies by expressing our views to policy makers and to the general public. When necessary, we will take political action to support elected officials who respond to our concerns or to replace those who - through ignorance, insensitivity or meanness - hurt us.

During the last six months I and my colleagues have been traveling around the state, meeting with service consumers and providers. We have been telling people about the political history of our system, the principles on which it is based, and the goals we had in mind when it was created. We have been listening to their experiences and feelings about how the system really operates.

* * * * *

First I will summarize what we tell them, and then what they have been telling us.

This is what we tell them:

We remind them about how things were 25 years ago - when there was no publicly supported community service system. Oh yes, very wealthy people could buy scattered medical, social and residential services. And small groups of families in some communities banded together and struggled to operate day programs and workshops for their children. But the State offered only the State Hospitals. That was it! And it was bad.

In the early -60's the average monthly cost of care in the State Hospitals was only $300. Residents were jammed into ancient overcrowded wards - imagine - 100 beds lined up, barracks style, gang toilets with no partitions, and no doors; no place for personal belongings, no privacy and very little program. It was institutionalization at its worst. In 1963, more than 13,000 people with developmental disabilities lived, if you can call it living, in these substandard State facilities and there were 3,000 more on waiting lists to get in. The response to the waiting list was to propose building another 3,000 State hospital beds.

This proposal did not come from unkind or insensitive people - it came from decent competent bureaucrats who had no choice but to work within the system as it existed.

If we had taken that route - if California had responded in the traditional way - by now we would have at least 20,000 residents in our State hospitals, now called Development Centers, at an annual operating cost of $1.5 billion, triple the current expenditures in our State facilities. Add to that the money that would have been spent construction another 7,000 beds. It's obvious that the State has saved billions of dollars by avoiding excessive institutional costs over the past 25 years. About half of these savings have been directed into community based alternatives; not enough money to guarantee services of good quality for all who need them.

We have been reminding people of the role played by consumers in choosing to create community based alternatives and thus shaping the system we have today. More than any other system in State government, the developmental disabilities system, as set forth in the Lanterman Act, is based on democratic principles. It was designed that way because we, the consumers, were deeply involved in its origins and because Frank Lanterman, a great humanitarian, statesman, and a conservative in the finest sense of the word - had more faith in the collective wisdom of consumers than in the motivations of bureaucrats. It's not that bureaucrats are either stupid or mean-spirited, but rather they cannot look outside their jurisdictional area of responsibility; if the only tool they have is a hammer, every problem for them has to be a nail.

Look at the system we created!

Imagine! A major state function - contracted out to independent agencies (Regional Centers) whose boards of directors would contain consumers.

Imagine! A State Council, controlled by consumers, to participate in shaping the State budget with State agency officials in an ex-officio non-voting capacity.

Imagine! Area Boards, controlled by consumers, as watchdogs over the entire system, with the power, to take legal action if necessary, when State and local agencies fail to correct poor practices.

Imagine! A law that spelled out the rights of consumers - for service, respect, dignity, and a decent quality of life - stressing productivity, independence, and control over their own destinies.

The system we created was, and still is, an anomaly in State Government. The State Administration didn't like it then, they haven't liked it since, and they don't like it now, even through with all its flaws, it works better than most of the other major public systems, such as mental health, welfare, corrections, and transportation, etc.

The State's administrative system is, by its very nature, a hierarchical system. Its central feature is "chain of command". Orders flow from the top down and everyone in the chain accepts and carries out these orders - like good soldiers. State Agency directors and their employees do not picket the Capitol to prevent cuts being made in their budgets.

When the idea of the Regional centers was first suggested, the Administration proposed they be operated by the State hospitals rather than contracted to independent agencies. In the early '70's, the State employees' union sued to try to make the Centers into State Agencies.

The system we created sticks in the craw of the bureaucracy like a foreign body. They are understandably uncomfortable when they have the responsibility and the consumers have the control. Their instinct is to reject or at least to change into their own image.

In recent years, we have witnessed the emasculation of the State Council. The day the State Agency directors were given voting rights on the Council - on that day, the Council lost its voice as an independent consumer-based authority in the annual budgeting process.

We have witnessed the Administration's attempt to defang the Protection and Advocacy Agency by loading its board with political appointees whose mission was to protect the State bureaucracy, rather than the clients.

We have watched the State avoid the marketplace by centralizing and controlling rates of payment to vendors, at levels too low to foster competition and to assure good quality.

We have seen the State Administration attempt to shift its legal responsibility onto the federal government and, in a brazen move, try to divert into the general fund, $27 million intended to <u>improve</u> case management services for people with developmental disabilities.

Despite all of these efforts to take away from the consumers any control over the system, we have accomplished a great deal. We have witnessed the blossoming of the new system we planted 25 years ago. And we can feel proud - many of our intentions have been realized. For although the population of the State has increased from 18 million to 28 million, we have reduced the number in the Development Centers from more than 13,000 to about 7,500, and we no longer have a waiting list. In addition, we now serve almost 100,000 clients in, or closer to, their own communities.

* * * * *

When we listen to consumers and providers around the State, this is what we hear:

That Regional Center caseloads have doubled and tripled from where they were originally, so that case overloads of 80 are now common.

Providers tell us that they cannot attract, train and retain good staff when workers can earn as much serving hamburgers at McDonalds as they can serving severely handicapped people. And still, a couple of years ago, the Governor vetoed a proposed modest rate increase that would have benefited community workers.

Regional Center personnel tell us that they cannot find suitable services of good quality for many of their clients. That out-of-home placements are becoming increasingly difficult under the load of State-imposed constraints. They tell us that they don't have enough time to handle all the paperwork <u>and</u> spend time with clients and their families <u>and</u> also monitor the quality of services.

Parents, who are perfectly capable of caring for their children at home, if given adequate support, tell us they have been forced to place their children, at high cost to the State, in State and Community institutions. These parents know their own child's needs; they can give round-the-clock care; they generate no liability expense; they don't require fringe benefits; they don't need expensive monitoring, and they are available immediately. How can we tolerate a program that breaks up families unnecessarily and increases State costs at the same time?

Parents and vendors tell us that they are increasingly frustrated by the bureaucratization of the Regional Centers. Tensions between democratic and bureaucratic forces, between providers and consumers, are increasing. The tensions are greater over issues that concern the amount, the control, and the distribution of money in the system. Many people earn their living serving us. In an economic sense, the consumers are the raw material upon which the industry fees. Many providers of service would prefer us to be silent, compliant objects. We, the consumers, on the other hand, demand greater control over the use of the money in the system. We do not see purpose of eating as mainly way to give employment to cooks.

This conflict between administration and consumer control has resulted in an adverserial relationship between the Department and most of the rest of the system which is inefficient and progressively corrosive. The State Administration's role is to monitor the system to assure that the objectives and goals of the Lanterman Act are being achieved, and that State funds are properly spent. But it should also inspire and nurture improvements. What I and my colleagues hear from consumers and providers as we travel around the State is that the State Administration is perceived as hostile to the community service system, that there is little goodwill and no trust. This spirit of antagonism upsets consumers, it angers vendors, it undermines Regional Center leaders, it discourages staff, it alienates the Regional Center Boards, it frustrates the Area Boards, and it unnecessarily saps energy from the whole service system. We cannot afford it. We should no tolerate it. It can be corrected, and at little or no cost. It requires only the will and the leadership of the State Administration. The cooperation of the rest of the system is bound to follow. Changing from an adverserial mode to one which is cooperative, from hostility to trust, is probably the single least expensive and most effective change we could make. We must make it.

The following ideas come from comments and suggestions we have received as we have met with different groups around the State. We share them with you as they may merit further consideration during the course of your studies.

* We must start to do something quickly to move towards greater parity in the compensation paid to those who work with people with developmental disabilities. The meager rate increases of recent years have barely kept up with inflation. The increases are often swallowed up for administrative purposes rather than salary increases. We should not tolerate the exploitation of community service workers. We will never build an excellent system of services without developing a trained, competent, and stable work-force. Considera-

tion should be given to requiring the Regional Centers to pay workers a minimum wage of nine dollars per hour - about half the average wage of State Development Center employees. Of course, Regional Center budgets will have to be augmented to make this feasible. But, how can we expect service personnel to treat people with disabilities with respect and dignity, when we don't show our respect for these workers and won't dignify their contribution with a decent wage.

* We need to unify State funding in order to create incentives for the most cost-effective use of our limited dollars. Regional Center placements into State institutions impose no burden on Regional Center budgets. Nor are Regional Centers able to use funds allocated for the State institutions to purchase alternative services. The budget is divided into two compartments and the money cannot follow the client.

We have two systems rather than one. This creates a financial incentive to place clients into the State institutions when at the same time that there is not enough money to develop high quality, stable alternatives in the community.

This proposal may, of course, put the State facilities at risk. They would be in a competitive rather than a protected position. A unified system, in which all service providers compete equally to offer the most beneficial programs at the most reasonable cost may, in the long run, produce the best choices for clients.

* We should consider removing the current constraints upon State operated programs. Why shouldn't State employees, many of whom have excellent training and experience, compete with all other community service providers to operate a variety of programs - as vendors to the Regional Centers? I am suggesting that you examine the advantages and disadvantages of creating a free marketplace and ending the split between State and community service provisions. I suggest that the committee examine the system developed in Michigan and replicated in several other states, in which the State purchases community care facilities which can then be operated by providers under contract to the State. This approach would allow for the development of very stable facilities, not subject to closure as when private owners go out of business.

* During the last ten years the State has invested at least $200 million in capital outlay improvements in the State institutions. They have at last been brought up to acceptable levels of safety, environmental quality, staffing and programming. But the State has spent almost nothing to create facilities in the community. This double standard is unacceptable. The Program Development Fund which was intended for community facility development and for program start-up costs has

proven to be grossly inadequate. Consideration should be given to adding money to the Program Development Fund. One possible method would be to budget an additional $100 annually for each Regional center client, earmarked for the Program Development Fund. This method would ensure that the fund would grow as the number of clients increases. It would also distribute the money fairly according to the number of clients in each of the 13 Area Board sections of the State. The initial costs of this proposal would be about $10 million. If properly invested, this money could be of enormous benefit in enabling the system to met the needs of clients currently enrolled and in preparing for the more than 50,000 <u>new</u> clients we are likely to have by the year 2000.

* * * * *

I recommend that this Committee listen carefully to the clients of this system - at least as much as you listen to the providers, administrators and bureaucrats. Many clients tell us that they want more independence and more power in the system. They want to work and live and study and play with people who re not disabled. But most of our services are organized in segregated ways - many communities don't offer independent living programs and integrated employment opportunities. They want to participated more fully on the boards and committees that make the decisions which affect their lives. They don't want to be viewed as objects to be case managed, placed, and evaluated.

We must take steps to show more respect for the rights of clients and their families to have greater control over the service choices available to them. I hope this Committee will examine ways of allowing consumers greater freedom to decide how the money will be spent to accomplish the objectives in their own individual program plans.

Over the years, our system has become increasingly bureaucratized. The State vendorizes and sets rates; the Regional Center purchases only from pre-determined providers. Even more money is spent on these bureaucratic processes that don't seem to produce a better product. The system is becoming too rigid. Let's free it up and open opportunities for creativity and new forms of service.

I would advise you to open up the entire system for review. All the parts are interconnected. Examine the functioning of the State Council, the Area boards, the State Department of Developmental Services, and the Regional Centers. Perhaps we should consider alternative forms of governance for the system. For example, the Board of Regents method of governing our vast university system, or a variation of that concept, may be a more effective method than the one we have. Is the system we designed years ago for a few thousand clients still appropriate for 100,000 clients? How will it work ten years from now when we will have to serve 150,000 clients?

At a minimum, if we retain the present State management system, I believe the next Director of the Department of Developmental Services should have demonstrated effective leadership in the administration of community services. Perhaps experience as an outstanding Regional Center Director would be a good recommendation for the job. I also believe that we should require that one of the Department's Deputy Directors be a consumer, (a developmentally disabled person or the relative of a developmentally disabled person) who as demonstrated leadership in the field.

* * * * *

In conclusion, I beg this committee not to be constrained in its thinking because of the State's temporary difficulties. Some of the suggestions I've made will require additional funding. We will not tolerate any suggestion that because other systems - like transportation or mental health - are in bad shape, that we should be happy with what we have. We will not stand by and see our system de diluted to the less than mediocre standard of many of California's other public services. If we need more money, we, the consumers, will take the steps necessary to get the money. If necessary, we will do what the school people did and exempt ourselves from the Gann limit and guarantee a percentage of the budget for the programs we need. Or we will take steps to enhance a revenue source earmarked for our system; or we will work in concert with others to reform the Gann limit and the entire tax structure. We are prepared to do whatever it takes. And we will not go away!

I cannot stress too much the importance of planning ahead. Our system is falling behind in its capability to respond properly to clients' needs. Let's not wait for a crisis of critical proportions before we react. Good services are not developed overnight. Offering good choices - that's what this system is all about. The obstacles are formidable. The opportunities are great. Our objective is to have the best system in the world. **NO LESS!**

To be entered into the record:

Testsmony of Paul Ferrario before the

Joint Hearing of
The Senate Subcommittee on Mental Health, Developmental
Disabilities and Genetic Diseases;
The Subcommittee on the Rights of the Disabled;
The Assembly Subcommittee on Mental Health and
Developmental Disabilities

SR 9: AN OVERVIEW OF THE STUDY OF THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICE ACT

June 16, 1989

Testamony of Paul Ferrario
June 16, 1989
p. 1

My uncle has been a resident of the Sonoma Development Center for fifty-five years. I and my family are members of the Sonoma Parents' Hospital Association and of the Association of Retarded Citizens (ARC).

Over the years, we have applauded the reforms enacted to raise the quality of life for the clients of the Sonoma Developmental Center. There are however, several areas which are of serious concern to us and many other families.

The first is the geographic location of the Community Care facilities. Unfortunatly, the real estate market determines the location of the facilities. My uncle was slated for placement in a community care facility on Seminary Avenue in Oakland.

This attempt at placement was due to the depopulation plan. The arguments supporting this plan are: "to allow individuals (such as my uncle) to reside in a less restrictive environment and become more fully participating members of society".

If we would adhere to these guidelines, a great number of Community Care homes would not be in operation because they exist in deteriorated, high crime neighborhoods.

Upon visiting the home, we were upset to find it located in a burned out, boarded-up section of Oakland. The vendor had no contingency plans in the event she became ill or had to leave the residence.

My uncle lives in a crime free environment at the Sonoma Developmental Center. This would not have been the case on Seminary Avenue.

Developmentally disabled clients are vulnerable. They have the right to the least restrictive environment, but the environment must be structured to provide safety and meet their needs. There can be no safety in a crack neighborhood.

We believe the depopulation plan was attempting to dump my uncle in a high crime area. This is not the least restrictive environment, but a convenient avenue for depopulating the state run Developmental Centers.

My family did pursue legal action, at great emotional and financial cost. We did prevail at the fair hearing, but are concerned that he may again be scheduled for a Community Care facility.

I hope that my testamony before this committee does not result in retribution against my uncle, i.e. a new effort to place him in a Community Care home.

We are also concerned regarding the qualifications, licensing and monitoring of vendors.

All of us here will agree that developmentally disabled clients have special needs. Running a Community Care facility is not something to be taken lightly. I recently observed a 'vendor' and four clients on a BART train. An acquaintance of the vendor greeted her and asked the vendor about the difficulty of being a Community Care provider. The vendor replied that it was not difficult, "whener a client messes (incontinence or vomit), I make them clean it up themselves". The vendor reported how the clients are at work during the day, so they are no burden. The vendor also told her acquaintance that it is a lucrative arraingment.

This is not the only instance of questionable care that I have witnessed.

I have contacted the Regional Resource Developmental Project, the Area Board V of Developmental Disabilities and the Regional Center of the East Bay in an effort to gather data critical to my presentation today. I received no reply. I did speak with Ms. Fletcher of the East Bay Regional Center in an effort to obtain information. The Regional Center was uncooperative and evasive.

The information I seek is a list of the addresses of all the Community Care homes located in the Oakland-Berkeley area. Perhaps Senator McCorquodale will intervene on my behalf. I understand the information I seek is a matter of public record.

I have sent Senator McCorquodale a video tape of a KTVU news segment featuring the shutdown of three Community Care homes which were operated by an individual who was not licensed.

In order to ensure quality for these clients, the committee should consider these reforms:

a) stringent licensing requirement
b) Vendors should be required to post a bond. The bond would be forfeited in the event of loss of licensure due to violations.
c) Vendors should be required to have a special education background and continue upgrading their skills, in order to maintain licensure.
d) Establishment of a mechanism for transfer of clients back to the Developmental Center in the event of failure of the Community Care centers.
e) Thorough background checks and drug screening of home providers and staff.
f) Support of Assembly Bill 1945, authored by Assemblywoman Delaine Eastin, which would require that fines levied against Community Care facilities be promptly paid.

g) Determining the least restrictive environment on a case by case basis rather than lumping all clients together in one group.

Directly related to this issue is surplus land and vacant structures which result due to the depopulation plan. On several occasions my family has voiced concerns regarding conversion of the vacant structures to more intimate, home like settings. We have always received the response that such a plan is too expensive.

We question this response because the most expensive components are already in place: land, street improvments and utilities.

Sonoma Developmental Center is located in the California Wine Country. We are concerned that this acreage may be sold to developers.

Unfortunatly, a precedent has already been set. At the Fairview Developmental Center, located in Orange County, surplus land was sold to a developer.

The current, unfortunate events (depopulation plan and moving all of the clients to one side of the highway) seem to point in the direction of sale of the surplus land.

A sizeable tract of acreage, which was formally grazing land for the Sonoma Developmental Center's dairy operation, was recently sold to the state park system. A walking trail was constructed on the acreage. What is the possibility of Sonoma Developmental Center recovering the acreage and putting it to productive use???

I believe that the State of California should direct its resources toward maintaining and expanding its Developmental Centers. Not only to provide quality services for it's current population, but to prepare for the influx of:

a) children infected with AIDS.
b) Babies born to drug dependent mothers (approx. 11% of children born)
c) Medically fragile (technology dependent) children.

Thank you for the opportunity to testify.

Sincerely,

Paul J. Ferrario June 16, 1989

To: SR 9 Committee

Re: Views on Providing Care to Persons with Developmental Disabilities

From: Stephen W. Dale PT
Licensed Psychiatric Technician
1191 Carey Dr, Concord, Calif 94520
(415) 682-1315

I have been a Psychiatric Technician for 20 years and have had the privilege of working in both the state system and in the community at various levels and I am pleased that this committee is taking a critical look at the operation of the entire delivery system for care of the persons with developmental disabilities. I belive that an objective look operating free of profit motive and protection of administrative careers could make fundamental changes that will improve the delivery of care taylored to the needs of the persons that the system was created to serve. I also firmly believe that it is possible to deliver the kind of services that the Lanterman Act was designed to deliver without significant increases in cost if it is done without the self serving motivations that plague the system today.

I would like to share a couple of my experiences with you today as examples of what I see are blocks to achieving the goals of the lanterman Act. As Senator McCorkadale may remember, I am president of the Sonoma CAPT, the union representing 1300 level of care employees at Sonoma Developmental Center, and he graciously accepted an invitation to meet with some of our members recently to hear our concerns about about the future delivery of services to persons with developmental disabilities. Today, the material I am presenting are my individual views.

I have worked in what I believe are the best and the worst conditions the system has to offer. One principle that I have found to be true without exception in caring for persons with developmental disabilities is that **GOOD CARE IS BASED ON A SACRED RELATIONSHIP BETWEEN THE INDIVIDUAL AND THE PERSON PROVIDING CARE, GUIDANCE, OR TRAINING.** I believe that providing direct care and training to persons with developmental disabilities is one of the most honorable occupations that one can have, and I am proud of the services I provide.

I have seen vast improvement over the past 20 years in both the delivery of care, and the attitudes of persons delivering the hands on care. My first position as care provider was on a residential unit at Napa State Hospital in 1970 for profoundly developmentally disabled individuals who also had sensory disabilities. The care provided at that time was true assembly line care where bathing was done with a hose, restraints and seclusion were the treatment of choice, toilet training consisted of tying residents to a toilet for long periods of time, and behaviors were controlled by massive doses of medication. When I worked under those conditions I did not view my residents as people, but instead saw them as objects to be controlled. It was inconceivable to me at that time that the objects of my labors could ever function with any degree of independence.

I was the resource developer for one year at Spectrum Center Community Services Residential Project in Contra Costa and Alameda County, a private non-profit program which has 4 residential group homes providing services and training for 24 children and adults. This is what I consider one of the best facilities the community system has to offer. Spectrum administration understood that level of care staff services were of great importance and attempted to provide pay and benefits far in excess of industry standards. Even so, the salary that Spectrum could offer based upon the rates provided by DDS prohibited offering compensation that anyone could consider making a career of and these limitations discouraged the most qualified persons from applying for direct care positions.

Even in the best of programs, direct care providers were on the very bottom of the career priorities and the better paying positions were out of touch from the very people that the system is designed to serve. I found in seeking services for my residents, the regional center system encouraged contractual relationships that have high administrative costs but low percentage of funding actually used for providing direct services.

I have been employed recently at Sonoma Developmental Center as a psychiatric technician in a behavioral program. I was initially amazed at the difference in care and staff attitudes upon my return to the State system and the improvements in the quality of life for the clients served by the system. Although much improvement is still needed, the care provided today does not at all resemble that provided 20 years ago when I first worked at Napa. Yet, recently because of a budget deficit from the 1988-89 budget when cuts had to be made level of care positions were reduced drastically while no management cuts were made. The priorities once again are preserving administrative careers at the expense of level of care services.

My hope for this study is that your recommendations will take the best from each system for the benefit of the developmental disability community. I would like to conclude with some specific recommendations.

CONSIDER USING LICENSED PSYCHIATRIC TECHNICIANS IN BOTH THE STATE AND THE COMMUNITY SYSTEM

One reason that the Developmental Centers have been providing superior care has been DC use of highly trained staff for level of care duties. Care of developmentally disabled persons is a highly specialized occupation that requires the ability to protect and preserve civil rights of the individual, make skilled observations about a clients needs and develop programs specific to those needs, and often to interact with other medical and social professionals to provide the best care and training possible in the least restrictive environment. By requiring a percentage of direct care staff to have this level of expertise, the cost of care could ultimately be reduced by emphasizing careers in direct care rather than management or administration.

USE OF LICENSED PSYCHIATRIC TECHNICIANS WOULD BRING ABOUT ACCOUNTABILITY THAT THE SYSTEM DOES NOT HAVE TODAY.

One problem faced today by the regional system is that services are provided in a multitude of settings and often without an effective accountability system. Licensed psychiatric technicians are accountable for their actions and the licensing board holds licensed psychiatric technicians accountable for their actions.

LICENSED PSYCHIATRIC TECHNICIANS ARE REQUIRED TO PARTICIPATE IN CONTINUING EDUCATION COURSES TO UPDATE THEIR SKILLS

One concern that I have seen in many studies including the DDS 5 Year Plan is recognition of staff training needs that are only haphazardly being provided currently. Licensed Psychiatric Technicians are required to take continuing education courses to renew their license and makes the perfect mechanism to implement staff training without the need for the Department of Developmental Services to add to the bureaucracy.

Secondly, the Residential Services Provider Training Curriculum currently being developed by DDS strongly resembles training that psychiatric technicians already receive. Use of Psych Techs might eliminate the need of setting up a parallel service provider.

USE OF LICENSED PSYCHIATRIC TECHNICIANS THROUGHOUT THE SYSTEM WOULD ENCOURAGE DEVELOPMENT OF PROFESSIONALS WHO WOULD PROVIDE DIRECT SERVICES AS A CAREER.

One problem that I saw in the community system was that very few direct care providers considered level of care a career option. One highly accepted principle is that persons with developmental disabilities do best in a stable, consistent environment. Services must be based on a personal, stable, relationship to allow the individual to reach his/her greatest potential. If a portion of care providers considered residential care as their career I believe that the number of clients returned to Developmental Centers would be greatly reduced and many persons currently in the centers could be placed.

BRIDGE THE GAP BETWEEN DEVELOPMENTAL CENTERS AND THE REGIONAL SYSTEM

I believe that both systems have much to offer each other. DCs should be sources of training, research, and program development for the community. Competition and isolation of the two systems only serves to waste the limited resources available.

DON'T TRUST THE SYSTEM

The DDS system has a bad habit of putting it's best face forward. under the guise of client rights and confidentiality. I have seen the system create window dressings to look good for the moment. Do not interview employees with their employers present. Even licensing and ACDD accreditation are well plan, staged events. For this study to do it's job you must visit all levels of services with no notice whatsoever. Developmentally disabled persons are not lepers, and though their privacy must be respected, their needs are not served if persons like yourself who do not have a financial or career interest in their care do not get a clear view of the system that serves their needs.

THE LANTERMAN DEVELOPMENTAL DISABILITIES SERVICE ACT REVIEW OF CLIENTS RIGHTS ASSURANCE STRUCTURE AND PERFORMANCE

M.J. Ketring

The enactment of the LPS Act into law - and the declaration of the RIGHTS OF THE DISABLED - gave every appearance of a promise finally realized. We parents of the developmentally disabled wouldn't have to worry about trying to live forever inorder to provide our dependent child with the protections and support they require. We saw those Rights tacked up on the wall of every facility and residence for the disabled. Giving the IMPRESSION that Rights so carefully worded, printed, and posted --were Rights assured and experienced by the disabled residents. That was the comforting assumption - which many of us made. The past 15 years of my daughter's life have proven time and again, the inherent dangers in that assumption.

These years amd the experiences of my daughter have demonstrated instead; that the POTENTIAL for the developmentally disabled person to ever fully realize the promises and guarantees as asserted in Title 17 were EFFECTIVELY DENIED by the very structure of the Clients' Rights' Assurance Process. The agents and agency responsible for the implementation of the Rights' Assurance Process (the Human Rights Division and the Clients' Rights' Advocates) were placed WITHIN the very department charged with operating the facilities for the developmentally disabled - The State Department of Developmental Services. The members of the Human Rights Division and the Clients' Rights' Advocates thus became EMPLOYEES of the Department of Developmental Services. .

This relationship within the DDS created a CONFLICT OF INTEREST in the execution of their responsibilities to the developmentally disabled. Within this structure - the Clients' Rights' Advocates lost their autonomy and were left to execute their responsibilities to the client under tremendous constraints. With each issue involving ACCESSING or the ASSERTION of a clients rights, the Advocate may come into DIRECT CONFLICT OF INTEREST with the INTERESTS, POLICY, or OBJECTIVES of his immediate employer.
the Executive Director or the interests, policy or objectives of the big BOSS --the Department of Developmental Services. That is a truly untenable position from which to assert and protect the Rights of the developmentally disabled. In our general society we have seen that Rights which are not asserted -- are rights which become ignored --eventually ceasing to exist in any real sense.Perhaps we should recall just how little true meaning the CIVIL RIGHTS LAWS had until they were ASSERTED by the group of people effected.

My daughter HAS experienced this compromised Rights' Assurance Process! As I summarize some of the incidents ofthe past 15 years, YOU decide if this autistic retarded woman of 26 years with an IQ of 20 was IN FACT SERVED by this SYSTEM OF DELIVERY of her Rights. You decide whether her Advocates WERE able to act with IMPUNITY and INDEPENDENCE in the discharge of their RESPONSIBILITY to ASSERT and PROTECT HER RIGHTS. You decide if there is currently in place a VIABLE PROCESS,of RIGHTS' ASSURANCE for my daughter and the rest of the developmentally disabled people in this State.

1976: At age 13 - the institution of psychotropic drug change without prior review by parent or ID Team. Apparent allergic reaction to drug resulting in severe deterioration of behaviors. Recomendations of PDR ignored - efficacy of drug not evaluated. Focus became CONTROL of behaviors. Adversives were employed: constant application of double "garden gloves" ,placed in isolation, use of "medical restraints" and finally many hours in a 5 point restraint chair equipped with "soft ties". My daughter experienced this "treatment" for an EXTENDED period of time --PRIOR to the REQURED REVIEW by the HUMAN RIGHTS TREATMENT AND MODALITY REVIEW COMMITTEE! ACTION OF ADVOCATE: RECOGNIZING the condition of my daughter and that HE COULD NOT REPRESENT HER ADEQUATELY against the facility BECAUSE OF CONFLICT OF INTEREST; he recommended "outside" legal assistance. The Legal-Medical Division of the District Attorney's Office for the County of Los Angeles gave me that assistance. RESOLUTION TIME : APROX. 1 YEAR

1981-1982: At age 18 - My daughter's RIGHT to PROMPT MEDICAL CARE and TREATMENT were DENIED. She was born with profound abnormalities in the URO & GYN tracts. Previous surgeries had indicated that she had only one ovary, with no evidence of a uterus or cervix. Yet she began to menstrate! This was remakable given her anatomy. There were immediate indications that this condition provoked physical pain as well as the normal hormone fluctuations. She deteriorated and became very assaultive and self-abusive. It was necessary once again to put her in 5 point restraint. My requests for an examination by the GYN at UCLA was at first ignored. I felt that her abnormalities warranted an evaluation by the specialists most familiar with her. The evaluation was finally obtained BUT his recommendation of the use of the BIRTH CONTROL PILL to address the hormone fluctuations and discomfort was RESISTED. THE STATED POLICY of the Executive Director was to REDUCE THE INSTANCE of POLY-PHARMACOLOGY! While PSYCHOTROPIC levels were being INCREASED to deal with her deteriorating behavior, the physician was told to"RESIST

my DEMANDS!" The Program Psychomotrist was able to demonstrate the correlation between the onset of the menses, the monthly cycle and my daughter's behavior. Finally the recommendation was implemented in an uneven manner and with stated "reluctance."
ACTION OF THE ADVOCATE: Total support of his Executive Director. He gave no assistance to his client, my daughter.
MY ACTION: Was to enlist the assistance of Protection and Advocacy Inc. Their subsequent investigation was delayed by 3 months by the Executive Director. RESOLUTION TIME:18 MONTHS

1982-1983 The DENIAL of PROMPT MEDICAL CARE and TREATMENT to one resident of my daughter's Unit. As a consequence of this NEGLECT and DENIAL of RIGHTS, this resident caused *"minor to serious physical harm to clients peers and unit staff." Thus causing * "all other clients the DENIAL of the RIGHT to saftey, security, and freedom from physical harm and abuse." Those *'s refer to excerpts from the STATEMENT OF DEFICIENCIES, charged to the facility . Other parents of injured residents had requested assistance from the ADVOCATE and the EXECUTIVE DIRECTOR. Their requests for a psychiatric evaluation for this resident were denied. PROTECTION and ADVOCACY was contacted, but was unable to assist without a direct request from the parent of the resident in question. Once again the clients' Rights' were NOT ASSERTED by the Advocate, and the Exec. Director had another objective to fullfill! At my request the HEALTH DEPARTMENT FOR THE COUNTY OF LOS ANGELES conducted an investigation, cited the facility and demanded that immediate corrective measures be taken.
RESOLUTION TIME: APROX. 1 YEAR.

1984-1985 THE DENIAL OF THE RESIDENT'S RIGHT TO BE FREE FROM HARM and the RIGHT TO DIGNITY AND HUMANE CARE
Immediately following the transfer of several women including my daughter to an all male Residential Unit, my daughter exhibited an abrupt deterioration of her appearance, her affect, her speech and her behavior. There was no explanation given other than adjustment to the transfer. Just as immediate were the beginning of a series of persistent urinary tract infections. After nearly four months, I requested a vaginal smear. She was found to have a sexually transmitted disease. It appeared that she had been sexually assaulted, given her apparent trauma and now the disease. I requested an investigation. The final report to me from the Administration - INCLUDING THE CLIENTS' RIGHTS' ADVOCATE was that "none found evidence of sexual abuse by others."When I questioned these findings, I was told that a SEARCH of her records had REVEALED an INCIDENT 10 YEARS previous!. My daughter was a resident on an adolescent Unit at that time. I was told that "incident" WAS recorded in her charts, BUT had NEVER BEEN REPORTED and my daughter had NEVER BEEN TREATED. This was the EXPLANATION given to me for the appearance of a sexually transmitted disease 10 years later.The

RECEIVED
JUN 12 1989
SEN. DIANE E. WATSON

May 31, 1989

JUN 22 1989

Janice Crose
178 Saxton Circle
Citrus Heights, CA 95621

Senator Dan McCorquodale
4N 2nd St., #590
San Jose, CA 95113

Dear Senator McCorquodale:

Just recently wrote you praising Senate Resolution 9 that refers to "The Lanterman Act". It's an excellent resolution that was introduced by you and Senator Marks.

Enclosed is a copy of an article from the North Bay Regional Center Report bulletin concerning transition of residents from Sonoma Developmental Center into community living. Please notice my written comment on the article.

Senator McCorquodale, this is only a very slight example of the lack of services for the 'autistic' population in all of California. I honestly feel that in order for you to get more complete information on the whole picture of the developmentally disabled (namely, the autistic), it would be very beneficial to get in touch with the local chapter of the "Autism Society of America" there in San Jose. They will be able to tell you about the sad state of affairs for the autistic in the State of California.

I don't know who you'd be able to get ahold of in San Jose, but the local chapter of the "Autism Society of America" here in Sacramento would probably be most happy to help you. Their address is 812 "J" Street, Comstock Bldg., Suite 48; Sacramento, CA 95814. The President is Marie White. Her phone number is (916)481-1264. Thank you very much!

Sincerely,

Janice Crose
Janice Crose

enc.

PS- It's now 6/1 (only one day since I wrote the above to you.) I just now got a phone call from SDC (Sonoma Developmental Center) where my son, Scott, is. I was told he was just sitting on the bed of another client in the client's room---two other clients walked in and found him there and beat him up (enough that he saw a doctor). And because of the budget cutbacks, the scanty staff was very, very busy elsewhere. There just aren't enough to go around. The staff on my son's unit are very dedicated and conscientious workers, but can only be in so many places at once when they're spread so thin to begin with.

Plus, the unit can't control what problem behaviors they're faced with. What's sad is my son doesn't even know to run away or how to protect himself. He probably didn't even know what was happening to him---just knew that it hurt.

And I was even told, by someone there who is unaware of 'his' needs, that he must be hard to be placed in the community. (And this is because probably that he has the label 'autistic'.) Autism is one of the most misunderstood, and consequently, the most overlooked handicap there is! They are usually 'lumped' into one category---and the word BEHAVIOR is thought of. So right away, people become skeptical.

Communication is their main handicap. My son got the 'label' of autism early in life because he can't talk at all. And, ofcourse, there's different degrees of autism. Some can talk very well.

Now that Scott is 'labeled', there's no telling what people think when they hear the word 'autism'. It's very interesting to note that I'm handicapped myself from a brain hemorrhage--very poor speech and walking. And when my son stays with me, I have no problems with him.

So if the 'community' is so afraid to take on autistic people, then the state needs to take over----and develop small places for people by looking at their individual needs, instead of dumping them into units of lots of people with all different kinds of problems.

Why can't the State put those same hard working individuals on my son's unit to work in smaller environments with people of 'similar' problems, instead of putting them on hugh units.

Please, please, Senator McCorquodale, help! From the many, many letters I've written, no one else has. Something sure has to happen. Does someone have to be killed before something is done?

cc: Governor George Deukmejian
Senator Milton Marks
Senator Joseph Montoya
Senator Nicholas C. Petris
Senator Robert B. Presley
Senator Diane E. Watson
Representative Douglas H. Bosco
Representative Eugene Chappie
Senator Barry Keene
Senator Jim Nielsen
Assemblyman Bill Filante
Assemblyman Dan Hauser
Assemblyman Don Sebastiani
Senator John Seymour
Assemblyman Michael Roos
Barbara Turner, President of PHA at Sonoma Developmental Center
Bud Thompson, Vice-President of PHA at Sonoma Developmental Center
Fred Valenzuela, Executive Director at Sonoma Developmental Center
Tom Ward, Clinical Director at Sonoma Developmental Center
Tom Gillons, Administrative Services Dir. at Sonoma Developmental Center
Patrick Martin, Ph.D., Program 4 Dir. at Sonoma Developmental Center
Beverely Olson, Community Liaison at Sonoma Developmental Center
Rosemary Schmidt, Assistant Program 4 Dir. at Sonoma Developmental Center
Toni Tucker, Director of RRDP (Regional Resource Development Project) at Sonoma Developmental Center
Gary Macomber, Director of DDS (Department of Developmental Services)
Don Bowling, Chief of Clinical Program Services Developmental Centers of DDS (Department of Developmental Services)
Bamford Frankland, Deputy Director of DDS (Department of Developmental Services

Area Board IV- Alan Kerzin, Executive Director
Area Board IV- Cindy Ruder, Community Programs
Department of Health Services Licensing
Department of Social Services Licensing
Dr. Gary Nakao, Executive Director-North Bay Regional Center (Napa)
Douglas W. Cleveland, Chief of Client Services at NBRC in Napa
Barbara Tobin, Community Resource Consultant at NBRC in Napa
Mildred M. Whitney, Chief, Administrative Services at NBRC
North Bay Developmental Disabilities Services, Inc- c/o Ann Klink
Nora Thompson-Board of Directors President of North Bay Developmental Disabilities Services
Harry Lewis, Community Resource Consultant-North Bay Regional Center in Santa Rosa
Tony Apolloni, Ph.D., Calif. Institute on Human Resources at Sonoma State University
Travis Lipscomb, Program Director at North Bay Regional Center/Santa Rosa
David Rydquist, Supervisor at North Bay Regional Center in Santa Rosa
Fran Bailin, Counselor at North Bay Regional Center in Santa Rosa
Suzette Soviero, Counselor at North Bay Regional Center in Santa Rosa
Marie White, President of Autistic Society of America (Sacramento Chapter)
Helen Richard of Autistic Society of America (Sacramento Chapter)
Ralph Levy, Executive Director at ACRC (Alta Calif. Regional Center)
James L. Stevens, Associate Director/Chief Counselor at ACRC (Alta Calif. Regional Center)
Anne Kitt at Alta Calif. Regional Center
Monsignor Keys of the Diocese of Santa Rosa
Rae Pivonka of ARC in Sonoma County
Diane Kassebaum of The People First of Sonoma County and Sonoma County Citizen Advocacy

RRDP TRANSITIONS RESIDENTS TO COMMUNITY LIVING

By Barbara Tobin, Community Resource Consultant, NBRC, Napa

In January, 1987, the Regional Resource Development Project (RRDP) was begun at Sonoma Developmental Center (SDC). Its stated goal was:

> *"To promote the delivery of appropriate services to persons with developmental disabilities in the most effective and efficient manner through enhancement of the current delivery system and the creation of innovative means of providing individual growth."*

The project grew out of the Department of Developmental Services' response to a report by Julie A. Jackson, titled, "FY 1984-85 Community Placement Plan: A Review and Policy Analysis." In this report, Ms. Jackson identified a wide range of policy issues and barriers affecting the placement of developmental center clients into community facilities. Her recommendations touched on all aspects of the community placement process and provided the Department of Developmental Services (DDS) with the information necessary to begin to address these issues.

One of the approaches that DDS took to accomplish this task was the

(continued on page 9)

RRDP

(continued from page 8)

creation and development of the RRDP. Through this project, Sonoma Developmental Center (SDC) became more involved in the community placement planning process, and five regional centers agreed to cooperate in a regional effort to facilitate development of community facilities and placement from Sonoma Development Center into these facilities. (The five regional centers participating include North Bay, Golden Gate, Alta California, Redwood Coast, and Regional Center of the East Bay.)

The RRDP receives policy direction from a steering committee composed of representatives from the four of the regional centers, SDC, DDS, and the Parent-Hospital Association (SDC parent group).

Over the past two years, RRDP has worked closely with parents, and staffs from SDC and regional centers, to implement a wide range of activities to meet the goal of successful placement of SDC clients into the community. These activities include:

Transition Services. These include conducting client transition visits to community residential facilities and day programs, and actually moving the clients at the time of placement.

Training Activities. These include recruitment of potential ICF-DD/H operators, addressing the immediate training needs of service providers and enhancing the understanding of SDC staff about the client placement process.

Client Profiles. RRDP has developed individual client profiles to ensure that individual client needs are identified and client groupings are created that meet these needs.

Transfers. RRDP has developed and implemented the process to facilitate the transfer of clients between regional centers when appropriate for placement.

Crisis Services. RRDP has developed and implemented crisis intervention services for community service providers working with SDC clients.

Since RRDP's inception, NBRC has opened three homes to serve SDC clients. Two are ICF-DD/H's (Intermediate Care Facilities — Developmentally Disabled/Habilitative), which are funded by Medi-Cal and monitored by Health Care Licensing. The third is a negotiated rate home, to which NBRC pays above the standard rates for the intensive care and programming needs of the clients. This represents a total of 20 clients. Also, three more ICF-DD/H's, serving a total of 18 clients, will be open by July, 1989. In addition, RRDP has facilitated 14 individual placements.

THIS LEAVES OUT THE AUTISTIC - AS USUAL.

In addition to these homes, a new day program is also in the process of being developed.

If you would like more information about the Regional Resource Development Project, contact Toni Tucker, Director, at (707) 938-6480, or Barbara Tobin, Community Resource Consultant at NBRC, at (707) 252-0444.

TESTIMONY

Presented to the

Joint Hearing of

The Senate Subcommittee on Mental Health, Developmental Disabilities and Genetic Diseases;

The Subcommittee on the Rights of the Disabled;

The Assembly Subcommittee on Mental Health and Developmental Disabilities

by the

Epilepsy League of the East Bay

on behalf of California Affiliates of the

Epilepsy Foundation of America

June 16, 1989

Lucie Van Breen
Executive Director
Epilepsy League of the East Bay
1615 Broadway, Suite 415
Oakland CA 94612
(415) 893-6272 (916) 441-2250

Introduction

On behalf of the California affiliates of the Epilepsy Foundation of America, I want to thank the members of these Joint Senate and Assembly committees for undertaking this timely and complex review of the Lanterman Developmental Disabilities Services Act.

I also want to commend you for protecting the rights and interests of developmentally disabled consumers and their families in your plans for grassroots involvement at all stages of development of this report.

Finally, I want to thank you for the opportunity to share our visions and our concerns for the services provided through the Lanterman Act to persons with epilepsy who are developmentally disabled persons.

In my comments, I reflect the collaborative views of epilepsy affiliates throughout the state. I will draw on all of our first-hand data as well as combined experiences.

I also base these comments on the findings of the Congressionally-mandated National Commission on the Control of Epilepsy and Its Consequences and on recently compiled research of the National Epilepsy Library of the Epilepsy Foundation of America.

About the Epilepsy Foundation of America

The Epilepsy Foundation of America (EFA) is the sole national voluntary health organization dedicated to the prevention and cure of seizure disorders, the alleviation of their effects, and the promotion of independence and an optimal quality of life for people who have these disorders.

Through its national network of affiliates, EFA seeks to accomplish this mission through support of research and direct services including

* advocacy supporting the rights of persons with epilepsy, whether it be for driving privileges, health insurance coverage, employment protection or other concerns

* information vitally needed by people in crisis or more simple concerns ranging from medication questions to queries about camps or medical procedures

* public education programs designed to eliminate the centuries-old stereotypes and stigma of seizures

* professional education programs to bring up-to-date protocols into practice everywhere from the hospital emergency room to the baseball diamond.

National Programs

Throughout the country our colleagues offer residential care, day treatment programs, respite care for families, employment training and placement services and a wide range of other programs specifically designed to mitigate the consequences of uncontrolled seizures.

These programs are community-based, and consumer leadership and participation in program development is a priority.

Frequently these services are funded in total or in part by state funds.

* in Maryland, a $6.2 million line item for services to persons with epilepsy and other non- mental retardation developmental disabilities compliments funding for programs for those persons for whom mental retardation is also a diagnosis.

* in Florida, case management, employment and medical services programs are operating at seven locations with $3 million in funds from the State.

* Other states supporting specific services for persons with epilepsy include Alabama, Connecticut, Illinois, Indiana, Maine, Minnesota, Missouri, New York, North Carolina, Ohio, Rhode Island, Tennessee, Wisconsin.

Affiliate Services in California

California's seven EFA affiliates provide services to 23 counties, representing over 20 million people (about 75% of California's total) population.

We provide services ranging from general information and referrals to other agencies to case management. Over 6,000 separate individuals received some service from an EFA affiliate in California during 1988. Another 2,000 received services through the national Epilepsy Hotline. Nearly 550 received some individual counseling services, 1,000 participated in self-help groups, and 250 were placed in employment.

These services were delivered by our privately-funded agencies with budgets ranging in size from $38,000 to $400,000. A combined $860,000 was spent for these and other program services.

No affiliate in California currently receives Department of Developmental Disabilities or any other state funds.

Our Concerns for DD Clients Served in California

We are concerned that individuals whose seizure disorder results in a substantial limitation of major life activities are routinely overlooked throughout the developmental disability service system or that they may be receiving services which are inappropriate.

We believe that a statewide needs assessment must be undertaken to accurately document available and appropriate services. Further, we believe that a careful review of the eligibility criteria and disability definitions is in order. Finally, we suggest that all protocols required of vendors and staff be surveyed to assure that current standards are indeed appropriate.

High Prevalence of Seizures Within the General Population

National research indicates that one individual in one hundred persons has epilepsy, an estimated 2,323,000 individuals nationally. More than 30% of these are children under the age of 18. Approximately 100,000 new cases are reported each year, and recent studies indicate that the incidence of epilepsy is higher in areas with high populations of very young children, minorities, poor people or elderly. (One such study compared the incidence of epilepsy in Watts, Los Angeles -- 1.6% of the population --- to the incidence in Rochester, Minnesota --- between .6-.7%.)

For between 75-85% of these individuals, seizures are presently controlled or do not interfere with major life activities. These are people with a hidden disability. In California, we conservatively estimate that 27,500 persons have a seizure disorder.

A national survey currently in progress suggests that 20% of those persons served through programs for the developmentally disabled have epilepsy as either a primary or secondary diagnosis.

According to a preliminary report provided to us by the Department of Developmental Disability Services, of 80,000 persons currently receiving regional center services during fiscal 1987-88, 1,459 are persons with the sole diagnosis "epilepsy". This amounts to fewer than .02% of the number of clients served. We do not know the number multiply-diagnosed.

Compare this for a moment with the experience of the state of Montana whose population of 880,000 is a little more than 3% of California's population. In Montana, developmental disability services are provided to 37 persons with a primary diagnosis of epilepsy and 436 with a secondary diagnosis.

Frequent Barriers to Service

Why is it that the service needs of persons with epilepsy appear so largely ignored, even with a system in place mandated to serve them? Let me suggest three reasons:

1) Epilepsy is an episodic disorder. Between seizures even those significant adjustment problems may appear to be coping successfully. Yet, that very episodic nature makes it difficult for individuals to develop a sense of confidence and to feel in control of their own lives. Even those with good seizure control never know for certain that another seizure will not occur.

2) Epilepsy affects people in very different ways. For the majority, epilepsy is a challenge but ultimately not a barrier to leading a full and productive life. For that reason the needs of those more severely impaired, whose epilepsy substantially limits major life activities, may be easier to overlook.

3) Unlike many forms of mental retardation, or cerebral palsy, seizure disorders are very rarely diagnosed at birth. The service systems which are in place to direct the parents of a newborn infant into the developmental disability system are farther from the reach of the parents of a five-year-old, or an older child.

Suffice to say that a comprehensive needs assessment would accurately document that persons with epilepsy are indeed included in the service system.

Eligibility Criteria is Sometimes Exclusive.

Of significant concern to our EFA affiliates is the observation that individuals with epilepsy may experience much difficulty in qualifying for regional center services...or no difficulty at all.

This appears to vary significantly from Regional Center to Regional Center, as by design, eligibility criteria is open for interpretation by each Center's administration.

This means that an individual who receives services through one Regional Center may be excluded from services if he or she is forced to relocate to another part of the state.

We believe that this concern may not be limited to those persons with the diagnosis of epilepsy, and we do recommend that future hearings address the dilemma of protecting the autonomy of community-based Regional Center agencies in contrasted to implementation of centrally-imposed criteria.

Definitions Require Sensitivity

The very definitions used to determine eligibility ought to be carefully reviewed through this hearing process. Neither categorical definitions which may be too rigid nor functional definitions which may be very subjective assure that persons with developmental disabilities receive necessary services.

For example, clients whose seizures constitute a serious handicap may not necessarily experience a loss of IQ, or may not experience the mobility restrictions which a person with a different physical disability may experience.

Particular definitions may mean that every individual for whom epilepsy is a secondary diagnosis and not a sole diagnosis easily enters the service system but persons for whom epilepsy is a sole diagnosis are underserved.

Appropriate Treatment Requires Monitoring

Finally, we are concerned that a review of first-aid, medical and other protocols must be reviewed to assure that vendors and staff alike have the benefit of state-of-the-art knowledge.

Persons with epilepsy who are institutionalized, for example, may be receiving inappropriate medical treatment or other services. This can mean that an individual may receive anticonvulsant medications at a toxic level, as was found recently by the State of Wisconsin's protection and advocacy agency.

"When to call an ambulance," and eliminating references to "place an object between the person's teeth," are two protocols which readily come to mind.

A Vision

It is our goal that all persons with seizure disorders lead full and independent lives. If the degree of an individual's disorder constitutes a substantial handicap, we believe that person should receive services to achieve this goal in the least restrictive, most appropriate environment.

We believe that to serve the needs of persons with seizure disorders appropriately several actions need to be taken by the State:

1. A full and complete statewide needs assessment must be undertaken to document the level of need, the adequacy of programs which do exist and to enable all of us to maximize the use of existing services.

2. Consideration must be given to redefining eligibility criteria for services within the developmental disability system to assure that the standards and definitions in effect are reflective of all developmentally disabled persons.

3. A complete review of training and protocols should be considered to assure that all protocols reflect the currently accepted responses to the needs of not only persons who have seizures but other disabilities as well.

We therefore urge this committee to carefully listen to these many voices, to understand the fragile balances at play, and to continue this strong, consumer-oriented service delivery system.

We look forward to participating in this process.

Epilepsy
FOUNDATION OF AMERICA
®

EPILEPSY SERVICES
STATE PLANNING AND FUNDING

INTRODUCTION

On July 29, 1975, the 94th Congress passed Public Law 94-63, an amendment to the Public Health Service Act. Among its provisions, the law specified that the Secretary of Health, Education and Welfare should establish a National Commission for the Control of Epilepsy and its Consequences. The law provided four specific mandates for this Commission:

1. To make a comprehensive survey of medical and social management of epilepsy in the United States;
2. To investigate and to make recommendations about the proper roles of federal and state governments and of national and local public and private agencies in research, in prevention, in the identification, treatment, and rehabilitation of persons with epilepsy;
3. To develop a comprehensive national plan for the control of epilepsy and its consequences bases on the most thorough, complete, and accurate data and information available;
4. To transmit to the President recommendation for legislation and appropriations.

The impetus for the creation of such a commission and the development of a national plan to help people with epilepsy has been building for years. The Commission conducted a nationwide review of services for people with epilepsy. Commission documented that epilepsy was a serious medical and psychosocial problem in our nation, and that people with epilepsy were generally underserved throughout the country. After the Commission's Report, the Epilepsy Foundation of America and its affiliates and the National Institute of Neurological and Communicative Disorders and Stroke, took significant steps to improve research in the epilepsies and the conditions for people with epilepsy.

However, despite these efforts and despite major advances in epilepsy research which have led to new diagnostic methods and treatment for those with epilepsy in the last decade, these individuals continue to face numerous problems. Among these problems are unemployment, inadequate health care, psychosocial maladjustment, and social stigmatization which seriously diminish their quality of life and their ability to be as productive members of the community as they could be. The problems that children with epilepsy face are particularly critical as they can take a substantial toll on the children's physical and psychological well being and development.

The Commission also urged that each state conduct its own statewide survey. In the decade since the report, many states have responded to this challenge; there have been needs, assessments and/or study commissions in Connecticut, Florida, Louisiana, Maryland, Michigan, Minnesota, New Jersey, New York, North Carolina, Puerto Rico, Texas, Washington State, Wisconsin, and Virginia.

Many states have also responded to these concerns by providing state funds for services to persons with epilepsy. In Florida, employment programs are operating at seven locations with funds from the State of Florida. Maryland's state budget includes a $6,227 million line item for services to persons with epilepsy and with other non-mental retardation developmental disabilities. Indiana funds epilepsy counseling at each of its Community Mental Health Centers, and the State of Illinois provides more than $500,000 to nine epilepsy agencies in the state. New York provides nearly $2 million for epilepsy services, Ohio $700,000, North Carolina $230,000, Tennessee $168,000 and Alabama $73,000.

More recently, the state legislatures in Connecticut, Maine and Wisconsin have appropriated funds for epilepsy services. Wyoming, Iowa, North Dakota and Kansas are doing needs assessments to examine the needs of persons with epilepsy. The Missouri Developmental Disabilities Council has funded EFA Affiliates in St. Louis and Kansas City to expand services statewide.

MARYLAND

In 1978 the Maryland State Legislature appropriated funds to study the needs of severely handicapped persons residing in the state who were not retarded. A statewide survey was conducted between August 1980 and March of 1981 and the findings were presented in a report published late in 1981.

For planning purposes the State of Maryland defined the developmentally disabled population as one whose members have severe physically or mentally handicapping conditions that originate early in life and interfere with several aspects of the individual's developmental progress. This definition emphasizes the degree of impairment in major life activities associated with a disability, rather than diagnostic criteria, in order to prioritize limited service resources for those with the most severe and substantial functional limitations. As enumerated in federal legislation, major life activities include (1) self-care, (2) receptive and expressive language, (3) learning, (4) mobility, (5) self-direction, (6) capacity for independent living and (7) economic sufficienty.

In addition to this emphasis on functional limitations, state policy differentiate the developmentally disabled into two sub-groups: those whose primary disability is mental retardation (MRDD), and those whose development is impeded by other physical or emotional handicaps (NRDD). This mandate to plan for special services to target the NRDD sub-group, then, ideally necessitates knowing the number of persons in the target population who have both a disabling condition and severe functional limitation(s).

Although, detailed statewide estimates of the NRDD population are unavailable, researchers have conservatively estimated that 1.63% of Maryland's total population is functionally limited in at least one of the enumerated seven major life activities because of a developmental disability. When this proportion of severely functioning limited persons was applied to Maryland's 1981 population estimates, approximately 69,300 persons are found to be developmentally disabled, 42,800 of whom are 18 years of age or older.

While no precise information was available to estimate the proportion of these developmentally disabled in Maryland who are non-retarded, an indirect indicator of the size of the NRDD proportion is available. Supplemental Security Income (SSI) referrals to Maryland's Crippled Children's Services show nearly 35% of the recipients reporting mental retardation, with the remainder (65%) reporting non-retarded developmental disabilities. Current national data used by the Department of Health and Human Services indicate the same 35% MRDD vs. 65% NRDD proportions. When this proportional relationships applies to the estimate of Maryland's DD population cited above, nearly 45,000 persons in Maryland are found to have NR developmental disabilities.

Legislative/Programmatic Rationale for Survey

The NR/DD program was mandated in 1972 to set up a comprehensive system of day programs and residential services for non-retarded disabled persons similar to those already in existence for the mentally retarded. As part of the recently re-organized MR-DDA Administration, the NR/DD program addresses primarily the problems of developmentally disabled adults, with two programs, the Crippled Childrens Services and SSI-DCP (Disabled Childrens' Program) serving the needs of NR/DD children.

Monies were available in the State 1980 budget "to study the residential needs of the non-retarded developmentally disabled." Coupled with the FY 1981-1983 program goal to analyze the differential needs of the NR/DD statewide population, this legislative directive gave the impetus to carry out a sample survey of this population. The data base created from the survey has continued in an effort to anticipate future need for services among the defined population. In 1987 the State of Maryland will spend more that $6.2 million to provide services for the NR/DD population, with more than $1 million going for services to persons with epilepsy.

MINNESOTA

In 1981 the Minnesota Epilepsy League (now the Epilepsy Foundation of Minnesota) wrote a proposal to the Minnesota Legislature to fund a study commission on epilepsy, in part to update an earlier state plan (1975). After an intensive lobbying and letterwriting campaign, the league received a grant to develop and staff a state epilepsy commission. Names of commission members were submitted to the Governor for his approval. They included both consumers and representatives of departments within state government which impact on the lives of people with epilepsy. The commission concluded its work with the publication of 100 recommendations. Each government department was advised of specific recommendations which impacted its mission. Although there was not a specific agency designated to follow up on the report, substantial progress has been made in at least the following areas:

- Improvement in driver's licensure statutes;
- Increased access for persons with epilepsy in Section 8 housing through the state;
- Improved medical treatment at state hospitals;
- Greater professional education;
- Improved understanding of epilepsy at the local school district level.

The recommendations have also continued to provide a framework for the advocacy efforts of the Epilepsy Foundation of Minnesota, as well.

In 1987, public funding was committed to establish a new independence living program for individuals with epilepsy and called SEARCH (Serving Epilepsy as a Related Condition in Housing) and operated by People, Inc. The project was initially funded by Hennepin County (Minneapolis) which provides $155,000 for start-up costs and the first 13 months of operation. The State Legislation subsequently appropriated $200,000 per year to continue the program.

NEW JERSEY

Following the passage of legislation in 1985 redirecting the name and focus of the New Jersey Division of Mental Retardation to the Division of Developmental Disabilities, the new Division undertook to familiarize itself with the needs of the epilepsy population. To accomplish this, and to demonstrate its commitment to improving the lives of children and adults with epilepsy, the Division asked the Epilepsy Foundation of New Jersey to commence a comprehensive review of existing services for those with epilepsy.

The Statewide Epilepsy Needs Assessment was designed to:

- provide a practical tool to assist state and local government administrators in decision-making which will affect the lives of approximately 105,000 persons with epilepsy in New Jersey
- put into one easy-to-read document the facts about epilepsy so that interested individuals, government officials, service providers and persons with epilepsy and their families have the information

- furnish to planning agencies in New Jersey current information on epilepsy for inclusion in their planning systems.

During the course of the nine-month study, hundreds of New Jersey residents with epilepsy provided detailed information regarding the difficulties that they had faced and the needs that they felt existed. In addition, over 100 individuals gave testimony based upon personal experiences with epilepsy at three public hearings held in late 1985 throughout New Jersey. Additional testimony was provided in written form by individuals unable to attend the hearings.

Efforts were also undertaken to assess needs in schools and institutions. Providers of services to the developmentally disabled were interviewed and numerous programs assessed. This entire process was overseen by an advisory committee comprised of experts and consumers in the fields of epilepsy and developmental disabilities.

While the Statewide Epilepsy Needs Assessment yielded a great deal of data and information useful for planning purposes, there were difficulties encountered. The time allotted to the study precluded adequate study of some issue areas. Moreover, it was not possible to arrive at a satisfactory reflection of the prevalence of epilepsy in New Jersey.

The Advisory Committee of the Statewide Epilepsy Needs Assessment determined that efforts should be undertaken to continue the needs assessment in areas not covered in this first edition. The Committee, furthermore, recommended that the Department of Human Services appoint an Epilepsy Task Force to be charged with the on-going responsibility for oversight of implementation of the 150 recommendations, as well as any further studies undertaken.

The New Jersey Needs Assessment report was organized along the lines of its national predecessor. The issue areas examined are: Prevention, Education and Employment, Social Adjustment and Mental Health, Medical Services, Research, Education (Patient, Family, Professional & Public), Living Arrangements, Independence & Equality and Researach. Each section contained findings and conclusions from the needs assessment and recommendations listing the appropriate agency or administrative body believed to be responsible for implementation.

The state of New Jersey provided $37,000 to conduct the initial needs assessment study. Since that time the state has substantially expanded their support of the Epilepsy Foundation of New Jersey to nearly $402,000 in FY 1989. Services funded include anearly state-wide respite care program for children with uncontrolled seizures and the development of new residential and vocational alternatives for individuals with epilepsy.

WISCONSIN

In 1986, an Ad Hoc Legislative Committee was established through the efforts of State Senator David Helbach with the assistance of the Wisconsin epilepsy association and the local epilepsy association across the state. The purpose of the Committee was to take a comprehensive look at all state statutes and administrative code which related to epilepsy. The initial study focuses on four broad areas:

- transportation, including drivers licensure;
- developmental disabled, specifically the "Chapter 51 System," which is mandated to deliver social services to persons with epilepsy;
- insurance, both public and private programs;
- employment, including both laws prohibiting discrimination and services provided by the Division of Vocational Rehabilitation.

Committee members came from throughout the state and included consumers, professionals, including neurologists and staff of several EFA affiliates, representatives of appropriate State of Wisconsin agencies, and other state legislators.

Recommendations included:

- Revisions in the state drivers licensure code (adopted);
- A survey of health insurance carriers by the commissioner of insurance (initial phase completed);
- Inservice training for Vocational Rehabilitation and Developmental Disability Institution staff (in planning);
- The development of standards for services to persons with epilepsy for the Division of Vocational Rehabilitation (in planning);
- A data reporting system for the Department of Health and Social Services which would provide information on clients with epilepsy who are receiving services from social service and mental hygiene programs.

As noted above, many of these recommendations have either been enacted or are in the process of being enacted.

The Task Force also recommended that funding by provided at the state level to expand the availability of psychosocial epilepsy services within the state. In FY 1989, the Governor recommended and the legislature approved $150,000 per year in grants for epilepsy services. This amount matched the $65,000 already provided by county developmental disability boards for case management, counseling and public education to several EFA affiliates in the state.

FLORIDA

Florida produced a five-year plan in 1973, pre-dating the national commission report, which became a model for other state plans. Primarily, because of the visiability due to the plan, the State of Florida began providing funding for the medical and psychosocial needs of persons with epilepsy in the state. This enabled several local affiliates to establish an office with paid staff. The funding level for 1974 was approximately $450,000. The plan was a cooperative effort between the state affiliate, the State of Florida's Department of Health and Rehabilitative Services and Developmental Disabilities Planning Council. Many of its recommendations remain valid today.

During the 1983 legislative session the state organization was able to convince the legislators that there was a need for a pilot project for employment and placement services statewide. The state provided $200,000 over a nine-month period for seven pilot projects which has been refunded with slight increases each year. Currently, the State of Florida also funds a medication program for persons with epilepsy who are indigent, case management and medical services under contract with local affiliates and district office of the Department in areas where there are no affiliates. Current funding for the medication program for 1987-88 is $675,000 and for medical, case management and employment services is $2,315,748. During the 1987-88 fiscal year, the services for persons with epilepsy moved from the Developmental Disabilities Program Office to the

Health Services Office. This will provide the state organization with better ability to monitor state funding since there will be a separate line item in the budget for epilepsy services instead of being commingled with other developmental disabilities. It is also hoped this will assist in producing additional funding for services based on teh ability to provide data to the Department of Health and Rehabilitative Services and the legislation of the statistics gathered. It also provides a staff person whose responsibility is to coordinate the epilepsy servcies in the Health Services Office and a consultant who will work with a thirteen member appointed task force to develop the future service provision to persons with epilepsy in the state. The task force includes staff members of three affiliates and four other persons who have been involved with the state organization. The first meeting of this task force was held on January 5, 1988. The direction of this task force could assist other state organizations in the future.