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COFFELT IMPLEMENTATION UPDATE NO. 7

TO: Interested Persons

FROM: Ellen Goldblatt, Daniel Juárez, Kim Swain, Eric Gelber, Catherine Blakemore

DATE: April 15, 1997

PLEASE FEEL FREE TO REPRODUCE AND DISTRIBUTE THIS UPDATE

This is the seventh *Coffelt* Implementation Update intended to let the community know the progress that is being made under the settlement and related efforts to improve the system of community living options available for people with developmental disabilities in California. **The system's successes in developing appropriate homes for thousands of persons who moved from the developmental centers to the community and other Bay Area consumers who moved to alternative living arrangements are currently being challenged. While we must all continue to work towards improving the quality of community living, it is important that the rights of individuals with disabilities to live in the community homes of their choice be supported.**

THE CHALLENGE TO THE COMMUNITY

Public attention has recently been focused on the well-being of persons with developmental disabilities and whether or not there should be a moratorium on moving persons with developmental disabilities out of large state institutions to homes in the community among their friends, relatives, and neighbors. Many of the proponents of a moratorium have focused on the mortality studies of Dr. Strauss, of University of California, Riverside. These studies assert that certain people with disabilities are at lesser risk of dying in the institutions than in community group homes or even in the homes of their families. The results of Dr. Strauss' studies have grabbed the attention of the San Francisco Chronicle, the California Medical Association and others. Unfortunately little attention has been paid to researchers who report a high quality of life in the community.

For example, the *Coffelt* Quality of Life studies conducted by nationally renowned disability researcher Dr. James Conroy, have gone almost unreported. Yet, as can be seen in Attachment A, Dr. Conroy's team members have visited nearly half of the *Coffelt* movers in their homes, interviewed the consumers when possible, reviewed records, spoken to those who know the person best and surveyed their families. The results of these studies

demonstrate that the vast majority of people who moved have benefitted greatly in almost all areas of their lives.

The challenge before us now is to support individuals' choices to live in quality community homes and to increase the attention paid to ensuring that the necessary supports and services -- including medical services -- are available and that adequate quality assurance systems are in place. It is important, for example, to convince the California Medical Association that every physician has an obligation to serve Medi-Cal patients with disabilities and that access to medical services will do more to improve quality care than a moratorium. We encourage you to share your experiences and successes in community living as well as your ideas for improving the quality of life with Governor Pete Wilson, Secretary of Health and Welfare Sandra Smoley, and the Legislature.[1] We must all redouble our efforts to achieve the promise of the Lanterman Act and the *Coffelt* settlement.

PAI has produced a videotape containing interviews with family members of former developmental center residents and former residents themselves, speaking about their personal experiences moving to community homes. This video is a powerful way for decisionmakers and others to become aware of what it really means to people with disabilities to control their own lives, live among friends and family and participate in the daily life of their communities. Copies of the video, titled "*Successful Community Living: Stories of People with Disabilities*" will be available to borrow from PAI soon.

MOVING TO APPROPRIATE COMMUNITY HOMES

Accomplishments

From April 15, 1993 to March 31, 1996, 2,487 persons have moved to appropriate homes in the community from the SDC's pursuant to their Individual Program Plans ("IPP"). A net reduction in the Developmental Center population of 2,192 persons from April 15, 1993 has been achieved. A chart showing the types of homes people have moved to is Attachment B, frontside. A chart showing the continued commitment of Regional Centers to making appropriate community homes available in FY 1996-97 is Attachment B, reverse.

Admissions to the SDC's have not stopped during this time. From April 15, 1993 to December 31, 1996, 523 individuals were admitted to the SDC's. For fiscal year 1996-97, through March 1997, 82 persons have been admitted to the SDC's. Details on recent admissions are on Attachment C.

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[1] A copy of PAI's Open Forum letter to the Chronicle is Attachment J. The addresses of people and organizations you may wish to write to are Attachment K.

A chart showing the continued commitment of Regional Centers to making appropriate community homes available in FY 1996-97 is Attachment B, reverse.

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From April 15, 1993 to December 31, 1996, 227 members of the Community Target Group ("CTG") (persons with severe disabilities from Bay Area Regional Centers) have moved to appropriate alternative living arrangements in the community.

The numbers alone are not the accomplishment -- rather it is the improved quality of life and satisfaction of consumers and families with their community homes. In order to assess these issues the *Coffelt* Settlement required an independent long-term study of individuals who moved from SDC's to the community and CTG members. DDS contracted with Dr. James Conroy, a nationally renowned medical sociologist, to conduct this survey. Dr. Conroy has conducted such surveys in many other states.

On an annual basis, Dr. Conroy conducts a comprehensive survey of the health, well-being, and quality of life of randomly selected individuals who moved under *Coffelt*. The survey consists of visiting where the individual lives, reviewing the individual's records and interviews with direct care staff. The surveyors also interview those individuals with a developmental disability who are able to speak for themselves and survey family members.

In February 1997, Dr. Conroy reported on the third year of *Coffelt* implementation, visiting 723 people who moved from developmental centers into the community. The executive summary of this report is Attachment A.

Highlights of the February 1997 report include:

- Two-thirds of Movers have labels of either "severely" or "profoundly retarded".

- Movers have sharply improved in challenging behavior, displaying the most rapid improvement ever seen by Dr. Conroy's research team.

- Movers have improved significantly in adaptive behavior which is a standardized and very reliable measure of self-care and independent functioning.

- Movers appear to be receiving a greater quantity and variety of services than they were before, according to their IPPs.

◆ Integration of movers nearly doubled -- as this is an explicit goal of the settlement it is a very positive outcome.

◆ An analysis of people in supported living settings shows that supported living is more conducive to self-determination, choice-making, and integration than other settings.

◆ There is evidence of a significantly lower rating of health care quality and an overuse of psychotropic medications in the community. Dr. Conroy emphasizes that health care in the community must receive strong attention and consideration, and points to DDS' Wellness Initiative as a much needed response.

◆ Movers who were interviewed were happier in their new homes than they had been in the SDC's.

◆ The majority of families who were against community placement when it was first suggested to them say they are either "for" or "strongly for" community living for their relatives after community placement.

What Remains To Be Done

Individuals continue to move from the SDC's to the community and CTG members continue to move to appropriate living arrangements. We need to continue to monitor the system to improve initial planning and quality assurance as discussed below. We need to focus upon remedies in those areas found to be of concern in the Conroy reports; e.g., use of psychotropics, self-determination and the low rates of payment for community care. We are pursuing with DDS and ARCA a plan to use Dr. Conroy's data as a quick turnaround information flow so that Regional Centers can precisely pinpoint and follow-up on quality shortfalls and highlight services which have the best outcomes for use as models.

DDS has begun a Wellness Initiative project which will address improved access to medical, dental and mental health services for persons with developmental disabilities. This should assist in addressing many quality concerns. See Attachment D for details.

PERSON-CENTERED PLANNING

Accomplishments

Under the *Coffelt* settlement a task force of DDS, Regional Centers, advocacy organizations, consumers and families came together to design materials which would be used by all Regional Centers to change the nature of the Lanterman Act Individual Program Plan ("IPP")

process. Under the new person-centered model, IPP development focuses on a consumer's strengths and choices and the supports needed for the consumer to achieve his/her life goals. With the input of the task force, DDS prepared an Individual Program Plan Resource Manual. This manual is now the legal basis of how all Regional Centers and SDC's prepare IPPs. DDS also published in seven languages and on audiotape a shorter consumer and family friendly version of the materials called More Than A Meeting. Copies of these materials are available from DDS, see Order Form, Attachment E.

PAI also publishes a manual for consumers, written by consumers, on preparing for one's IPP called "Your IPP: It's More Than A Piece of Paper." Useful materials from trainings put on by DDS or Regional Centers, available from PAI, are:

- *From Process to Action: Making Person-centered Planning Work*
- *A Quick Look at Planning Methods & Team Building*
- *A Quick Look at Consumers with Communication Challenges*
- *A Quick Look at Offenders with Developmental Disabilities*
- *Natural Supports...They're All Around You!*
- *A Quick Look at How to Be Culturally Responsive*

All Regional Centers and SDC's have trained their staff on this person-centered approach. Some Regional Centers have brought in national experts in person-centered planning to do several day training sessions for their staff. Some Regional Centers have also done trainings for consumers, families and service providers. Although in our experience well facilitated person-centered planning has not yet become the norm, there is a shift in focus in many planning meetings. As consumers and families become more educated about their rights to choice and a person-centered approach, further changes will occur.

What Remains To Be Done

One significant obstacle to the achievement of true person-centered planning is the large caseloads of most service coordinators. Thus, PAI and others in the developmental disability system should advocate for additional funding to reduce the size of caseloads.

Another obstacle is the conflict of interest for service coordinators between being advocates for their consumers' needs and choices and the service coordinator's function as "gate keeper" and implementer of Regional Center purchase of service policies which often restrict service options. System advocates have suggested that truly independent case management be pilot-tested at some Regional Centers. Further, many Regional Centers do not allow decisions on services to be made at the IPP team meeting, but rather refer them to POS or

funding committees; this violates the Lanterman Act and the concept of person-centered planning. PAI is looking at means to address this problem.

Finally, an ongoing issue with person-centered planning is that Regional Centers and SDC's need to institute some means of quality control to monitor their service coordinators' and SDC staffs' implementation of person-centered planning. Without such management level review, we cannot expect to complete the change in approach. An IPP quality control process is beginning to be implemented at all SDC's. It is also needed at Regional Centers. DDS needs to take a leadership role in ensuring that person-centered planning becomes a reality for consumers in all Regional Centers and SDC's.

Consumers, families and advocacy groups have the opportunity to request FREE trainings on person-centered planning in their areas from DDS. See Attachment F.

SUPPLEMENTATION OF CONSUMER SERVICE PERSONNEL

Accomplishments

Regional Centers have used their consumer service personnel funds both to reduce caseloads for service coordinators serving persons who moved from SDC's or are otherwise at risk and in a variety of innovative ways. A few examples include:

- Many Regional Centers have resource developers who focus on supported living.
- Regional Center of Orange County has 20 Intervention and Referral Service Coordinators with no ongoing caseloads who have responsibility to assist in placement and crisis intervention.
- San Andreas Regional Center and several other Regional Centers has added quality assurance specialists who work to enhance consumer/family satisfaction with living arrangements.
- Regional Center of the East Bay added a case management liaison to work with Alameda and Contra Costa Counties Psychiatric Emergency Services.

Each Regional Center will submit an annual report on its *Coffelt* efforts in July 1997. If you are interested in the report from a particular Regional Center, contact that Regional Center, DDS or PAI.

What Remains To Be Done

Creating a mechanism whereby consumers/families, advocacy organizations and the other Regional Centers are aware of what is being tried in a particular area could assist to spread positive innovations across the state.

EXPANDING COMMUNITY LIVING OPTIONS

One of the mandates of the *Coffelt* agreement was for DDS and the Regional Centers to take a number of actions to increase the variety of flexible living options in the community from which consumers can choose.

Accomplishments and What Remains To Be Done

Supported Living

Supported living is an option whereby consumers with all kinds of disabilities may live in homes they own or lease with supports available for as often and as long as is needed. Supported living agencies are generally used to coordinate and ensure the delivery of all needed supports. Consumers or parents may also be vendored to coordinate their own or their loved one's support system. PAI has lists of supported living providers in each Regional Center area and a list of Regional Center supported living contact people. Call PAI for a copy.

The availability of supported living arrangements for consumers with all levels of disability has increased in many areas of the state. In other Regional Center areas supported living is not increasing and may not even exist for those consumers who need 24-hour support. The supported living vendor regulations became final but unfortunately contain restrictions in the area of costs and moving expenses which prevent some individuals from achieving their dreams of living in a home of their own. Only 70 of the 2,487 persons who moved to the community from the SDC's moved to supported living. Overall the objective of creating more normalized living options for adults with developmental disabilities is still lagging behind expectations. Attachment G contains charts showing current supported living development.

Supported Living Information and Mentoring: A Center for Information and Resources on Community Living (CIRCL) was formed last year using *Coffelt* funds. CIRCL is made up of individuals with many years of experience as providers of service, Regional Center administration, consultants and people who use supported living services. CIRCL provides a variety of support services individually tailored to the needs of the person or group that requests the help, including on-site internet and phone consultation, mentoring,

provider and Regional Center staff training, materials and advocacy. Many of these services are offered free of charge. Attachment "H" is a CIRCL flyer you can use to get on their mailing list.

DDS publications called *What About IHSS; Labor and Wage Issues for Supported Living; How To Plans: Home Furnishings for Supported Living* and *Supplemental Security Income: Questions and Answers for Persons Residing in Supported Living Arrangements* are available by calling Phyliss Key of DDS at (916) 654-1956.

In order to improve this picture several approaches are necessary. DDS need to strengthen its leadership role and take responsibility for developing an accurate system to capture the numbers of persons who are receiving supported living services both under and outside of the specific vendor regulations. When it is determined that a Regional Center is not expanding development in this area, DDS should take appropriate actions.

One way to encourage Regional Centers to increase their development of supported living options is through the performance contract process. You have the opportunity to participate in the setting of your Regional Center's objectives - objectives for the next year are set each fall.

CIRCL was only funded for one year -- if you have benefitted from their information and services or believe it is a needed resource, you can advocate for its continued funding.

PAI continues to be interested in all instances where individuals are being kept from moving to supported living by Regional Center reliance on the unlawful cost ceiling or by any other barriers or impediments. Call PAI for an intake appointment.

Alternative Homes for Children

In some areas, foster family agency homes for children and homes for children with special health care needs are expanding. In other areas, this is not true. Attachment I contains charts showing development of children's homes.

One barrier to foster home placements is that families of children with disabilities seem to view them as less "professional" than group homes. Another barrier is finding families who wish to provide homes. Continuing education of families is needed. Again, DDS needs to strengthen its leadership role and ensure that children's services exist in all areas of the state.

Affordable Housing

The Affordable Housing Policy and Technical Assistance Work Group was started by DDS to make recommendations to the Department on activities and policies related to increasing consumer opportunities for home ownership and affordable rental housing. As a result of the Work Group's input, two affordable housing technical assistance projects were funded in September 1996. FNRC was awarded $20,000.00 and is considering working with a national rural housing development corporation. RCEB was awarded $30,000.00 and is contracting with East Bay Housing Consortium. Copies of both proposals are available from Mr. Bock.

The Work Group held its first meeting on Thursday, March 20, 1997 at the Westside Regional Center. The agenda for this first meeting included the following discussions:

- The development of a long range DDS Affordable Housing Plan;
- How to encourage the establishment of housing advocacy groups in areas not currently served by such groups;
- Strategies for the communication of housing information;
- The possibility of expanding Fannie Mae Home Choice Program to Northern California.

The next meeting will be held on Thursday, June 19, 1997 at the Harbor Regional Center.

DDS will sponsor free affordable housing institutes to provide information on topics including Section 8, Community Development Block Grants, HUD reorganization, the new Fannie Mae home loan plan and the contracts to FNRC and RCEB.

A new Fannie Mae low-cost loan program called *HOMECHOICE: Homeownership for People With Disabilities* is being sponsored by the Southern California Coalition. For more information on this program you can contact David Silva of H.O.M.E. at (310) 258-4036.

A Housing Choices Project has also been started in the SARC area by Parents Helping Parents. The Project is meeting on April 24, 1997 in Santa Clara to discuss two proposed San Jose city ordinances which will negatively impact housing for people with developmental disabilities. For more information on this meeting, you can contact Susan Silveira at (408) 733-4938. For general information on Housing Choices, call Clare McDermott at (415) 914-5814.

Calman Bock is DDS' Housing Coordinator and can be reached at (916) 654-1571. He is available to answer questions and provide technical assistance on financing and affordable housing issues and he can provide information and materials on all of the above. The Residential Resource Directory published by DDS is no longer available.

Living Options Trainings

DDS has sponsored numerous excellent statewide and local trainings on issues related to person-centered planning and living options over the last two years and published excellent training materials. Lists and copies of these materials are available from PAI or DDS. This year's Living Options trainings are as follows:

- ***Whole Person Assessment and Treatment***

A two day workshop by Dr. Ruth Ryan about appropriate diagnosis and treatment of mental health and medical needs of persons with a developmental disability. Emphasis on transdisciplinary assessment, interagency collaboration, and specific interventions that produce positive outcomes. Target audience regional center staff, family members, providers and representatives from involved community agencies, e.g. mental health.

- ◆ 4 sites - May 1997: 12th-13th in Fresno, 14th-15th in Sacramento; 16th-17th in Ontario and 20th-21st in San Diego.
- ◆ Registration forms are now available, call DDS at (916) 654-1739.

- ***Positive Behavioral Supports***

The process for supporting change in individuals with challenging behaviors by Katie Bishop (USD), Jackie Anderson (CSUH), and Tom Neary (CA Confederation on Inclusive Education). Focus is on building positive behavioral plans. Training will involve teams including a focus individual, family members and support staff and include very intensive follow-up.

- ◆ 3 sites with training and follow-up for 4-5 consumer's teams at each site
- ◆ Teams will be recruited in site specific areas

- ***Psychopharmacological Medications: Safety Precautions for Persons with Developmental Disabilities***

One day workshops conducted by clinical experts who have direct and extensive experience with individuals with developmental disabilities. Focus is on drug interactions, dosages, identifying over/under medication, etc. Target audience is residential and day providers, and family members.

- ◆ 6 sites

- ***Building Natural Supports for People with Severe Reputations***

One day workshops focusing on practical ways in which natural supports can be nurtured and developed and developing community networks. National presenters with experience in developing community and natural supports will present. Target audience is regional center staff, providers, consumers, and family members.

  - 8 sites

- ***Person-centered Planning and Self-Determination***

Department staff developed a series of training guides on varied aspects of person-centered planning. The Department will make a concerted effort to conduct training in person-centered planning and self-determination with parent and consumer groups, including People First Groups at developmental centers (will continue into 1998).

  - 11 or more sites
  - See Attachment F on how to request for your area or group.

- ***Person-centered Living Options and Supported Living Services Public Access Videos***

Two videotapes designed for telecast on public access channels were developed from training done by Becky Donofrio during a 1995 CLO training. The department is in the process of distributing tapes in the format appropriate to local public access channels to regional centers, area boards, and PAI. The target audience is individuals who cannot attend more traditional trainings (i.e., direct care staff).

For more information on any of the above trainings or videotapes, contact Margaret Anderson or Ann Smith at DDS, (916) 654-1739.

Supplemental Services

As required by the settlement, DDS issued a clear policy which permits Regional Centers to fund supplemental staffing or additional supports in all types of residential settings when necessary to prevent placement in a more restrictive setting. Advocacy is needed to ensure that this policy continues clearly in effect after the *Coffelt* agreement ends.

Funding Mechanisms Need To Be Shifted To Support Development of Alternative Living Options

Thirty-six percent of individuals moving from the SDC's to the community now live in one to six bed Intermediate Care Facilities - Developmental Disabilities Habilitation on Nursing (ICF-DD-H/N) group homes. Conversely, in most states the number of ICF homes is decreasing. We believe the fact that in California ICFs are funded through the Department of Health rather than through Regional Center budgets at least is partially responsible for the proliferation of this model over other community living options. ICF funding should be shifted to Regional Center budgets so as to reduce the fiscal incentive for ICF development.

CRISIS AND EMERGENCY SERVICES

Under the terms of the Settlement Agreement each regional center was required to develop a Crisis Service Plan (CSP). The goal of the services described in each regional center's CSP is to provide services as needed to maintain a person in the living arrangement of their choice. The CSPs contain information on the types of services they provide to fulfill their obligations under the Settlement Agreement and §4648(a)(10) of the Lanterman Act. In summary, §4648(a)(10) provides that if relocation becomes necessary, emergency housing in the person's home community should be available through the regional center. If dislocation cannot be avoided, every effort shall be made to return the person to the living arrangement of their choice. Every regional center has developed and supposed to be implementing a crisis service plan--approved by the Department of Developmental Services (DDS)--that includes provisions for 24 hour response and providing necessary supports to prevent the disruption of the person's current living arrangement.

Each regional center will submit semi-annual crisis services reports in April 1997 and again in October 1997. The regional center reports contain information on implementation of each regional center's crisis services plan. If you want a copy of your regional center's report, contact the Regional Center, DDS or PAI. Unfortunately, DDS has refused to require regional centers to collect and report outcome data which would be necessary to determine the availability and adequacy of crisis services in each catchment area. Dr. Conroy has expanded his data collection, which will provide a sampling of more complete information on crisis services.

There will be trainings on psychopharmocological medications and whole person assessment and training of dually diagnosed individuals. See, Living Options Trainings section, above.

Accomplishments

DDS has dedicated two staff persons to provide technical assistance (TA) to all twenty-one regional centers in the area of crisis services during the past year. In conjunction with their TA visits, Area Boards and Mental Health representatives were, in most instances, contacted to gain their feedback in regard to crisis services in their regional center's area. Onsite assistance has now been provided to all 21 regional centers and written reports have been completed. These reports can be obtained from DDS or PAI. PAI would not agree with all the conclusions in these reports as to the adequacy of crisis services.

RRDPs are available, upon request, to provide extensive supports to persons who move from the Developmental Centers (DCs) and to persons at risk of admission to a DC. **This is an important resource** -- you may request that it be used in appropriate circumstances.

The ARCA/CMDHA Task Force on Mental Health Services for persons with developmental disabilities met in February 1997. The group has recommended some draft guidelines for consideration in the development of interagency agreements for community mental health services for persons with developmental services. The draft guidelines are to be shared with regional center directors and County mental health directors and adopted at their respective meetings in June 1997. The guidelines include both agencies working collaboratively to address consumer's service needs and a method for the regional to reimburse counties for administrative days as needed. PAI is seeking to obtain these draft guidelines so that the community can provide their input.

DDS has convened a workgroup made up of regional centers, RRDPs and DDS staff to identify best practices, service gaps, and make recommendations to DDS. The committee has met three times so far and plans to meet again in the near future to discuss any innovative programs that could be considered for replication in another part of the state. The Porterville Youth Incorporated Crisis Facility described below is one such program to be considered.

Youth Crisis Facility Started: The Porterville Regional Project in collaboration with Central Valley Regional Center has developed a regional crisis facility for children under 14. The facility opened in July with Porterville Youth Incorporated (PYI) as the vendor. The facility accepted its first individual in September and the program appears to be working very well according to staff from the regional project. The facility's capacity is for two individuals and includes psychiatric, psychological and transportation services. Since opening, the facility has accepted five children ages 6, 9, 11, 15 and 16. Two are currently at the facility. The three children that have been treated successfully are characterized as follows:

- One lived at home and could no longer be handled due to aggression, AWOL, self-injurious and resistiveness. PYI provided behavior management, medication review and speech/language evaluation. After a stay of approximately 126 days, a successful placement was made in a home close to the family.

- One lived at home with his family and exhibited aggression, AWOL, resistive and harmful behavior toward animals. PYI provided behavior management and time to develop an appropriate living resource close to the family after a stay of approximately 49 days.

- One lived at home with family and exhibited uncontrolled seizures, physical aggression, AWOL, and property destruction. PYI provided services to stabilize the individual and to facilitate reunification with family after approximately 67 days at PYI.

What Remains To Be Done

Emergency and crisis intervention services is an area where there has been continuing concern regarding regional center performance and the coordination of appropriate services with Community Mental Health agencies.

The lack of coordination between regional centers and community mental health has manifested itself in some unfortunate examples of regional center clients experiencing prolonged stays in psychiatric facilities. In an effort to learn the extent of this problem and exactly how it occurs, Patient Rights Advocates throughout the state are being contacted for information on this problem and they are, in turn, being provided with information on regional center services including crisis services.

In January 1997, a survey was distributed to all Patient Rights Advocates in California. The survey asks about the current level of training and general interaction between regional centers and local mental health agencies. A second survey was also distributed that gives Patient Rights Advocates an avenue to describe any instances where regional center consumers experience prolonged stays in psychiatric facilities.

PAI continues to be interested in information on individual instances of inadequate or exemplary crisis services. Call PAI for an intake appointment.

The community should advocate strongly for DDS and Regional Centers to be required to develop adequate outcome measures on the success and barriers to crisis services and reporting mechanisms on the use of psychiatric facilities for Regional Center consumers.

QUALITY ASSURANCE

Accomplishments

Substantial progress has been made in the development of a values-based, Quality Assurance system for consumers in community living arrangements. The enhanced system covers all individuals in supported living and licensed health care and community care facilities. The system consists of a variety of components, some of which have been implemented and others of which are still underway, including:

- **25 Individual Life Quality Outcomes**, in the areas of choice, relationships, lifestyle, health and well-being, rights and satisfaction. These outcomes will be used on both an individual basis to improve people's lives as well as on a system basis to improve services and making them more outcome driven.

- **Individual life quality assessments with each consumer, on a triennial basis,** based on the *Looking at Life Quality - Visitor's Handbook*, which is an interview assessment tool used to solicit information directly from the consumer and other family and friends, as appropriate. These materials are available in several languages and on audiotape by contacting Ann Smith of DDS at (916) 654-2217. Each Regional Center is implementing the life quality assessment process -- some are doing the interviews with in-house staff while others have contracted this function out. Some Area Boards have received the contracts.

- **Quality enhancement efforts, including use of *Looking at Service Quality Handbook,*** which is a voluntary self-assessment tool to be used by providers to assist them in improving their services based on the 25 outcomes, including consumer satisfaction. The handbook can be obtained from Ms. Smith.

- **Regulatory reforms to improve Regional Center quality assurance and monitoring** in licensed living options. DDS issued the Community Living Arrangement Services regulations for comment and is now considering the voluminous public response.

What Remains To Be Done

A *"Preliminary Review of Looking at Life Quality at Six Selected Regional Centers"* has been completed and is available from Ms. Smith. The independent evaluation of the various Regional Center models of conducting the Life Quality Interviews will be completed by Allen & Shea in October 1997. Thereafter, the finalization of a system containing this element of quality assurance will be undertaken.

Serious consideration should be given to having this component of quality assurance conducted by the Area Boards, entities independent of both the Regional Center and service providers. The life quality outcomes and the method for conducting Life Quality Interviews should then be integrated into the Lanterman Act and regulations.

Improved Regional Center monitoring for consumer health and safety and special incident reporting is necessary. The system needs to have a standardized approach to assessing situations where consumers have died or allegedly been subject to abuse. It needs to be clear that Regional Centers can make unannounced visits to care facilities.

Equally important, is the need to provide mandatory training and technical assistance to service providers to increase consumer opportunities for choice and self-determination. This is an area in which Dr. Conroy has found California is lagging behind other states and yet it was a major objective of the SB1383 amendments to the Lanterman Act.

Finally, only through substantially reduced service coordinator caseloads can the service coordinators play a meaningful role in consumer's lives and thus assist in ensuring quality.

FUNDING

Accomplishments

Achievement of the Coffelt settlement objectives is funded with up to $334 million dollars generated by California's receipt of an increase in federal funds as a result of the expansion of our Medicaid Home and Community Based Waiver population from 3,360 to 20,000 consumers. The settlement also provided that annual expenditures under Coffelt could be increased by up to $45,000 per client for each full year placement for net reductions in the SDC population that exceed the settlement milestones. The settlement also projected $6,000 per client in start-up funds.

What Remains To Be Done

As the anticipated net reduction of 2,000 persons has been achieved, there is obviously a need for additional start-up and ongoing funding as more individuals move from the SDC's to the community. Furthermore, as pointed out by Dr. Conroy, California's current level of community funding is about half the average cost of SDC care -- a significantly lower ratio than in other states -- and may not be adequate.

This speaks to the importance of the developmental disabilities community actively advocating for additional funding. The Governor's budget proposes to raise the rates of community care homes 3%, plus other amounts necessary to reimburse providers for the cost

of the minimum wage increase. These increases should be supported and also need to be expanded to include increases for supported living. In order to reduce caseloads for service coordinators, additional funding will also be required. All possible mechanisms to make adequate funding for quality services and support available and to place more control over existing funding in the hands of consumers and families should be explored.

CONCLUSION

We hope you are pleased by the accomplishments of *Coffelt* implementation thus far. As the developmental disabilities system faces significant pressures from many directions, your continued vigilance, efforts, and support will be necessary to keep the momentum of *Coffelt* implementation moving forward consistent with the values of the Lanterman Act and SB 1383.

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or the minimum wage increase. These increases should be supported and also need to be expanded to include increases for supported living. In order to reduce caseloads for service coordinators, additional funding will also be required. All possible mechanisms to make adequate funding for quality services and support available and to place more control over existing funding in the hands of consumers and families should be explored.

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Executive Summary

The twelfth report of the Coffelt Quality Tracking Project provides further evidence that California's deinstitutionalization process has benefited most Class Members, and in major ways. It also confirms that community supports cost much less than institutional care.

These findings are consistent with a large body of related research, both in California and in other states. Larson & Lakin (1989, 1991) reviewed dozens of studies of community placement of people with mental retardation, and concluded that people who moved from institutions to community living gained in independence, and that their families grew to be very pleased with the move, even if they initially opposed it.

In addition to the consistently positive behavioral and family outcomes from the research literature in other states, the Coffelt Quality Tracking Project has extended the list of positive outcomes.

1. The people who have moved from institution to community under Coffelt are, on the average, somewhat higher in self-care abilities than those still in Developmental Centers; they also display somewhat less challenging behavior.
2. Nevertheless, two thirds of the Movers are labeled either "severely" or "profoundly" retarded. This has not been a process of placing only the "higher functioning" people into community living.
3. This Report's central analysis is based on 64 Class Members who we visited in 1994, when they were living in Developmental Centers, and who we recently visited in their new community homes. We can now see whether they are better off, and if so, in which way(s).
4. The Movers have improved significantly in adaptive behavior, which is a standardized and very reliable measure of self-care and independent functioning.
5. The Movers have improved sharply in challenging behavior, displaying the most rapid improvements this research team has ever seen.
6. The Movers appear to be receiving a greater quantity and variety of developmentally oriented services than they were before, according to their Individual Program Plans.
7. The staff who work most closely with the Movers reported on how much progress they had seen in the Class Member on each individual program goal during the preceding year. When at DCs, the average staff rating was 48 on a scale of 100 points; in the community, the average staff rating is 77. This implies that much more progress is occurring in the community, and this is consistent with the behavioral outcomes in (4) and (5) above.
8. Integration of the Movers, measured as the number of times per month they went out to places where they were in the presence of non-disabled citizens, nearly doubled. Insofar as integration and inclusion are explicit goals of DDS, this is an extremely positive outcome.
9. The Class Members who were willing and able to complete an interview (with whatever assistive devices or techniques they needed) told us that they were extremely happy in their new community homes, happier than they had been in the DCs, and generally very satisfied with many aspects of their lives

10. The Class Members, or those who knew them best, rated their qualities of life in 10 areas, "A Year Ago" and "Now." The data revealed significant increases in every one of the 10 areas, by either of two methods of analysis (pre-post and recollection).
11. Staff in community programs reported higher job satisfaction than did the DC staff. They also reported that they "liked working with" the Class Member more than did the DC staff. They also appeared to have as broad or broader a battery of training.
12. The Movers' new community homes received significantly higher physical quality ratings than did the DCs, including comfort, cleanliness, decor, and attractiveness.
13. Moving beyond the 64 Mover pre-post design, we found strong satisfaction among the 197 Movers who were able and willing to be interviewed. Only 4 out of 197 described their living situations as "Very Poor," while 80 said "Very Good."
14. Open ended comments revealed a large number and variety of positive statements about community homes, and relatively few negative statements.
15. Analysis of people in supported living settings showed that these settings were more conducive to self-determination, choicemaking, and integration than other settings. The supported living model is being used to support people with major behavioral challenges.
16. The survey of the families of the Movers revealed very strong satisfaction across many areas. Families perceived that their relative's qualities of life had improved significantly in 10 out of 10 areas.
17. Among the current group of 120 families who have responded to our survey, there were 22 who reported that they had changed drastically from opposition to support of community living. There were no families that said they had changed from support to opposition.
18. Cost analyses performed in 1996 revealed that these positive community outcomes were being obtained at lower public cost than Developmental Centers.

Despite the strong evidence that the Coffelt placement process has been highly successful, there were also some important concerns and cautions in the data. These were:

1. Probable overuse of psychotropic and sedative medications in the community.
2. The lack of emphasis on productivity, employment, and earnings in the community.
3. The lack of increase in choicemaking and self-determination after community placement.
4. Significantly lower rating of health care quality in the community.
5. Rare, but urgently in need of attention, were open ended comments reflective of abuse, unhappiness, and loneliness.

Finally, we intend to propose that the Coffelt Quality Tracking process can and should be used for another important purpose in the future: creation of a rapid feedback system so the needs and problems that we uncover during our visits can be addressed quickly. Next year, we will visit more than 1,000 Coffelt Movers.

DISTRIBUTION OF COMMUNITY PLACEMENTS BY REGIONAL CENTER

04/14/93 to 03/31/97

PLCMT. TYPE / REG CTR.	AD FAM HOME AGCY	SUP. LIV.	OWN HOME RELA.	OWN HOME IND.	ICF /DD	ICF /DD-H (1-6 BEDS)	ICF /DD-H (7-15 BEDS)	ICF /DD-N	SNF	CCF LEVEL 2	CCF LEVEL 3	CCF LEVEL 4A	CCF LEVEL 4B	CCF LEVEL 4C	CCF LEVEL 4D	CCF LEVEL 4E	CCF LEVEL 4F	CCF LEVEL 4G	CCF LEVEL 4H	CCF LEVEL 4I	FFA	FF HOME	OUT OF STATE	OTHER	TOTAL
ACRC		3	18		7	18		27		4	26			1			6	2		1		1		12	126
CVRC		7	13		1	69		94		9	61						3		1			2		4	264
ELARC			2			22		8	1		1		2	2			3	9		10					60
FDLRC		1	4			11		1	1	2	1							2	3	25				1	52
FNRC			6		1	9		19	2	1	14	2		1		3	1	1		8				6	74
GGRC		1	5	1		36		20	1	4	20			1			4	16	14	20				5	148
HRC		1	2		1	26		8	2	1	7	2		1			1	17		3	1			1	74
IRC			5		2	62	1	6	1	2	16	1	3	1			2	28		20				8	158
KRC	2	1	24	1		42		41		1	11				9		47	1		7			1	9	197
NBRC			10			30		13		2	33	1	5	7	1	1	11	1	6	21		1	2	9	154
NLACRC	3	3	1			9	3	1	3	3	10			3	2		2	5		10				6	64
RCEB			5		1	43		13		5	29				1			10	14	39				3	163
RCOC		7	3			15	1	31	2	4	9						4	16		22	1	1	1	1	118
RCRC		17	3			6		1		4	7					4	1	2	1	1				4	51
SARC		9	14		1	12		30	1	2	49			13	5	8	7	7	3	39				4	212
SCLARC			5			26		1	2		1			1			6	19	7	4			1	1	74
SDRC		4	6		3	30	2	2	1	4	13	2		3	5		14	25	3	5		1		8	131
SGPRC						24		8	1		1			1	1		1	13	7	4				3	64
TCRC	2	5	6		3	23		24	2	2	7				3		1	17	13	13				5	126
VMRC		10	9	1		18		12		8	40				1		1	1	4	1				14	120
WRC		1	1			12		3		1							2	21		14				2	57
TOTAL	7	70	142	3	20	543	7	363	20	59	356	8	10	35	28	16	117	213	76	267	2	6	5	106	2487

ATTACHMENT "B"

ata Source: RRDP Information System
'10/1997 12:48:19 PM
cxrc rsl

TOTAL ADMISSIONS AND PLACEMENTS THROUGH MARCH, FY 1996-97

REGIONAL CENTERS	AGNEWS		STOCKTON		NAPA		CAMARILLO		LANTERMAN		PORTERVILLE		SONOMA		FAIRVIEW		TOTAL:		YTD RC NET	YTD RC GOAL	DIFFERENCE	ANNUAL RC GOAL-*REV.
	AD	PL	AD	PL	AD	PL	AD	PL	AD	PL	AD	PL	AD	PL	AD	PL	AD	PL				
ACRC	0	6			5	6	2	1			0	7	0	7	0	0	7	27	20	29	-9	39
CVRC					2	3	1	1	0	1	2	27					5	32	27	23	5	30
ELARC							0	1	0	1	0	0			0	0	0	2	2	11	-9	15
FNRC	0	3			6	6	0	0		0	0	0	0	3			6	12	6	14	-8	19
FDLRC	0	0					1	4	0	6	0	0			1	0	2	10	8	13	-5	17
GGRC	0	8			7	6	0	0			0	0	0	1			7	15	8	21	-13	28
HRC	0	1					0	2	0	0	0	0			0	5	0	8	8	15	-7	20
IRC	0	0			0	0	5	5	0	6			0	0	0	0	5	11	6	34	-28	45
KRC					5	5	3	12	0	0	1	16				0	9	33	24	26	-2	35
NBRC	0	0			9	8	2	0			0	0	0	10			11	18	7	14	-7	18
NLACRC							0	5	0	4	0	3			0	2	0	14	14	16	-2	21
RCEB	0	9			8	4	0	0	0	0	0	0	0	13			8	26	18	37	-19	49
RCRC	0	0			1	5							1	10			2	15	13	11	2	15
RCOC	0	1					2	1	0	3					0	16	2	21	19	30	-11	40
SARC	1	19			1	7	0	3		1	0	0	0	7			2	37	35	61	-26	81
SDRC	0				0	0	2	3	1	4	0	2			0	10	3	19	16	26	-10	34
SGPRC							0	2	0	3					0	1	0	6	6	19	-13	25
SCLARC					0	0	0	8	0	3			0	0	0	2	0	13	13	22	-9	29
TCRC	0	1			0	0	4	16	0	0	0	0	0	0	0	0	4	17	13	30	-17	40
VMRC	0	0			5	5	1	1			0	1	0	2			6	9	3	16	-13	21
WRC	0	0					3	4	0	2		0			0	4	3	10	7	19	-12	25
No Regional Center **																	0		0	0		
TOTALS	1	48	0	0	49	55	26	69	1	34	3	56	1	53	1	40	82	355	273	485	-212	646
RRDP NET		47		0		6		43		33		53		52		39		273				

(individual YTD RC GOAL figures have been rounded up using the computer formula - the total represents the correct figure without the rounding)

***RC ANNUAL FY 1996/97 GOAL SUBJECT TO REVISION IN 6/97**

ESG

NEW ADMITS: REASON FOR ADMISSION BY DEVELOPMENTAL CENTER
01/01/97 to 03/31/97

Reason for Admission	Sonoma DC	Lanterman DC	Porterville DC	Fairview DC	Agnews DC	Camarillo DC	Stockton DC	Napa State Hosp	TOTAL
Assaultiveness						2		1	3
Danger to others				1					1
Danger to self			1						1
Destruction of property									
Family or community emergency									
Fire starting						2			2
Inappropriate sexual behavior						2		1	3
Medical		1			1				2
Other, explain in memo								12	12
Pica behavior									
Runaway									
Screaming									
Self abuse	1					1			2
Smearing									
Suicidal									
Undesireable behavior								1	1
Verbal abuse									
Wandering									
TOTAL	1	1	1	1	1	7	0	15	27

ATTACHMENT "C"

Data Source: RRDP Information System
/16/1997 8:32:18 AM
:rrdm.rsl

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To Ellen Goldblatt	From Jennie Hamilton
Co. State	Co.
Dept. Developmental Services	Phone #
Fax # (916) 654-3611	Fax (510) 839-5780

SDC ADMISSIONS

Of those, how many were re-admissions, how many were forensic admissions, how many have had conferences within 90 days of admission?

Name	Jan 1997				Feb 1997				Mar 1997			
	Admits	Re-Ads	Forensic	Confs	Admits	Re-Ads	Forensic	Confs	Admits	Re-Ads	Forensic	Confs
Agnews DC					1	1						
Camarillo DC	1		1		4	1	4	2	2	1	2	
Fairview DC	1			1								
Lanterman DC	1	1		1								
Napa State Hosp	6	2	6	2	8	4	8		1		1	
No SDC Given												
Porterville DC	1	1		1								
Sonoma DC					1	8						
Stockton DC												
TOTAL	10	4	7	5	14	14	12	2	3	1	3	0

Data Source: RRDP Information System - SDCADS.RSL
4/16/1997 8:29:41 AM

DDS WELLNESS INITIATIVE

Mission: *To promote the health and well-being of all Californians with developmental disabilities.*

Track I: Wellness Focus of the Department of Developmental Services:

Focus of responsibility:

- Policy direction
- Public Awareness
- Training and technical assistance
- Research and evaluation

Current Activities and Projects:

(1) Managed Care Policy Development and Problem Resolution

This project is a collaborative effort with the Department of Health Services to ensure that persons with developmental disabilities receive needed medical services within managed care systems.

Time frame: Current year and on-going
Resources: Existing DDS staff resources

(2) Task Force on Mental Health Services for Persons with Developmental Disabilities

DDS, the Department of Mental Health (DMH), the Association of Regional Center Agencies (ARCA), and the County Mental Health Directors Association (CMHDA) are collaborating on guidelines for improving the provision of local mental health services to regional center consumers.

Time Frame: Current year, to be completed June, 1997.
Resources: Existing operations resources.

(3) Developmental Center/ Regional Center "Telehealth Project"

This pilot project will utilize telecommunications technology to allow regional centers to access the uniquely experienced medical and clinical staff at developmental centers.
Time frame: FY 96-97: planning and start-up
FY 97-98: full implementation

Resources: Current year DC and RC operations resources

(4) Quarterly "Wellness Letter"

DDS will publish a quarterly "Wellness Letter" to provide the best information available on medical, dental and mental health issues. The letter will be distributed statewide to consumers, families, providers and practitioners. The first edition will focus on dental health and will be published in spring, 1997.

Time frame: Current year and on-going
Resources: Current year DDS operations

(5) DDS Web Page for Wellness and Assistive Technology

DDS will add new components to its existing Web Page to expand on the Wellness Letter and to provide information on ways to obtain Assistive Technology (resources, funding, eligibility, etc.).

Time frame: March 1, 1997 and on-going
Resources: Current year DDS operations

(6) Expansion of Psychology Internship Program

Three psychology internship programs have been developed with the graduate programs of the University of the Pacific (1987), UCLA (1996) and the University of Judaism (1997). Behavioral supports and services are provided by graduate students under the supervision and guidance of developmental center staff to persons who are in jeopardy of losing their community placement due to their challenging behavior.

Time frame: Current year and on-going
Resources: Existing DC resources

(7) Conferences

The Department is sponsoring the following conferences:

National Developmental Disabilities Nursing Conference – March 3-5, 1997, San Diego, CA. (In collaboration with Columbus Medical Services)

National Physicians' Conference on Developmental Disabilities Medicine – March 3-5, 1997, San Diego, CA. (In collaboration with Columbus Medical Services)

"Partners in Prevention V" – February, 1998

Resources: DDS operations resources/federal Early intervention resources

(8) FY 96-97 trainings

The following trainings have been planned for consumers, family members, service providers, regional and developmental center staff, and other professionals. The trainings are delivered in multiple locations, with a combined attendance of over 3,000.

- Whole Person Assessment and Treatment -- A two-day workshop about appropriate diagnosis and treatment on mental health and medical needs of people with developmental disabilities. Emphasis on transdisciplinary assessment, interagency collaboration and specific interventions that produce positive outcomes.

- Positive Behavioral Supports-- A one-day overview of the process for supporting change in individuals with challenging behaviors.

- Psychopharmacological Medications: Safety Precautions for Persons with Developmental Disabilities-- A one-day workshop conducted by clinical experts who have direct and extensive experience with people with developmental disabilities. Focus in on drug interactions, dosages, identifying over/under medication, etc.

Time frame: Current year (FY 96-97)
Resources: DDS operations resources

Track II: Wellness Focus of Regional Centers

Focus of responsibility:

- Outreach to and liaison with local medical, dental and mental health communities.
- Monitoring of consumer health outcomes.
- Program and resource development.
- Provider training and technical assistance.
- Resource information for consumers and families.

Current Activities and Projects:

The Department issued a Request for Idea Statements from regional centers for wellness projects to be funded during FY 96-97. 52 idea statements have been received from 16 regional centers, totalling approximately $3.2 million. The projects all address medical, dental or mental health needs.

The proposals received generally fall into the following categories:

- Development of curricula and training programs for physicians, dentists and other allied health professionals.
- Medication reviews and health care exams of consumers.
- Expanding access to specialists through telemedicine.
- Resource development for persons with a dual diagnosis.
- Development of resource materials and training programs for parents and consumers.

The Department will make its funding decisions by March 15, 1997.

Track III: California Wellness Partnership

Focus of Responsibility:

- Advice and consultation to the Department.
- Projects of statewide significance.
- Long-term evaluation of health outcomes

In conceptualizing the "Wellness Initiative," the Department realized that there are many experts and public leaders in the field of health and wellness who could be of immeasurable assistance in helping with our mission to "promote the health and well-being of all Californians with Developmental Disabilities." As a system, we need to reach outside our customary borders and forge partnerships with allied organizations. . Accordingly, the Department has approached the following organizations to join with us to form the "California Wellness Partnership. The project proposals that have been discussed with the partners are, at this point, **in concept only.** It is the Department's intent to work with the partners to secure grant funding from a variety of sources including, but not limited to, the Packard Foundation, The California Endowment and the Sierra Foundation for Health Care.

(1) UCLA Center for Health Promotion and Disease Prevention

In collaboration with Lanterman Regional Center, UCLA is interested in replicating a successful physician training program which targets the reluctance of some health professionals to serve stigmatized populations. They are also interested in collaborating with DDS and the Office of Statewide Health Planning and Development (OSHPD) in a health outcome study.

(2) U.C. Berkeley "Wellness Project"

U.C. Berkeley is interested in developing a developmental disabilities companion guide to its enormously successful "Wellness Guide." They are also interested in developing

one-minute video vignettes on wellness issues to be aired on television for daytime audiences.

(3) Kaiser

Kaiser is interested in collaborating on a health outcomes study. They have a large patient data base that could be instrumental in setting up an evaluation design.

(4) California Dental Association

The CDA has named two of its members to provide on-going advice and consultation to DDS on issues of oral health.

(5) The Academy of Pediatrics

The Academy, and specifically its developmental disabilities committee, has offered the expertise and advice of its membership.

(6) California Department of Health Services (DHS)

DDS is collaborating with several of DHS's subdivisions.

- The *Managed Care Division* is collaborating with DDS in the development of policy and problem resolution for regional center consumers.
- The *Office of Disability Prevention* has developed a strategic plan for preventing disabilities in California which targets specific developmental disabilities.
- The *DentiCal Division* has provided the advice and consultation of its lead dental consultant to assist DDS in producing its Wellness Letter.

(7) Office of Statewide Health Planning and Development

OSHPD is interested in partnering with UCLA and Kaiser to develop health outcome measures for persons with developmental disabilities and to conduct a long-term evaluation.

(8) State Council on Developmental Disabilities

The State Council has established medical, dental and mental health services as priorities for funding under the current cycle of the Program Development Fund. In addition, their upcoming 3 year plan supports the Department's Wellness Initiative in its goals and objectives.

The Department will continue to refine and expand these partnerships during FY 96-97 and FY 97-98. It is hoped that several partnership projects will secure grant funding during this time period. (Initial contacts with charitable foundations have been encouraging.)

Summary

The DDS "Wellness Initiative" represents a planned, comprehensive and multi-dimensional strategy designed to enlist the support of all segments of the developmental services system in pursuit of a common goal: the health and well-being of all Californians with developmental disabilities.

Order Form

Person-Centered Planning Materials
California Department of Developmental Services
January 1995

Please complete the information on both sides of this form, then fold and mail as shown on the other side of this form, or:
FAX to: 916/654-3641
IPP Materials Coordinator
Adult & Supported Living
Services, Room 320

Note: If an item you request is not in stock, we will contact you and let you know when it will be available.

Item	Quantity	Language
Individual Program Plan Resource Manual: A Person-Centered Approach The Department's official guide for developing Individual Program Plans that are centered on the person and family. The manual explains the values that support the person-centered approach. Roles and responsibilities are also explained. The specific requirements for conducting a person-centered planning process are described and referenced to their bases in law. Examples of person-centered planning methods and stories of how person-centered planning has worked in the past are also included. 300 page technical manual, spiral-bound. Available in English only.		
More Than A Meeting: A Pocket Guide to the Person-Centered Individual Program Plan An easy to read and brief summary of the official Resource Manual described above. This guide is intended to assist consumers, families and friends as they engage in the person-centered planning process. 42 page booklet. Available in English, Spanish, Chinese, Vietnamese, Tagalog, and Korean.	_____ _____ _____ _____ _____	English Spanish Chinese Vietnamese Tagalog Korean
More Than A Meeting: A Pocket Guide to the Person-Centered Individual Program Plan (Audiotape version) An audiotape version of More Than A Meeting. This tape is intended to assist consumers, families, friends and professionals as they engage in the person-centered planning process. Available in English and Spanish.	_____ _____	English Spanish
Person-Centered Planning: Building Partnerships and Supporting Choices A 14 1/2 minute VHS videotape of how the person-centered planning process has worked for three consumers and their families. The values that support the person-centered planning process are reviewed by Dennis Amundson, Director of the California Department of Developmental Services. Available in English and Spanish.	_____ _____	English Spanish

ATTACHMENT "E"

Please enter the information that applies to you.

Name:	Street Address:
Agency:	Room Number:
Title:	City:
Phone:	State:
FAX:	Zip Code:

↘ *Fold first. Fold between lines.*

↘ Fold second. Fold between lines.

Place Postage Here

IPP Materials Coordinator
Adult & Supported Living Services Section
Department of Developmental Services
Room 320
P.O. Box 944202
Sacramento, CA 94244-2020

↘ *Please fasten with tape. Staples damage sorting equipment.*

DDS Presents:

Training Opportunities on Person-Centered Planning Supported Living Services and Managed Care

ATTACHMENT "F"

Building Partnerships, Supporting Choices"

The Department of Developmental Services provides training in a continuing effort to assure the highest quality of service delivery for consumers. If you are interested in any of the training sessions listed below, please contact the person listed, the Department of Developmental Services, (916) 654-1954, or E-Mail: DDSHQ1.ASLSS@HW1.CAHWNET.GOV

❑ PERSON-CENTERED PLANNING - Offering a general overview of person-centered planning, this training includes a review of the different techniques that can assist a consumer and those supporting him/her to develop a person-centered plan. Contact: Marva Hamilton (916) 654-3767.

❑ TEAM BUILDING AND CONFLICT RESOLUTION - The use of team building and conflict resolution concepts that may be used by person-centered planning teams are examined. We will identify a number of ways to build your team. Participants will also learn about and discuss possible sources of conflict in order to learn how to resolve conflict and support team building. Contact: Kellie Gillman (916) 654-1828.

❑ INTRODUCTION TO MANAGED CARE - Like it or not, managed care strategies are being implemented not only in health care, but in many service systems with many different populations. Provided is an overview of managed care, new trends in service delivery, the implications for persons with disabilities, and various experimental models being implemented in different states. A resource list for more information is provided. Contact: Rick Ingraham (916) 543-2205.

❑ EVERYTHING YOU WANTED TO KNOW ABOUT SUPPORTED LIVING REGULATIONS - This training offers assistance on the interpretatio and implementation of the Supported Living Services Regulations. Contact: Marvin Brienes (916) 654-1553.

❑ HOME FURNISHINGS FOR SUPPORTED LIVING - Methods and strategies for getting free and/or low-cost furnishings for consumers starting out in their new home are discussed. Also explored are ideas on how to get free or low-cost furniture storage. Contact: Mike Kulisek (916) 654-1755.

❑ CONSUMERS WITH COMMUNICATION CHALLENGES - Five person-centered steps are presented on getting to know persons with communication challenges. These steps may improve our ability to understand the life preferences of the people we work with. Contact Mike Kulisek (916) 654-1755.

❑ SUPPLEMENTAL SECURITY INCOME (SSI) QUESTIONS AND ANSWERS FOR PERSONS WITH SUPPORTED LIVING ARRANGEMENTS - Designed to assist those planning to or currently living in their own home, general information is offered about SSI benefits. Contact: Mike Kulisek (916) 654-1755.

❑ LABOR & WAGE ISSUES FOR SUPPORTED LIVING - Understanding applicable employment practices is important for those involved in a supported living arrangement. Information is

presented on fair labor and wage laws relevant to supported living, employment relationships found in supported living arrangements, and direction to find information on tax and wage requirements. Contact: Marcia Boyd (916) 654-2703.

❑ HOW TO BE CULTURALLY RESPONSIVE - Addressed are the ways diversity can be recognized and valued as individuals and their families make choices and plans that are influenced by their cultural background. Contact: Marva Hamilton (916) 654-3767.

❑ WHAT ABOUT IHSS? - The In-Home Supportive Services (IHSS) program is used as a resource for personal care and household services by individuals receiving supported living services. This training provides a guide to the workings of the IHSS program and contains nuts and bolts information from eligibility and application through appeal. It has useful information for regional center staff, supported living vendors and consumers - anyone who accesses IHSS or works with IHSS requirements. Contact: Shirley Thomas (916) 654-2208.

❑ FROM PROCESS TO ACTION: MAKING PERSON-CENTERED PLANNING WORK - This presentation focuses on the "who-does-what-by-when" process. This may assist the planning team to make the decisions necessary to produce action. Contact: Paul Smith (916) 654-3351.

❑ IDENTIFY AND DEVELOP NATURAL SUPPORTS - How to develop natural supports and how natural supports benefit individuals with developmental disabilities will be discussed. Contact: Kellie Gillman (916) 654-1828.

❑ TECHNIQUES OF PERSON-CENTERED PLANNING - Through interactive techniques and discussion, we will introduce methods of person-centered planning, including Making Action Plans (MAPS), use of the Dream Deck, Planning Alternative Tomorrow with Hope (PATH), Futures Planning, Essential Lifestyle Planning and various techniques of their application. How these techniques relate to the individual plan program (IPP) will also be shared. Contact: Kellie Gillman (916) 654-1828.

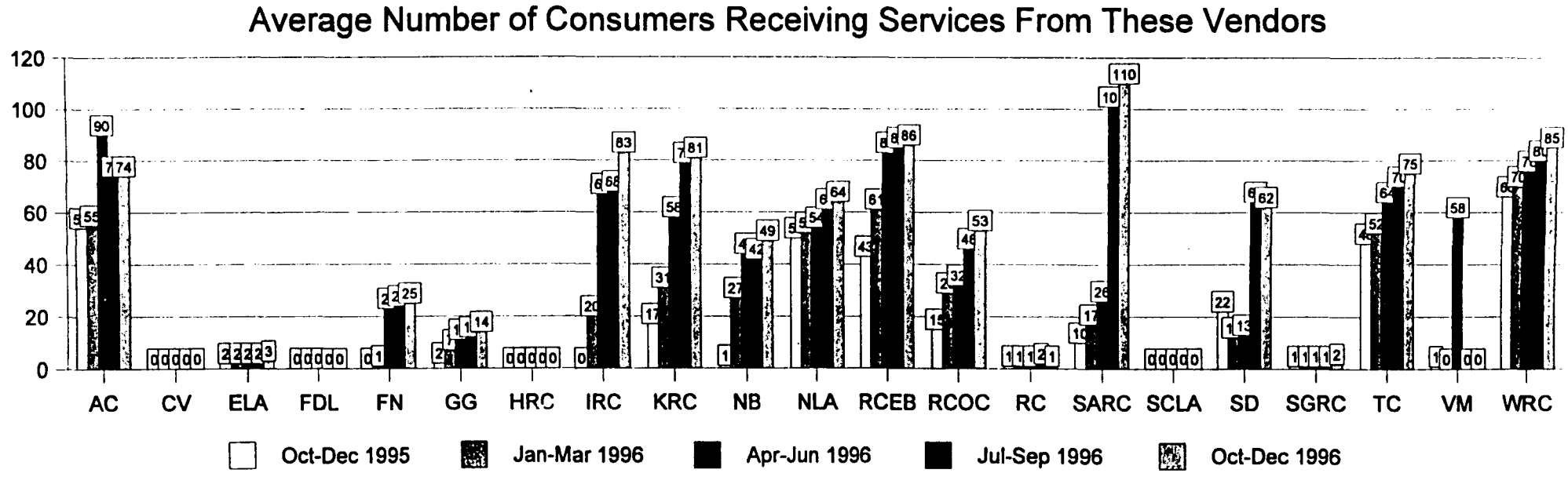
❑ "DO'S AND DON'T'S" FOR PROVIDERS CONTRACTING WITH MANAGED CARE ORGANIZATIONS - This presentation provides a brief summary of the lessons learned by service providers who have contracted with managed care organizations. Topics include different types of risk, capitation contracts, outcome measures, "absolutes" for every contract, and resources and handbooks. Contact: Rick Ingraham (916) 654-2205.

❑ OFFENDERS WITH A DEVELOPMENTAL DISABILITY - Trainers offer a pragmatic overview of the issues support team members may encounter in developing a person-centered plan for a consumer who has become involved in the criminal justice system when a consumer has become involved in the criminal justice system. Contact: Everett McGinnis (916) 654-2975.

Average Number of Consumers Receiving Services from these SL Providers (both Agency and Individual) (as vendored under the Supported Living Regulations)

	AC	CV	ELA	FDL	FN	GG	HRC	IRC	KRC	NB	NLA	RCEB	RCOC	RC	SARC	SCLA	SD	SGRC	TC	VM	WRC	Total
Oct-Dec 1995	54	0	2	0	0	2	0	0	17	1	50	43	15	1	10	0	22	1	48	1	66	333
Jan-Mar 1996	55	0	2	0	1	7	0	20	31	27	52	61	29	1	17	0	12	1	52	0	70	438
Apr-Jun 1996	90	0	2	0	23	11	0	67	58	44	54	83	32	1	26	0	13	1	64	58	76	703
Jul-Sep 1996	74	0	2	0	24	12	0	68	79	42	61	85	46	2	101	0	64	1	70	0	80	811
Oct-Dec 1996	74	0	3	0	25	14	0	83	81	49	64	86	53	1	110	0	62	2	75	0	85	867

This data represents average number of consumers with paid claims through December 31, 1996 and does not represent all consumers receiving a supported living arrangement.

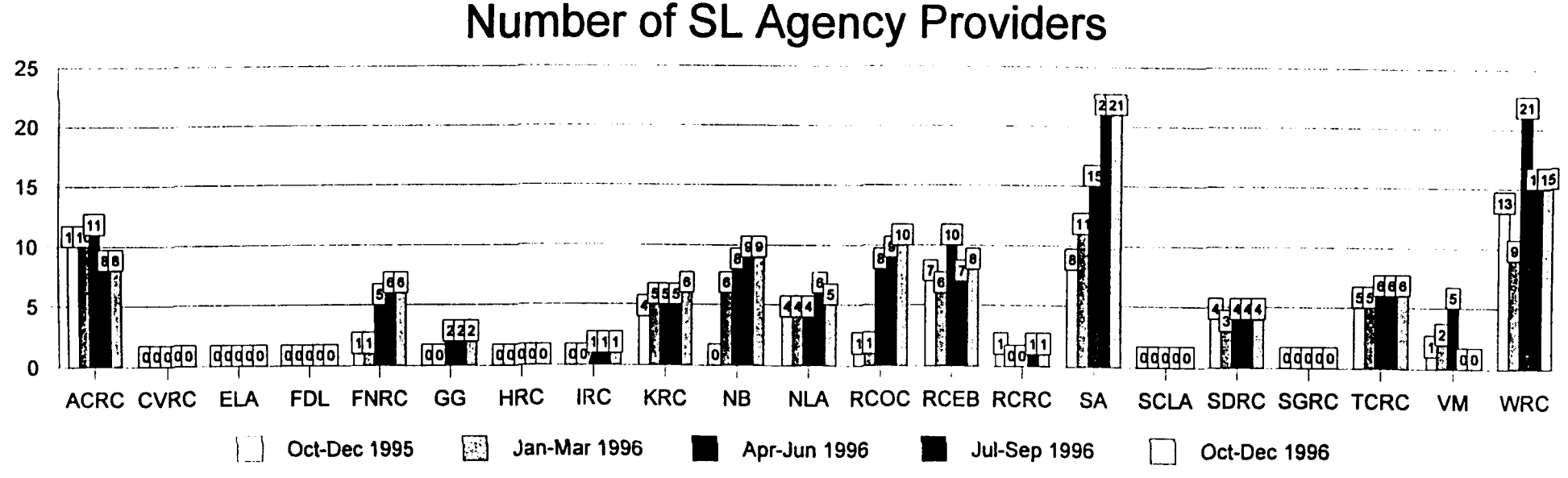


ATTACHMENT "G"

Number of Supported Living *Agency* Providers as vendored under the Supported Living Regulations

	ACRC	CVRC	ELA	FDL	FNRC	GG	HRC	IRC	KRC	NB	NLA	RCOC	RCEB	RCRC	SA	SCLA	SDRC	SGRC	TCRC	VM	WRC	TOTAL
Oct-Dec 1995	10	0	0	0	1	0	0	0	4	0	4	1	7	1	8	0	4	0	5	1	13	59
Jan-Mar 1996	10	0	0	0	1	0	0	0	5	6	4	1	6	0	11	0	3	0	5	2	9	63
Apr-Jun 1996	11	0	0	0	5	2	0	1	5	8	4	8	10	0	15	0	4	0	6	5	21	105
Jul-Sep 1996	8	0	0	0	6	2	0	1	5	9	6	9	7	1	21	0	4	0	6	0	15	100
Oct-Dec 1996	8	0	0	0	6	2	0	1	6	9	5	10	8	1	21	0	4	0	6	0	15	102

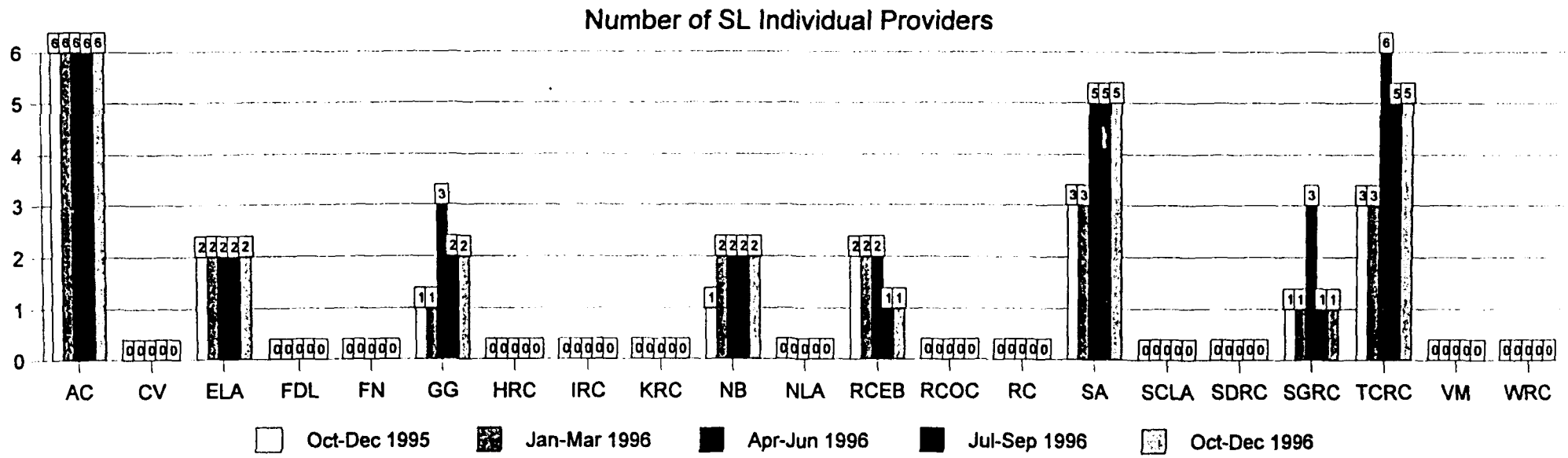
This data represents SL agency providers (as vendored under the emergency regulations promulgated in August, 1995 and adopted in September, 1996) with paid claims through December 31, 1996



Number of Supported Living *Individual* Providers as vendored under the Supported Living Regulations

	AC	CV	ELA	FDL	FN	GG	HRC	IRC	KRC	NB	NLA	RCEB	RCOC	RC	SA	SCLA	SDRC	SGRC	TCRC	VM	WRC	Total
Oct-Dec 1995	6	0	2	0	0	1	0	0	0	1	0	2	0	0	3	0	0	1	3	0	0	19
Jan-Mar 1996	6	0	2	0	0	1	0	0	0	2	0	2	0	0	3	0	0	1	3	0	0	20
Apr-Jun 1996	6	0	2	0	0	3	0	0	0	2	0	2	0	0	5	0	0	3	6	0	0	29
Jul-Sep 1996	6	0	2	0	0	2	0	0	0	2	0	1	0	0	5	0	0	1	5	0	0	24
Oct-Dec 1996	6	0	2	0	0	2	0	0	0	2	0	1	0	0	5	0	0	1	5	0	0	24

This data represents SL individual providers (as vendored under the emergency regulations promulgated in August, 1995 and adopted in September, 1996) with paid claims through December 31, 1996



CIRCL's mission is to create opportunities for building and sharing individual, organizational and community strengths in supported living.

Center for Information and Resources on Community Living (CIRCL)

http://www.napanet.net/business/personal/CIRCL/CIRCL.html

CIRCL officially began providing services on May 1st. The purpose of this resource network is to encourage and enhance supported living services in California through information sharing, on-line and in-person consultation, technical assistance, training and mentoring. If you are interested in receiving the CIRCL newsletter and information on other CIRCL resources and training please complete the following form and return it to:

CIRCL • P.O. Box 1168-881 • Studio City, CA • 91604

Are you?

____Supported Living Services provider
____Person who receives regional center services
____Regional Center staff
____Independent Living Service provider
____Family member
____Other:_____

Name _____

Agency (if applicable) _____

Address _____

_____Zip_ _____

Phone ( )_____ FAX _____ E-Mail _____

We plan to create a circle of sharing and at the same time optimize resources and services by matching up people or organizations who have experience, knowledge, and skills with people or organizations who have interests and needs. To do this we need your help in two areas:

Do you have knowledge, skills, and resources in supported living that would benefit others learning about supported living?

Do you, your agency, or a group you are a part of, have an interest in receiving the services of the CIRCL network?

If so, please answer the questions on the other side of this flyer. While we have a limited budget all requests for assistance will be seriously considered.

ATTACHMENT "H"

What you would like help with (training, technical assistance, focus groups, network with others): Please be specific about the topic area and give us as much detail as possible about your needs and yourself or your agency or group. Include information on how you think your needs would be best met (e.g., on-site technical assistance, phone support, staff training, local, regional or state focus groups, large group, small group, or materials). Please include your current experience with supported living and your plans for the future related to your request.

What you would like to share (knowledge, skills, and resources): Please be specific and give us as much detail as possible about the topic. Also, please include information under which the resources you have are available (e.g., consultation fees, geographic area).

Do you or your agency have meeting space available if we were to provide training or focus groups in your area? Please describe the space you have available (e.g., number of people, when it is typically available, any fees for use, etc.).

Are you willing to help us organize trainings or focus groups in your area?

Be a Part of the CIRCL of Learning and Sharing

CIRCL • P.O. Box 1168-881 • Studio City, CA 91604 • Phone and Fax (818) 752-7484

Children Served by Regional Centers
Foster Family Agency Services

(children who have been assessed as needing residential services for children with special health care needs may be placed either with a Foster Family Agency or in a home providing care for children with special health care needs. A Foster Family Agency may serve children with special health care needs or provide foster family agency services. Therefore, there may be duplicates in the figures provided.)

Number of Children Who Are Receiving Foster Family Agency Services

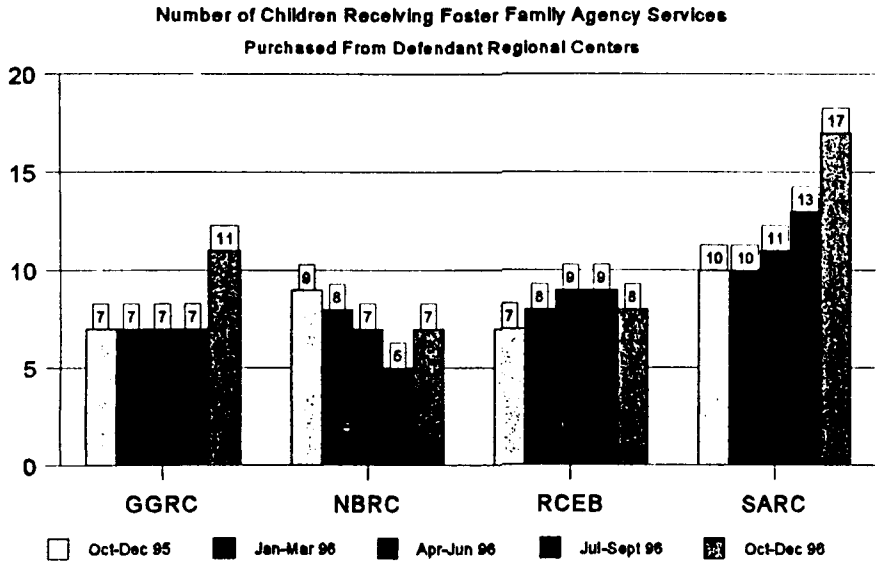
	GGRC	NBRC	RCEB	SARC
Oct-Dec 95	7	9	7	10
Jan-Mar 96	7	8	8	10
Apr-Jun 96	7	7	9	11
Jul-Sept 96	7	5	9	13
Oct-Dec 96	11	7	8	17

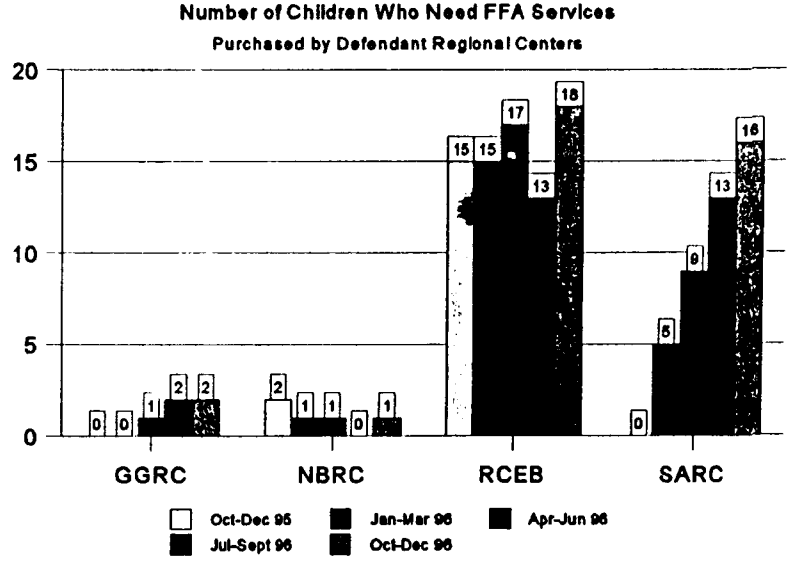
Number of Children Whose IPP Reflects the Need for Foster Family Agency Services

	GGRC	NBRC	RCEB	SARC
Oct-Dec 95	7	11	22	10
Jan-Mar 96	7	9	23	15
Apr-Jun 96	8	8	26	20
Jul-Sept 96	9	5	22	26
Oct-Dec 96	13	8	26	33

Number of Children Who Need Foster Family Agency Services

	GGRC	NBRC	RCEB	SARC
Oct-Dec 95	0	2	15	0
Jan-Mar 96	0	1	15	5
Apr-Jun 96	1	1	17	9
Jul-Sept 96	2	0	13	13
Oct-Dec 96	2	1	18	16

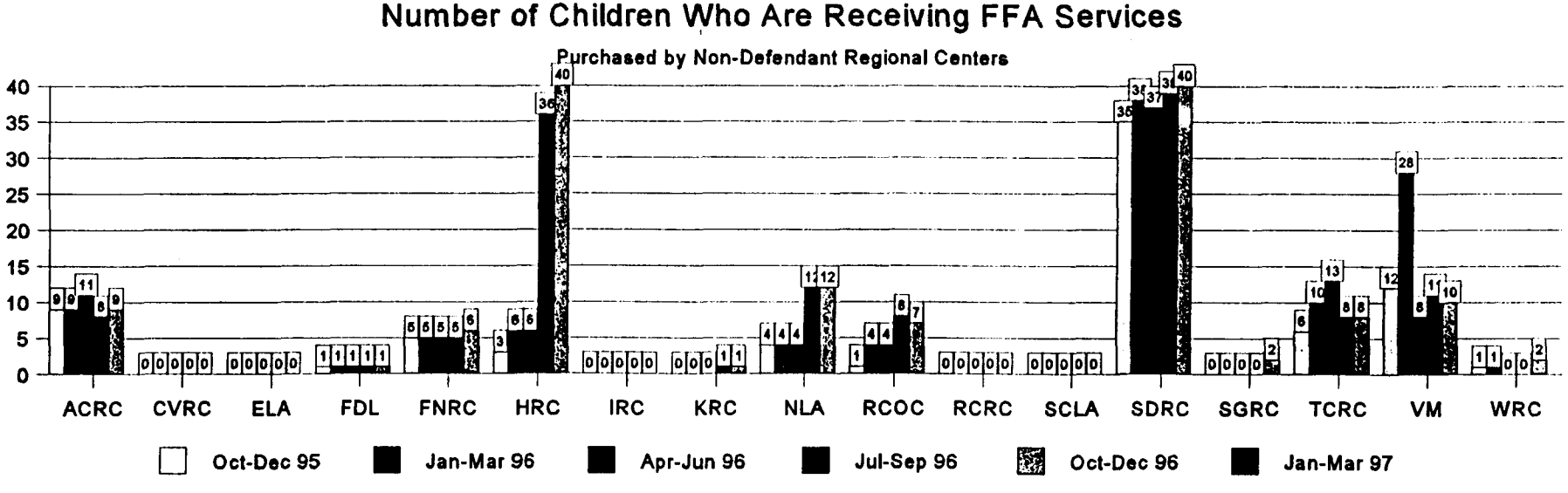




ATTACHMENT "I"

Number of Chilren Who Are Receiving Foster Family Agency Services Purchased by Non-Defendant Regional Centers

	ACRC	CVRC	ELA	FDL	FNRC	HRC	IRC	KRC	NLA	RCOC	RCRC	SCLA	SDRC	SGRC	TCRC	VM	WRC	Total
Oct-Dec 95	9	0	0	1	5	3	0	0	4	1	0	0	35	0	6	12	1	77
Jan-Mar 96	9	0	0	1	5	6	0	0	4	4	0	0	38	0	10	28	1	106
Apr-Jun 96	11	0	0	1	5	6	0	0	4	4	0	0	37	0	13	8	0	89
Jul-Sep 96	8	0	0	1	5	36	0	1	12	8	0	0	39	0	8	11	0	129
Oct-Dec 96	9	0	0	1	6	40	0	1	12	7	0	0	40	2	8	10	2	138



Children Served by Regional Centers
Services for Children With Special Health Care Needs

(Children who have been assessed as needing residential services for children with special health care needs may be placed in either with a Foster Family Agency or in a home providing care for children with special health care needs. A Foster Family Agency may serve children with special health care needs or provide foster family agency services. Therefore, there may be duplicates in the figures provided.)

Children Who Are Receiving Residential Services for Children With SHC Needs

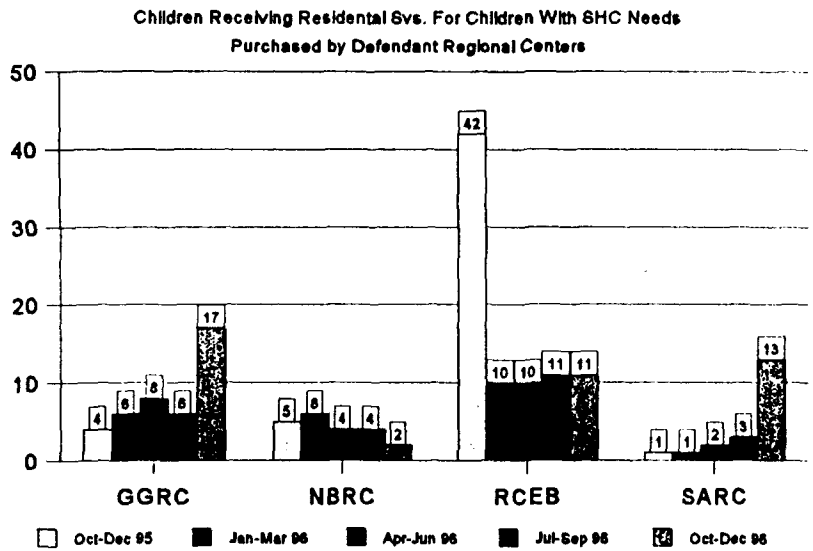
	GGRC	NBRC	RCEB	SARC
Oct-Dec 95	4	5	42	1
Jan-Mar 96	6	6	10	1
Apr-Jun 96	8	4	10	2
Jul-Sep 96	6	4	11	3
Oct-Dec 96	17	2	11	13

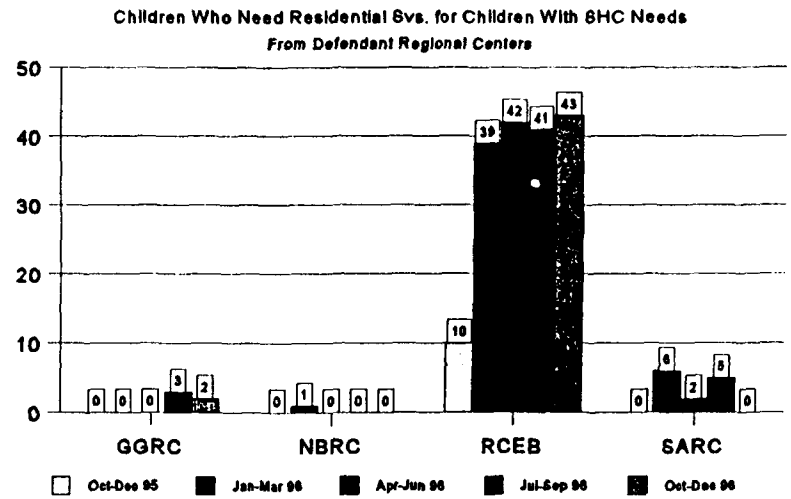
Children Whose IPP Reflects the Need for Residential Services for Children With SHC Needs

	GGRC	NBRC	RCEB	SARC
Oct-Dec 95	4	5	52	1
Jan-Mar 96	6	7	49	7
Apr-Jun 96	8	4	52	4
Jul-Sep 96	9	4	52	8
Oct-Dec 96	19	2	54	13

Children Who Need Residential Services for Children With SHC Needs

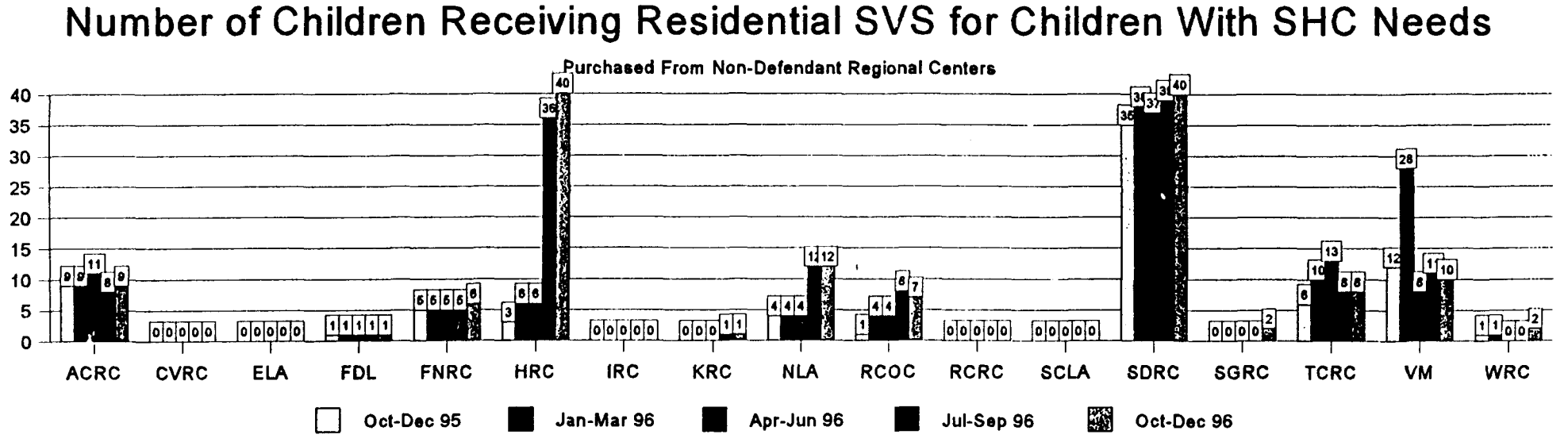
	GGRC	NBRC	RCEB	SARC
Oct-Dec 95	0	0	10	0
Jan-Mar 96	0	1	39	6
Apr-Jun 96	0	0	42	2
Jul-Sep 96	3	0	41	5
Oct-Dec 96	2	0	43	0





Number of Children Receiving Residential Services for Children With Special Health Care Needs Purchased by Non-Defendant Regional Centers

	ACRC	CVRC	ELA	FDL	FNRC	HRC	IRC	KRC	NLA	RCOC	RCRC	SCLA	SDRC	SGRC	TCRC	VM	WRC	Total
Oct-Dec 95	45	10	3	0	6	0	0	1	4	11	0	21	22	4	27	76	1	231
Jan-Mar 96	45	18	5	0	6	1	0	1	4	11	0	14	23	3	28	61	0	220
Apr-Jun 96	38	18	6	6	7	6	0	2	4	11	0	9	22	3	19	42	1	194
Jul-Sep 96	40	18	14	0	7	3	0	2	5	11	0	15	23	3	16	33	1	191
Oct-Dec 96	48	18	16	0	7	3	0	1	6	11	0	17	22	4	16	39	1	209



OPEN FORUM San Francisco Chronicle

IURSDAY, APRIL 3, 1997

Perspectives on Deinstitutionalization

Focus Needed on Group Home Quality

By Catherine Blakemore, Eric Gelber, Ellen Goldblatt, Daniel Juarez and Kim Swain

THE CHRONICLE, in a sensationalistic "special report" asserts that the retarded are paying the price with their lives for the state's allegedly fiscally driven campaign to close down its "asylums." The report is as one-sided and misleading as its terminology is outdated and its conclusions inaccurate.

The implication that the state's current efforts to move large numbers of people with mental retardation and other developmental disabilities out of its large state institutions into the community are in any way similar to the precipitous dumping of people with psychiatric disabilities out of its state psychiatric hospitals during the Reagan administration is outrageous and inaccurate (although it makes for very dramatic headlines). It was, in fact, the lessons of those earlier disastrous experiences that have guided the current carefully planned efforts to provide people with developmental disabilities with the services and supports they need to give them opportunities to live safe and productive lives and enjoy the benefits of life in the community. As a result, literally thousands of former developmental center residents are now successfully realizing that dream, some in licensed-care facilities, some with their families and some in their own homes or apartments.

The reported comment of one developmental center parent, and a theme of The Chronicle's special report, is that the state's actions are being driven by "money, money, money." While it generally is fiscally unsound to keep people in developmental centers who can be appropriately served in the community, what drove the state to act was, in large part, a class-action lawsuit (Coffelt vs. the Department of Development Service) initiated by people with developmental disabilities and families of developmental center residents whose sole motivation was quality of life.

That lawsuit brought to light the fact that at least 2,000 of about 6,000 developmental center residents were institutionalized only because there were not sufficient community resources to meet their needs and enable them to live in the community. As a result of the settlement of the Coffelt lawsuit, the state has identified sources of federal money which in turn has helped it to expand community resources, develop a new quality-assurance system and, on a case-by-case basis, identify and provide the services and supports necessary to permit more than 2,000 former developmental center residents to lead quality lives in the community.

The Chronicle's report relies heavily on the work of Dr. David Strauss, a professor of statistics. Unfortunately, the report fails to point out that Strauss' work has been criticized by other researchers — for its methodology and its misleading and exaggerated interpretations of the data. In a recent, as yet unpublished, study, cited by The Chronicle, Strauss reports that there were about 45 deaths among 1,900 people moved from developmental centers to the community between April 1993 and January 1996, which is a higher mortality rate than he computed for people living in developmental centers between 1980 and 1992. Data provided by tne Department of Developmental Services, however, reveal that there were about 292 deaths among the 4,000 to 6,000 residents of developmental centers over roughly the same period during which the 45 reported community deaths occurred. That which would seem to indicate a higher mortality rate in the institutions during that period.

ATTACHMENT "J"

We all should be concerned about the deaths of individuals with developmental disabilities, whether they occur in the community or in institutions. Sadly, The Chronicle appears to adopt Strauss' reliance on mortality to measure the outcome of de-institutionalization rather than quality of life. Strauss has said that he measures mortality because life quality "is notoriously difficult to quantify and measure." Fortunately, other researchers have not adopted this narrow view; so considerable data exist on the positive and profound impact the opportunity to leave large state institutions has had on the lives of Californians with developmental disabilities since the settlement of the Coffelt case.

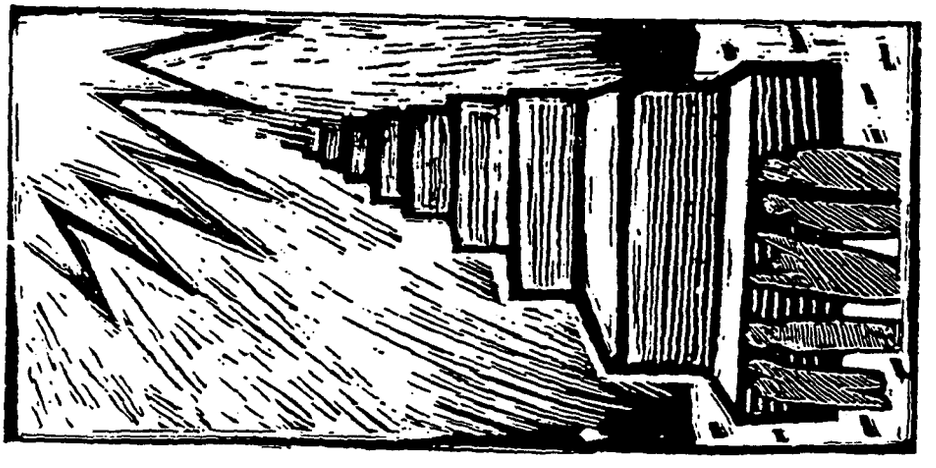
Dr. James Conroy, an expert on evaluating outcomes for individuals who have moved from institutions to the community, has found that people who move from developmental centers improve significantly in skills involving self-care and independent functioning; sharply reduce challenging behaviors; receive a greater quantity and variety of services; double their integration with non-disabled people; and report being happier in their new homes. Movers rated their homes higher in comfort, cleanliness, decor and attractiveness. Families of movers report that their relatives' quality of life improved in all areas measured, and many families of movers reported changing drastically from opposition to support of community living. These positive community outcomes were being obtained at lower public cost. Unfortunately, Conroy's findings get only passing, indirect reference in The Chronicle's report.

If The Chronicle had chosen to do so, it could have interviewed Belinda, a woman with autism who left a developmental center three years ago and now lives in her own apartment with a roommate. She works part-time and also goes to school. She sees a doctor weekly for proper treatment of her seizures. When asked if she was happier now that she lives in the community, Belinda said, "It's lovely. I can do my own shopping and do my own laundry. I can eat what I want to eat. If I can't sleep, I can watch TV 'till I get sleepy. The bottom line is that I just like being free."

Are developmental centers all bad and the community all good? Of course not. Conroy's study also acknowledges concerns and problems. There are instances of abuse and neglect in the community, just as there are in developmental centers. There needs to be better feedback systems so that problems can be identified and responded to more quickly. There needs to be better funding and training for community-care providers and case managers.

Strauss' data should remind us that we must continually be vigilant and aware that more work needs to be done to minimize risk and increase quality of life for people with developmental disabilities. It would be tragic if we, as a society, instead reacted to such reports by calling for unconstitutional moratoriums on letting people out of institutions or by otherwise retreating to the time when people with disabilities were routinely segregated in locked facilities. Instead, let's work toward increasing opportunities for people with disabilities to lead meaningful, productive lives in the community among their friends, relatives, and neighbors.

The authors are attorneys with Protection & Advocacy Inc., the state's federally mandated system established to advocate for the rights of people with disabilities and are counsel for the plaintiff class in Coffelt et al.



It would be tragic if our society retreated to a time when disabled people were routinely segregated in locked facilities

ATTACHMENT K

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