INTRODUCTION

For seven years, the Office of Clients' Rights Advocacy (OCRA) has provided advocacy services for the consumers of California's 21 regional centers. During those years, OCRA has come to be a respected provider of advocacy services by the people and families who it serves and by the community and agencies that support people with developmental disabilities. As OCRA moves into its final year of the current contract, staff remains dedicated to providing excellent service to people with developmental disabilities. OCRA is justly proud of its services and the difference that staff has made in the lives of so many people.

During the past year, OCRA handled 9,067intakes and cases and provided over 290 trainings attended by approximately 12,198 people. The number of intakes increased from the preceding fiscal year by 809 intakes, which is noteworthy, because OCRA's number of staff remains the same. This is truly representative of the dedication with which each staff person approaches his or her job.

OCRA operates 23 offices throughout the State of California, most of which are staffed by one CRA and one Assistant CRA. A list of our current staff and office locations is attached as Exhibit A.

Significantly, consumer satisfaction surveys continue to average above 90 percent satisfaction in most of the areas of performance surveyed. OCRA staff makes a strong effort to provide high quality advocacy services to the consumers that it serves. That effort is reflected in the statistics quoted, the outcomes reported, and the spirit that abides among OCRA staff. This is captured so clearly in the many letters of appreciation that the staff receives. Below are edited portions of a few of these letters:

To the most wonderful person that you are. I just wanted to just thank you so very much for what you did and help me get my finance about as quick as I did. Please always remember that I will always come to you or call you if I ever have another problem with anything. You will be the one I will call on.

En nombre de los niños, jovenes y adultos, mil gracias por toda la ayuda que nos da. Que dios le bendiga en todo. Muchisimas gracias. (In the name of all children, youths, and adults, many billions of thanks for all the help you provide. May God bless you richly in everything. Many thanks.)

We received this e-mail from a regional center service coordinator:

This morning I was asked to participate in an IEP for a family.... The meeting started out immediately with an almost surreal level of animosity directed toward the student's mother, particularly with regards to the length of time that had already been expended in previous meetings to develop the pending IEP.... Add to this scenario the mother's need for English-to-Spanish translation and one can quickly appreciate how important effective communication is when negotiating within such a hostile environment. This is just a short note to commend your clients' rights advocate for handling a difficult situation with calm, poise and intelligence. She was terrific, professional and effective. She immediately attempted to diffuse the situation and asserted the child's and family's rights. Eventually, the advocate insisted that the offending party (i.e. the teacher) be excused (removed) from the meeting. This of course was not well received by the teacher but it was exactly the right thing to do. Once the teacher was removed, we went from seriously considering canceling the (IEP) meeting to actually getting something done. This wouldn't have happened without your advocate's skills.

I don't know if I can fully express my son's and my deep appreciation for all the effort and work you two have put in towards getting my son's drivers license returned to him. I'm sure we would have had a much tougher time getting his driving privilege back without your help. He is a much better driver now and appreciates his license so much more.

I cannot thank you enough for all your time, patience and expertise in the area of patient's rights. Working in the field myself, I know how complex matters can get....You have been objective and consistent with your feedback. I know that you

truly listen and not "just hear." You have always made an effort to return calls and I know that in this day and age this is not so common. I am grateful to report that with your assistance, my stepson has been accepted as a client of the regional center. It was a process that took a lot of patience and perseverance. Your listening skills and direction helped that process....

All of these letters, plus the many others that staff receive, show OCRA's continuing effectiveness and dedication.

PAI greatly appreciates the support and efforts of DDS and the regional centers in OCRA's performance of this contract. Without support from these agencies, OCRA's efforts to ensure the rights of Californians with developmental disabilities would not be so successful.

I. CONTENTS OF ANNUAL REPORT

PAI's contract with DDS, Paragraph 14, Exhibit D, specifies that the following information is to be contained in the Annual Report:

- 1) Number and type of clients' rights denials;
- 2) Nature, status, and outcome of complaints filed under the Contractor's grievance procedure;
- 3) Nature, status, and outcome of complaints filed under Title 17, California Code of Regulations, Section 50540 Complaint Procedure;
- 4) Aggregate data on consumers provided with services, including, but not limited to, age, sex, primary disability, ethnicity, type of residence, type of services provided, and examples of the outcomes of those services;
- 5) Achievement of the performance objectives;
- 6) Summary of the content, attendance, frequency; and evaluation of self-advocacy training provided;

- 7) The amount and source of any attorney's fees and costs collected; and
- 8) Recommendations for enhancement of services to be provided under the terms of the contract.

II. PERFORMANCE OBJECTIVES

PAI's contract with DDS requires performance evaluation measures. On January 8, 2002, former Contract Manager, Suzanne Joy-Livingston, met with PAI and gave verbal approval to the performance objectives that OCRA had proposed to DDS.

1. 7,560 issues will be resolved for people with developmental disabilities on an annual basis.

OCRA has continued its tradition of serving a large number of people with developmental disabilities and exceeded this performance objective by nine percent. The performance objectives require OCRA to resolve 7,560 issues for people with developmental disabilities during the time period covered in this report. The statistics, attached as Exhibit B, show that OCRA resolved 9,067 issues for consumers during this time period, an increase of 809 over 2004. In 2004, the increase of intakes was 244 more than from 2003. Thus, over a 2-year period, OCRA services have increased by over 1,000. It is clear that OCRA resolved significantly more issues for people with developmental disabilities than required by the performance objective and that OCRA's staff continues to strive to provide as many services as it possibly can.

2. 75 percent of requests for assistance will be resolved informally as measured by the quarterly data.

OCRA continues to exceed this performance objective. OCRA handled 9067 requests for assistance during this reporting period. Of these, 119 were handled as requests for direct representation at hearing or filing of a formal complaint. This means that 99 percent of the requests for assistance were resolved informally. Informal is defined as all services resolved below the

due process hearing or formal complaint level. Therefore, significantly more than the required 75 percent of the cases were resolved informally. Data showing this is attached as Exhibit B.

3. 80 percent of individuals with developmental disabilities receiving service from OCRA will be satisfied with those services as measured by the consumer satisfaction survey.

OCRA exceeded this performance standard with all areas of satisfaction significantly exceeding 80 percent, except for one area. From the survey results, it is clear that OCRA consumers are overwhelmingly satisfied with the services provided by OCRA. With a 40 percent return rate, of those who answered the questions, 92 percent of the responders felt they were treated well by the staff, 92 percent understood the information they were provided, 92 percent believed their CRA listened to them, 76 percent believed they were helped by the CRA, and 88 percent would ask for help from the CRA again. See Exhibit C which discusses the results of OCRA's survey.

4. 75 percent of individuals with developmental disabilities receiving services from OCRA will indicate that their issue(s) was resolved in a timely manner as measured by the consumer satisfaction survey.

See Exhibit C which shows that OCRA provided timely services to over 75 percent of the consumers that OCRA served last year. In fact, 84 percent of the responders to the consumer satisfaction survey indicated that they received a call back within two days.

5. A minimum of one self advocacy training for individuals with developmental disabilities and/or their families will be held each year in each regional center catchment area.

At least one self advocacy training for consumers and their families was held in each regional center catchment area during the past year. The chart below reflects the training dates.

OCRA has developed five separate packets of information for staff to use in the mandated trainings on self-advocacy. The original self-advocacy packet was approved by DDS, as required under the previous contract. The more recent packets have been sent or shown to DDS, and though the current contract does not require the approval of DDS, OCRA welcomes comments from DDS. Additional trainings were developed on voting rights, fair hearing rights and a game called Clients' Rights Bingo. The game is similar to a traditional bingo game, except that pictures used depict various rights to which people with developed disabilities are entitled. This year, staff developed a new training on consumer finances.

The evaluations for the self-advocacy trainings are too numerous to submit to DDS but, almost without exception, consumers attending those trainings rated them as satisfactory. OCRA's standard rating sheet was used at the trainings. Consumers have the choice of evaluating a presentation as satisfactory or unsatisfactory in six basic areas. The rating sheet has previously been reviewed and approved by DDS. The individual rating sheets are available for review if DDS desires to do so. Each OCRA office met its mandated self-advocacy training on the following dates:

Central Valley RC November 8, 2004

East Los Angeles County RC October 16, 2004

Far Northern RC April 6, 2005

Golden Gate RC October 19, 2004

November 8, 2004

Harbor RC July 1, 2004

August 16, 2004

Inland RC March 24, 2005

March 25, 2005

Kern RC September 16, 2004

Lanterman RC August 18, 2004

North Bay RC September 29, 2004

October 5, 2004 June 28, 2005

North Los Angeles County RC September 9, 2004

Redwood Coast RC March 16, 2005 RC of East Bay June 29, 2005

June 30, 2005

RC of Orange County June 28, 2005

San Andreas RC August 26, 2004

San Diego RC March 5, 2005

San Gabriel/Pomona RC July 27, 2004

South Central Los Angeles RC February 16, 2005

Tri-Counties RC March 11, 2005

Valley Mountain RC October 6, 2004

October 13, 2004 October 14, 2004 November 5, 2004

Westside Regional Center August 16, 2004

<u>6. OCRA will present at a minimum of 160 trainings per year on a variety of topics of interest to consumers, their families, regional center staff or other interested persons.</u>

OCRA presented at 290 trainings during the past year. This was 130 more than required by this performance objective and 44 more than last year. One reason for the large number is that OCRA recognizes that outreach and training is an essential part of providing effective advocacy for regional center consumers. In fact, one of the essential services that OCRA offers is

training on a wide variety of issues, including but not limited to, consumers' rights, various public benefits, special education, and conservatorships.

During the past year, OCRA presented at 290 trainings with a total attendance of approximately 12,198 people at the various trainings. It is obvious that OCRA presented information to an extremely large number of people.

7. In addition to the self-advocacy trainings, OCRA offices will present at a minimum of three outreach trainings to underrepresented communities each year.

OCRA has a priority of providing assistance to individuals from traditionally underserved communities. Eva Casas-Sarmiento serves as the Statewide Outreach Coordinator, Lisa Navarro as the Northern California Outreach Coordinator, and Emma Hambright as the Southern California Outreach Coordinator. The outreach coordinators assist the OCRA offices in development and implementation of their outreach plans and provide the formal evaluation of each office's outreach plan.

The target outreach plans were initially written for a year's time period and identified underrepresented groups in each catchment area for the offices to target for extra contact. A detailed report on targeted outreach and training is included here as Exhibit D.

The targeted outreach plans that were developed for fiscal year 2004-2005 were in effect for one year. Review of the statistics on OCRA's services to underrepresented groups show steadily increasing services to most people of color and underrepresented groups. The conclusion must be reached that OCRA's outreach to underrepresented groups has been instrumental in causing the increases.

8. To lead to greater cooperation with regional centers, OCRA will:

A. Develop or revise Memorandums of Understanding (MOUs) with each regional center that address that center's individual needs, concerns, and method of operation by July 1, 2002.

The OCRA Director met with the all of the regional centers during the first year of the current contract. MOUs have been revised as needed and copies of all revised MOUs have been forwarded to DDS when the MOUs are finalized.

In general, meetings regarding the MOUs are productive and extremely congenial. It is clear that OCRA's working relationships with the various regional centers have become well established and that concerns between the two agencies can be addressed with minimum difficulty in almost every situation.

B. PAI's Executive Director and OCRA's Director will offer to meet with ARCA on an annual basis to discuss any issues of concern.

Jeanne Molineaux and Bob Baldo, the Executive Director of the Association of Regional Center Directors, met on February 7, 2005. At that time, it was agreed that there were no significant outstanding issues between OCRA and the regional center directors and that a meeting did not need to take place between Catherine Blakemore, PAI's Executive Director, and ARCA's Director. Meetings will be convened, should concerns arise.

III. OCRA ADVISORY COMMITTEE

PAI's contract with DDS requires that, "(t)he provision of clients' rights advocacy services (will be) coordinated in consultation with the DDS Contract Manager, stakeholder organizations, and persons with developmental disabilities and their families representing California's multicultural diversity(.)" OCRA meets this outcome by working with the OCRA Advisory Committee, as discussed below.

OCRA works through the OCRA Advisory Committee to ensure that this performance outcome is achieved. Attached as Exhibit E is a list of the current members of the committee.

Vacancies on the committee are listed on PAI's website and in its newsletter. In the selection process, consideration is given to geographical diversity, both rural and urban and north and south, type of developmental disability represented, and ethnic background, in addition to the qualifications of the individual applicants. The current committee has five consumer members and three family members who represent diverse geographical and ethnic backgrounds. Additionally, most of the members belong to other stakeholder organizations.

The OCRA Advisory Committee is a knowledgeable, constructive, and helpful group of volunteers who continue to provide valuable guidance to the OCRA staff. The meetings are lively and informative and provide a forum for exchange of ideas and information. The Committee meets three times a year. Minutes for the meetings held this fiscal year, that DDS does not already have, are attached as Exhibit E.

DDS staff is invited and encouraged to participate in any of the meetings. The remaining committee meeting for this calendar year is in Oakland on September 24 and Los Angeles on December 3, 2005.

IV. EXAMPLES OF OUTCOMES OF SERVICES PROVIDED

OCRA has requested that each advocate provide on a quarterly basis a summary of an administrative hearing or other case that has unique situations from which other advocates can learn and that can be used as examples of the advocacy that OCRA is accomplishing. These summaries for the last two quarters are compiled and attached as Exhibit F. OCRA is extremely pleased that such outstanding examples of advocacy are available to show the value of the work that OCRA accomplishes. A few examples of the advocacy:

SSI Benefits Awarded To 18-Month-Old.

F.A., an 18-month-old diagnosed with Rubinstein-Taybi syndrome (RT), was denied SSI eligibility. RT is a rare disorder characterized by unique physical characteristics and developmental delays. In response to F.A.'s

parent's request for assistance, the CRA reviewed F.A.'s file and agreed to represent at an eligibility hearing for SSI benefits. Following the hearing, F.A. received a fully favorable decision granting eligibility, including retroactive benefits to December, 2003.

OCRA Assists Client in Accessing a Blocked Account to Purchase an Adaptable Vehicle.

R.R. is a non-ambulatory adult woman who lives with her elderly parents. Several years ago, R.R. was involved in an accident when being transported from her day program. R.R.'s family settled a lawsuit and an award of approximately \$7,000 was put into a blocked Minor's Account for R.R., even though R.R. was not a minor.

Over the years, R.R.'s family has tried to get a disbursement from the account to pay for repairs to the family's sole vehicle, which is used daily to transport R.R. to and from her day program. The Probate Department of Superior Court has denied the family's petitions for transportation expenses, stating the family's transportation needs are not R.R.'s responsibility.

In the last two years, R.R.'s father's own physical health began to decline and he started experiencing significant difficulties in lifting R.R. and her wheelchair in and out of the truck on a daily basis.

OCRA wrote an opinion letter that was submitted along with a petition requesting a complete disbursement of the Minor's Account. OCRA attached documents verifying the limited income and resources of the family, a doctor's statement describing the declining physical health of R.R.'s father, R.R.'s current DD Waiver beneficiary status, vehicle adaptation funding information through the DD Waiver, the physical therapist assessment report substantiating R.R.'s and her father's physical limitations, R.R.'s revised IPP identifying R.R.'s transportation needs, and case notes reflecting the regional center's efforts to obtain vehicle adaptation funding. The letter opined that a refusal from the Probate Department to disburse the remaining funds from R.R.'s account would violate the principles of the Americans with Disabilities Act, as set forth in the United States Supreme Court's Olmstead decision.

After receiving verification of R.R.'s father's current auto insurance and good driver standing through the Department of Motor Vehicles, and a non-binding quote from an auto dealer, the court permitted the bank to release the remaining funds.

D.L. Can Go to School with Her Peers.

D.L.'s mother contacted OCRA for assistance in locating an appropriate school placement for her daughter. The school district informed D.L.'s mother at an IEP meeting that, due to her medical needs, D.L. could only be placed at the school in the district where a nurse is on campus. D.L.'s mother disagreed with the placement as not being the least restrictive, requesting that D.L. be placed in an inclusion class rather than a special day class. D.L. has multiple seizures per day and an unsteady gait requiring the assistance of a walker. The district felt that D.L. could fall and injure herself at school and needed a nurse on campus.

OCRA scheduled an IEP meeting and advocated for a placement in one of the district's blended inclusion classes where a nurse is present on campus three days a week and a nursing aide is present two days a week. The district agreed with the placement, providing that D.L.'s doctors agreed the placement was appropriate. Initially, D.L.'s doctor refused to sign a medical release form after the district informed her that there was no nurse on campus. OCRA intervened, providing the doctor with accurate information on the presence of nursing and school staffing ratios. The doctor met with district representatives and agreed to the placement, and D.L. was able to attend school with her peers.

Disabled Adult Child Benefits Will Not Stop if Recipients Marry.

For many years, N.F. and V.C. have lived together in a supported living arrangement. They want to get married, but were told that if they did marry, V.C. would lose her entitlement to the DAC benefits she was about to receive. They asked OCRA whether this was true.

OCRA confirmed that there is a general rule that people lose DAC benefits if they marry, but that V.C. and N.F. would come within the exception that says a person remains eligible for DAC if she marries someone who also receives one of the "Title II" Social Security

benefits, such as DAC or Social Security Disability Insurance (SSDI) benefits. Because N.F. receives SSDI, the two could marry without it having an adverse effect on V.C.'s DAC benefits.

V. DENIAL OF CLIENTS' RIGHTS

CCR, Title 17, Sec. 50530, sets forth a procedure whereby a care provider may deny one of the basic rights of a consumer if there is a danger to self or others or a danger of property destruction caused by the actions of a consumer. Attached as Exhibit G is the current log of Denials of Rights from the OCRA Offices.

VI. TITLE 17, SECTION 50540 COMPLAINTS

CCR, Title 17, Section 50540, sets forth a complaint procedure whereby a regional center consumer, or his or her authorized representative, who believes a right has been abused, punitatively withheld or improperly or unreasonably denied, may file a complaint with the Clients' Rights Advocate. The Complaint process is similar to that established by the Welfare & Institution Code, Section 4731. However, the later law offers more consumer protections. There were no Title 17 complaints filed during the last fiscal year.

VII. COLLECTION OF FEES

OCRA does not charge consumers, their families or advocates fees for services nor does OCRA seek to recover costs from these individuals. Clients' Rights Advocates who are licensed to practice law in California, or Assistant Clients' Rights Advocates working under the supervision of an attorney, can collect attorney's fees and costs similar to those collected by

private attorneys or advocates for special education cases or other cases where there are statutory attorney's fees. OCRA collects fees only in special education cases or Writs of Mandamus filed against the State Department of Social Services. Fees and costs may be negotiated at mediation or can be received in those cases where an Administrative Law Judge has made a determination that the petitioner is the prevailing party. Fees are collected from the opposing party, which is normally the school district. Costs include any expenses to the Petitioner or OCRA for bringing the suit, such as filing fees or costs of expert evaluations. Neither PAI nor OCRA ever collect attorney's fees from consumers.

The amount collected for any individual case depends upon several factors such as the geographical location where the Petitioner lives, and the years of experience of the attorney who handled the case. Attached as Exhibit H is a chart showing the amount and source of any attorney's fees and costs collected by OCRA during the past fiscal year.

VIII. CONSUMER GRIEVANCES

Exhibit C, Paragraph 11, of the contract between DDS and PAI requires OCRA to establish a grievance procedure and to inform all clients about the procedure. DDS has approved the grievance procedure developed by OCRA. The procedure is posted prominently in both English and Spanish at each office. Additionally, the grievance procedure is provided when staff learns that a consumer or family is dissatisfied with the services that OCRA has provided.

Four grievances were filed by consumers or their families against OCRA last year. The grievances were all resolved at the first level and information concerning the grievances has previously been submitted to DDS. Attached as Exhibit I is a chart detailing the grievances filed against OCRA.

IX. ANALYSIS OF CONSUMERS SERVED

OCRA handled a total of 9,067 cases from July 1, 2004, through June 30, 2005. This represents a significant amount of advocacy assistance and continues a trend for OCRA to intake increasing numbers of cases in the last years. The complete compilation of data for the fiscal year is included as Exhibit B.

The data has been compiled by:

- 1. Age
- 2. County
- 3. Disability
- 4. Ethnicity
- 5. Gender
- 6. Living Arrangement
- 7. Problem Areas
- 8. Service Level

The majority of the OCRA statistics remain consistent with OCRA's previous statistics. For example, the largest number of consumers served by age, 2,339, has consistently been the 3-to-17 years-old age group. The next largest is the 22-40 age group with 1,388 people served. The consistency remains in the ratio of males to females served, also. OCRA has traditionally served more males than females, with approximately 62 percent of the consumers served being male and 37 percent being female. For one percent of OCRA's intakes, the gender is unknown. These statistics are consistent with the percentage of regional center consumers who are male versus female. As of July, 2005, 60 percent of all regional center consumers were male and 40 percent were female.

Consumers residing in their parental or other family home remain by far the largest number of consumers served, with 5,880 consumers or 65 percent of those OCRA served living in their family home. The next largest group served is those living independently, with OCRA serving 1084 people or 12 percent with this living arrangement. DDS statistics show that 68.87 percent

of regional center consumers live in their parent's home and 9.86 percent live independently.

OCRA's statistics on the ethnicity of consumers served from July 1, 2004, through June 30, 2005, show OCRA's continuing commitment to serve underserved communities. The percentage of consumers from various ethnicities served by OCRA was:

Ethnicity	%	%	%	%	%	%	%
	Regional	OCRA	OCRA	OCRA	OCRA	OCRA	OCRA
	Center	Clients	Clients	Clients	Clients	Clients	Clients
	Clients	04/05	03/04	02/03	01/02	00/01	99/00
	(current)						
African-	10.68	10	10	10	9	9	8
American							
Latino	30.76	29	28	27	24	24	24
American	.41	1	1	1	1	1	1
Indian or							
Alaskan							
Indian							
Asian	5.53	4	5	4	3	5	4
Pacific	2.29	1	1	1	1	1	1
Islander							
White	43.65	44	47	49	47	48	56
							_
Multicultural	Not	5	3	4	4	4	3
(self-	listed						
identified)							
Refused to	6.68	5	5	4	11	8	8
State/Other							

OCRA's statistics show increased services to the Latino population and the multicultural population and the same level of services as previously given

to all ethnicities except the services to the Asian population declined by 1 percent and the white population by 3 per cent.

The types of problems which OCRA handles remain fairly consistent. For the time period covered by this report, OCRA handled 2,007 special education cases, 2,496 regional center matters, and over 900 cases in income maintenance which includes SSI, California Children's Services, and In Home Support Services, among other benefits. Over 300 cases were handled in each of the following categories: alleged abuse; conservatorships; consumer finance; health issues; and housing matters.

Lastly, the statistics once again point out the discrepancy between the number of cases that arise in any one regional center. OCRA believes that the number is affected by many factors, including but not limited to, the number of consumers served by the regional center, the level of experience of the advocate and the assistant advocate, continuity of staff, the willingness of a regional center to work cooperatively with OCRA in making referrals, the availability of other advocacy resources in the catchment area, and the effectiveness of OCRA's outreach in a catchment area.

X. RECOMMENDATIONS FOR ENHANCEMENT OF SERVICES

The contract between DDS and PAI requires that on an annual basis PAI make recommendations to DDS as to methods of enhancement of the services that OCRA provides for regional center consumers. In the past, OCRA has expressed concerns about the number of consumers who request a greater level of service than OCRA is able to provide due to lack of sufficient staff. OCRA has been especially concerned that one advocate is mandated to serve the consumers of each regional center even though the number of consumers that a regional center serves may vary by thousands of people.

OCRA recognizes and is extremely appreciative of the fact that DDS has consistently supported this organization in its efforts to provide effective

statewide advocacy to all consumers. When the state budget is more stable, OCRA will renew its efforts to increase its staff in order to more adequately protect the state's most vulnerable residents. In the interim, PAI remains appreciative of the state's on-going confidence placed in OCRA's ability to provide advocacy services to people with developmental disabilities.

XI. <u>CONCLUSION</u>

OCRA's statistics show its staff's continuing commitment to the protection of the rights of people with developmental disabilities. OCRA handled over 9067 cases last year, provided 290 trainings to approximately 12,198 people, and met each of its performance objectives. OCRA remains dedicated to ensuring that the rights of all of California's citizens with developmental disabilities are enforced.

F:\DOCS\ALICE\annual report.2005.july26.doc