

March 6, 1979

ASILOMAR MEETING OF FRIENDS OF DEVELOPMENTAL SERVICES, MARCH 3/4/5

The group gathered out of a mutually felt need to come together, a need to grasp a picture of the whole, and a need to affirm the future based on law. ATTENDANCE ATT. # 1

Each person stated desired outcomes. ATT. # 2

The group compiled a list of problem statements. ATT. # 3

The group attempted to identify crisis issues. There was information given about each issue so that the group was able to decide whether or not it chose to address an issue. ATT. # 4

Some attempt was made to prioritize each issue. This attempt failed.

The group collectively drafted Position Statements. ATT. # 5

The group collectively drafted crisis statements with recommendations for action. ATT. # 6

Each person present is asked to circulate the Position Statement, the Crisis Statements, and encourage groups and/or individuals to endorse and forward to the Legislature and the media. (NOTE: IN ALL MATERIAL FORWARDED TO OTHERS, PLEASE DELETE ALL PERSONAL REFERENCES.)

The group compiled a list of others who should be informed immediately of this meeting and identified the individual who should give the information. ATT. # 7

There was strong feeling expressed that this group is not strong enough yet to withstand negative input. When a larger meeting is held, each person here will invite two others, from the list.

NEXT MEETING, MARCH 31, APRIL 1. Mike Danneker will find a place in the L. A. area. (This is not a larger meeting.)

ATTACHMENT # 2

NOTES FROM ASILOMAR

DESIRED OUTCOMES

SOME DIRECTION ON CURRENT LEGISLATION

GOALS AND STRATEGIES FOR THE TROOPS AT HOME

A PARTY LINE

WHAT DO WE TELL THE PEOPLE

DETERMINE IF THERE IS A CONTEST WITH THE COUNCIL - SOME FEEDBACK

A PICTURE OF THE WHOLE

AN ACTION CALENDAR

KNOW OUR FORCE

IDENTIFY PROBLEMS - DETERMINE IF THERE ARE TOO MANY - TOO FEW

SOME DIVISION OF LABOR IN ADDRESSING ISSUES

PLAN FOR FISCAL RESPONSIBILITY

DETERMINE PRESSURE POINTS - TARGETS

DETERMINE WHAT WE MUST DO BY JUNE 30 - NEXT FISCAL YEAR - LONG RANGE

DEVELOP A COMMUNICATION NETWORK



- \* Other issues raised as smokescreen to suck off energy, i.e. CEDAR
- \* No viable coalition in the Human Services
- \* Agree on what we have to agree on vs. what we don't have to agree on
- \* No commitment to manpower development, service providers, volunteers
- \* No agreement on enforcement of good Legislation
- \* No relief - too much burn out
- \* Lack of public awareness
- \* Disincentives to doing advocacy
- \* Two years too long to obtain Title XIX dollars
- \* No ceiling on administrative costs
- \* No definition of administrative costs
- \* Consumer and voluntaries don't communicate
- \* No political commitment to prevention - support to natural families

(Note; this list is off the charts. Bill is organizing it into categories.fs.)

SUMMARY OF SOME IDENTIFIED PROBLEMS  
IN  
DEVELOPMENTAL SERVICES SYSTEM

POLITICAL/ORGANIZATIONAL ISSUES

Consumer and voluntaries don't communicate.

Lack of consensus position on part of consumer movement.

Lack of uniform information base and dissemination machine.

Selfish pursuits.

No viable coalition human services.

Agree to agree on vs. what we don't have to agree on.

What unifies us/what separates us

No strategies for making law come alive.

What ingredients should be nourished to keep us together.

Who's got the problem?

Exclusion of "majority" of need.

Black, poor, Chicano, etc., not being served, have no power in the movement

Is there really a movement? What is it?

Lack of visibility - disenfranchised community.

Lack of public awareness

No relief - too much burn out.

Too much time and energy on crisis.

Issues raised as smokescreen to suck off energy, e.g., CDER.

No brain center and strategy action tank to support advocates and new challenges.

Divide and conquer strategy on part of administration, regional centers, Area Boards, Protection and Advocacy.

Governor's attitude - more political incentives to oppose human services.

## SYSTEM ISSUES

Leadership vacuum.

Law not clear related to mandate for who obtains or provides services in IPP and the overall responsibility of the State.

Civil service barriers to competence.

No agreement or enforcement of good legislation.

No political commitment to prevention - support to natural families.

Disincentives for doing advocacy.

No unified regional governance, lack of power.

Should we have regional centers? System design.

Area Boards, State Council, Protection and Advocacy.

## ADMINISTRATIVE ISSUES

No agreement on quality and outcomes.

No commitment to manpower development.

Lack of uniform accounting and management procedures for regional centers.

No ceiling on administrative costs.

No definition on administrative costs.

Two years too long to get Title XIX.

## REGIONAL CENTER ISSUES

More precise mission for regional centers.

Inadequate funds or poor allocation to regional centers to meet service needs.

No mandate for regional center priorities to assure quality provision of services.

CRISIS ISSUES

CRISIS DEFINITION: A PROBLEM IN FY 78/79, WHICH IF NOT  
ACTED UPON IN NEXT THREE MONTHS WILL LOSE OPPORTUNITY.

- \* LEADERSHIP CRISIS
- \* INADEQUATE FUNDING FOR POS FOR SERVICES IN IPP
- \* PEOPLE CUT FROM SERVICES, DENIAL OF SERVICES, REDUCTIONS, SUSPENSIONS
- \* LOSS OF PROVIDER RESOURCES
- \* LEGISLATIVE CRISIS
- \* PROPOSED ELIMINATION OF TITLE XX AND HOW THAT WILL IMPACT TRAINING \$'s  
(NEED MORE INFO ABOUT HIS)
- \* GARAMENDI BILL STATE HOSPITALS S.B. 354
- \* FUNDING FOR S.B. 3275
- \* A.B. 486 , SATELLITE BILL
- \* ABORTION CUTS
- \* DILLS BILL FOR EDUCATION SB 234
- \* RODDA BILL SB 260 for SPECIAL EDUCATION
- \* SSI SSP SB 1
- \* INDEPENDT LIVING CENTERS BILL BATES AB 204
- \* HABILITATION, BATES
- \* BUDGET BILLS
- \* RATES
- \* ZONING
- \* REGULATIONS ICF/DD OUT, MUST BE CHANGED
- \* FEDERAL LAW 95.602, IMPLICATIONS
- \* LICENSING, COMMUNITY CARE FACILITIES
- \* LITIGATION, HARBOR REGIONAL CENTER, WASHINGTON ARC WOULD  
REQUIRE STATE TO PLACE INDIVIDUALS IN COMMUNITY  
PROSPECTS OF JOINT ACTION BY LEGAL AID, L.A., PAI, CAR
- \* AREA BOARD VI ACTION AGAINST STATE HOSPITALS, IMPLICATIONS  
IN EDUCATION, TREATMENT, HABILITATION, RATES
- \* DEPARTMENT OF FINANCE STUDY ON HABILITATION SERVICES
- \* KEENE ACR 103, STAFFING STANDARDS IN STATE HOSPITALS
- \* DEPARTMENT'S POSITION PAPER ON PRIORITIES  
( DOES FAIR HEARING PROCEDURE APPLY, IS SERVICE MAINTAINED  
DURING NEGOTIATIONS?)
- \* AFTERMATH OF THIS MEETING
- \* APPOINTMENTS PROCESS
- \* MARCH 22 STATEWIDE CONFERENCE, LOMA PRIETA HEARINGS, MARCH 7

OVERVIEW AGENDA CLUSTERLEGISLATIVE/ADMINISTRATIVEBUDGET

Title XIX Reshaping  
 ICF/DD Regs  
 AB 486 - Satellites in Community  
 SB 354 - Hospital appropriations  
 AB 3274 - Continuum  
 ACR 103 - S.H. staffing  
 Department CLA Paper  
 Licensing Standards  
 CIL Bill (Bates)

Budget Bill  
 SSI - SSP  
 State buy out  
 Bates Habilitation Act (to  
 be submitted)  
 DOF Study on Habilitation  
 Equitable Rates

Education financing  
 Dills SB 234 - Pub. School \$  
 Rodda SB 260 - Spec. Ed. \$  
 SH/DOE Legislation  
 DDS/DOE Interagency Agreement

Title XX Training  
 Institute Scheme

95-602 Federal Regs

Prevention/Abortion  
 High Risk Infant Follow Up

State Law and Regs

Leadership Problems

Aftermath of Friends Meeting  
 Division of Labor

NOTES FROM ASILOMAR

POSITION STATEMENTS

1) THE STATE IS ABSOLUTELY RESPONSIBLE FOR ASSURING THAT SERVICES ARE PROVIDED WITHOUT INTERRUPTION TO ALL PERSONS WHO HAVE A DEVELOPMENTAL DISABILITY BASED ON:

- a) THE INDIVIDUAL ASSESSMENT OF NEEDS
- b) THE INDIVIDUAL PROGRAM PLAN
- c) THE PRINCIPLE OF NORMALIZATION AND THE LEAST RESTRICTIVE ALTERNATIVE
- d) THE UTILIZATION OF LOCAL RESOURCES

AND THAT UNDER NO CIRCUMSTANCES WILL SERVICES BE DENIED BY ANY SYSTEM OF PRIORITIES.

2) THE STATE SHALL NOT ABROGATE THESE RESPONSIBILITIES, BY CONTRACT OR DELEGATION.

3) IN ANY CONTRACT OR DELEGATION BY THE STATE WHICH AFFECTS THESE RESPONSIBILITIES THE STATE SHALL GUARANTEE THAT THESE SERVICES BE PROVIDED.

4) THE ADMINISTRATION IS RESPONSIBLE FOR INFORMING THE LEGISLATURE OF THE FUNDS NECESSARY TO ASSURE PROVISION OF THESE SERVICES AND THE LEGISLATURE IS RESPONSIBLE FOR MAKING AN APPROPRIATION TO FUND THESE SERVICES.

5) IN THE EVENT THAT THE INFORMATION PROVIDED BY THE ADMINISTRATION RESULTS IN AN APPROPRIATION THAT IS INADEQUATE, THE ADMINISTRATION IS RESPONSIBLE FOR REQUESTING, IN A TIMELY MANNER, THE NECESSARY ADDITIONAL FUNDS TO MEET THESE RESPONSIBILITIES.

6) THE STATE HAS A DUTY TO DEVELOP AND MAINTAIN IN-HOME FAMILY SUPPORT AND ALTERNATIVE COMMUNITY LIVING ARRANGEMENTS WITH A CONTINUUM OF ALL OTHER SERVICES LOCALLY.

THE RATE STRUCTURE FOR THESE SERVICES MUST BE UNIFORM AND EQUITABLE. ANY EXCEPTION SHALL BE AN INCREMENT BASED ON QUALITY OF SERVICES WITH REASONABLE PAYMENT FOR ACTUAL COST. THE STATE MUST PROVIDE FUNDS AND COMPETENT RESOURCES TO ASSURE THE ESTABLISHMENT OF NEW AND EXPANDED LOCAL SERVICES AND SYSTEMS NECESSARY TO MEET THE NEEDS OF INDIVIDUALS.

ATTACHMENT # 6

NOTES FROM ASILOMAR

CRISIS STATEMENT # 1

REGIONAL CENTER CLIENTS ARE LOSING SERVICES BY DENIAL, REDUCTION, SUSPENSION AND TERMINATION. THERE IS A LACK OF COMMITMENT BY THE ADMINISTRATION TO PROVIDE ALL SERVICES NECESSARY.

- a) THE STATE HAS NOT ESTABLISHED A UNIFORM ACCOUNTING PROCEDURE FOR REGIONAL CENTERS.
- b) THE STATE HAS NOT ESTABLISHED A UNIFORM ENCUMBRANCE SYSTEM.
- c) THERE IS INADEQUATE MANAGEMENT DATA FROM WHICH TO BASE ALLOCATION.

WHERE IS REMEDY: GOVERNOR CAN DIRECT DEPARTMENT OF FINANCE TO TRANSFER MONEY FROM GENERAL FUND TO BUDGET OF DEVELOPMENTAL SERVICES VIA SECTION 28A LETTER.

LEGISLATURE CAN APPROPRIATE NECESSARY FUNDS.

RECOMMENDED ACTION: ASK LEGISLATURE TO APPROPRIATE \$4.2 MILLION TO DELIVER ALL SERVICES WITHOUT DENIALS, SUSPENSIONS, TERMINATIONS, PRIORITIES. PAY ALL BILLS TO JUNE 30 FOR SERVICES IN INDIVIDUAL PROGRAM PLANS. NO CUTS! NO WAITING LIST! NO PRIORITIES!

CALENDAR: MARCH, 1979

CIRCULATE POSITION STATEMENT AND CRISIS STATEMENT AND PETITION AND RECOMMEND ACTION STATEMENT TO ALL INTERESTED PARTIES. URGE THAT SUPPORT LETTERS BE SENT TO GOVERNOR BROWN WITH COPIES TO JOHN GARAMENDI, CHAIRMAN, SENATE HEALTH AND WELFARE.

- ALBERT RODDA, CHAIRMAN SENATE FINANCE
- DANIEL BOATWRIGHT, CHAIRMAN ASSEMBLY WAYS AND MEANS
- ART TORRES, CHAIRMAN, ASSEMBLY HEALTH
- TOM BATES, CHAIRMAN ASSEMBLY SUB-COMMITTEE MENTAL HEALTH AND D.D.

ORIGINAL LETTERS CAN BE SENT TO LOCAL CONTACT TO MAKE AND SEND ALL COPIES.

WHO WILL DO WHAT:

CONTACT UCPA . . . . .	JIM BURCHELL
ARC'S . . . . .	BURNS
JUDY HEUMAN . . . . .	BILL
L.A. ORGS AND BRUCE CURTIS . . . . .	CYNTHIA
ALL AREA BOARDS . . . . .	JIM SHORTER
PEOPLE FIRST . . . . .	AL ZONCA . . JOHANNA
LOS PADRES . . . . .	AMALIA AND HECTOR

DRAFT PETITION . . . . .	JOHANNA
OUTLINE LETTER . . . . .	
REQUEST R.C.'S TO SEND OUT FLIER TO THEIR MAILING . . . . .	DD COUNCIL

ENCOURAGE PEOPLE TO ATTEND MARCH 22 STATEWIDE CONFERENCE. . . . ALL

CRISIS STATEMENT #2

THE COMMUNITY LIVING ARRANGEMENT SYSTEM IN CALIFORNIA IS INCORPORATED IN THE CONTINUUM BILL, AB 3274 (TORRES) SIGNED BY GOVERNOR BROWN, SEPTEMBER 26, 1978. AB 486, INTRODUCED FEBRUARY 6, 1979 (EGELAND) TO ESTABLISH SIX RESIDENTIAL FACILITIES UNDER STATE HOSPITAL CONTROL, IS IN DIRECT CONFLICT WITH THE POLICY OF THE STATE OF CALIFORNIA AND WILL SERVE ONLY TO PERPETRATE THE DIVISION BETWEEN THE PRIVATE SECTOR AND STATE OPERATIONS

ACTION: (FOUR PEOPLE, ALLAN I. BERGMAN, AS ONE, WILL COMMUNICATE WITH TORRES, BATES AND RESPECTIVE STAFF.)

3274 MUST BE FUNDED IN THE 79-80 BUDGET FOR \$6-8 MILLION FOR THE DEVELOPMENT OF 3-5 REGIONAL PILOTS DURING 79-80. THIS MUST BE LINKED TO PROGRAM DEVELOPMENT FUND PRIORITIES TO ASSURE COMPREHENSIVE SERVICES IN THE PILOT REGIONS.

ACTION: SUPPORT FOR ILP. (BILL WILL MEET WITH ED ROBERTS IN 7 DAYS. BURNS WILL MEET WITH JUDY HEUMAN.)

ACTION: CONTROL LANGUAGE MUST BE WRITTEN INTO THE BUDGET BILL TO ESTABLISH THREE MODEL REGIONS, FOR A THREE-YEAR PERIOD. LANGUAGE MUST ADDRESS STAFF RECRUITMENT AND TRAINING INCLUDING ATTENTION TO TRANSFER OF STATE HOSPITAL EMPLOYEES.

(BILL WILL DO ANALYSIS OF 3274 AS PASSED TO DETERMINE WHAT MUST BE PICKED UP FROM ORIGINAL VERSION BY MARCH 9.)

(BURNS WILL RECEIVE THIS INFORMATION TO USE IN WORKING WITH LEGIS. TO SECURE APPROPRIATION.)

INFORMATION ABOUT TITLE XIX

THE POSSIBILITY OF USING FEDERAL TITLE XIX DOLLARS TO MATCH STATE DOLLARS TO DEVELOP COMMUNITY LIVING ARRANGEMENTS IS BEING ADDRESSED THROUGH THE CAR RESIDENTIAL COMMITTEE: JIM AUSTIN IS WORKING WITH THE POSITION PAPER DRAFTED BY THAT COMMITTEE WITH SENATOR JOHN GARAMENDI. MARY SHORT AND RICHARD SILVERMAN IN FINANCE ARE AWARE. DEPARTMENT OF DEVELOPMENTAL SERVICES HAS ASSIGNED CARL SECHRIST TO WORK ON THIS ISSUE.

TO DO:\* AMEND CALIFORNIA'S TITLE XIX PLAN

- \* EXPLORE WITH HEW IF DEVELOPING ALTERNATIVE LIVING ARRANGEMENTS IN COMMUNITY WILL SATISFY BRINGING STATE HOSPITALS UP TO CODE BY 1980
- \* OBTAIN COPIES OF PLANS OF OTHER STATES

(TONY WILL WORK WITH DD COUNCIL COMMITTEE, MILT BLACKSTONE AND MUST BE KEPT INFORMED OF ALL DEVELOPMENTS.)

ATTACHMENT # 7  
NOTES FROM ASILOMAR

WHO ELSE WE NEED

PERSON		CONTACT
AL ZONCA	Citizen Advocacy	Tony
LOTTIE MOISE	P. & A.	Lonnie
JAN KYNE	Regional Center Board	Jack
DOROTHY MILLER	CSAC	Kack
DOUG CLEVELAND		Mike
ARMIDA GRAYDON	CANHC	Mike
STEVE HILL	EPILEPSY	Richard
BEV MCKEE	Community Colleges	Richard
MILTON BLACKSTONE	SDDC	Tony
MARSHA MAC DONALD		Tony
BOB KUHN	P & A, Autism	Jack
HARVEY AND CONNIE	LAPIN	
CONNIE BOLES		Jack
RUTH GOVORCHIN		Cynthia
ANN DONNELLAN		Jack
TOBI ARENBERG		Jack
JOAN SCHULMAN		Cynthia
BETTY LOMBARDO		Cynthia
RUTH STIERS		Cynthia
STANLEY FLEISCHMAN		Bill
VALERIE VANNEMAN		Cynthia
CHARLIE GALLOWAY		Ed
MARY SHORT		Ed
JIM AUSTIN		Ed
PAT HENNING		Cynthia
SANDY WEISS		Bill
LORE RADISCH	CASH/PCR	Lonnie
MARILYN PENNEBAKER	CANHC, SDDC	Fran
RALPH GRIFFIN	AREA BOARD V	Fran
EARL LONG	PROJECT IMPACT	Allan
ANNETTE DAHLMAN		Mike
IVY MOORING		Mike
PHIL DRAPER	CIL	Bill
JUDY HEUMAN	CIL	Bill

LYNDA STEELE	County D. D. Council	Fran
CARI ORR-KISSNER	UCPA	Fran
LANCE MILLER	UCPA	Fran
ROZ WOFSY	County D. D. Council	Fran
JANE LEFFERDINK	UCPA, Area Board V	Fran
CAROL RISLEY	Area Board II	Jim S.
JOHN COLEMAN	Area Board XII	Cynthia
SANDY THLICK		Cynthia
BEV MORGAN		Bill
ACT ATKINSON	Area Board XII	Cynthia
MIKE COONAN	P. & A.	Jack
MIKE MCNAMER		Burns
JEAN & ED OTTO	Regional Center Board	Allan
TOM WHALLEY	Somerset House	Ed
JOAN LAEHY		Bill
STEVE WAHLE	Easter Seal	Allan
MAGGIE FRASER		Burns
STEVE BENNETT	SPASTIC FOUND.	Cynthia
SOCCO, Johnnie Pratt		Fran

(The Position Statement should be mailed to this list with a note that each of us wants to share this information with them, ask for support. We are working toward the future and invite each person to participate with us. We were a group of friends, working informally over the weekend and want to share this with them.)