

## **INTRODUCTION**

This marks the fifth year of the Office of Clients' Rights Advocacy's provision of advocacy services to the consumers of California's 21 regional centers. During those 5 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.

During the 5 years, OCRA has directly served over 40,000 consumers and provided over 1,100 trainings attended by over 65,000 people. Significantly, consumer satisfaction reports continue to average above 90 percent satisfaction in almost all areas of performance surveyed. OCRA staff makes a strong effort to provide advocacy services to the consumers that it serves. That effort is reflected in the statistics given, the outcomes reported, and the spirit that abides among OCRA staff. This is summarized so well by Martha Sanchez, the mother of a young South Central Regional Center consumer, who wrote in June of this year:

This letter is written with the intention to express by gratitude for your help and guidance regarding the school district's residency/home visit practice and procedures. I felt very comfortable with your support and guidance through the process. I was particularly impressed with your ability to relate to my concern and with your quick response to my request. Also, I need to mention that the options you provided helped me to bring closure to the situation in a timely manner.

Thanks again, and I wish that your work on behalf of families like mine be blessed forever.

OCRA continues to operate 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.

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**

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, 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 six 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 8,014 issues for consumers during this time period. It is clear that OCRA resolved significantly more issues for people with developmental disabilities than required by the performance objective.

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

OCRA continued to exceed this performance objective. OCRA handled 8,014 requests for assistance during this reporting period. Of these, 87 were handled as requests for direct representation at hearing. 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 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. From the results of the annual survey, it is clear that OCRA consumers are overwhelmingly satisfied with the services provided by OCRA. With a 31 percent return rate, of those who answered the questions, 96 percent of the responders felt they were treated well by the staff, 93 percent understood the information they were provided, 95 percent believed their CRA listened to them, 88 percent believed they were helped by the CRA, and 92 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, 86 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 sole exception was Inland Regional Center's training, which had been scheduled but was continued to August 5, 2003. The chart below reflects the training schedule.

OCRA developed two 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 most recent packet has been sent to DDS and though the current contract does not require the approval of DDS, OCRA welcomes comments from DDS. Additionally, a few offices have developed their own materials which are available for review if DDS so desires.

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 checking 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.

Alta California RC	May 14, 2003
Central Valley RC	July 11, 2002
East Los Angeles RC	May 31 and June 7, 2003
Far Northern RC	May 28, 2003
Golden Gate RC	April 17, 2003
Harbor RC	June 20, 2003
Inland RC	June 17, 2003(Continued to August 5)
Kern RC	March 13, 2003
Lanternman RC/LA Area	June 20, 2003
North Bay RC	July 7, 2002
North Los Angeles County RC	October 22, 2002
Redwood Coast RC	July 1, 2002
Regional Center of East Bay	July 8, 2003
Regional Center of Orange County	July 20, 2002

San Andreas RC	Nov., 2002 and April 17, 2003
San Diego RC	May 10, 2003
San Gabriel/Pomona RC	May 30, 2003
South Central Los Angeles RC	June 24, 2003
Tri-Counties RC	August 13, 2002
Valley Mountain RC	Feb. 25, March 7, and March 18, 2003
Westside RC	May 27, 2003

**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.**

OCRA presented at 234 trainings during the past year. This was 74 more than required by this performance objective. One reason for this 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 234 trainings with a total attendance of approximately 9,802 people at the various trainings. This is significantly more than the 160 trainings required during this time period. It is obvious that OCRA presented information to a tremendous 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 serves as the Northern California Outreach Coordinator, and Patricia Carlos as the Southern California Outreach Coordinator. The three 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 completed June 30, 2003, had been in effect for six quarters. Plans developed for fiscal year 2003-2004 will be in effect for one year. Review of the statistics on OCRA's services to underrepresented groups (see Section IX of this report) show steadily increasing services to 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 all of the regional centers during the first year of the current contract. Subsequently, the Director has met with regional centers to revise existing MOUs, as needed. The MOU with Golden Gate Regional Center is now in draft form. Copies of all revised MOUs have been forwarded to DDS when they 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.**

Catherine Blakemore and Jeanne Molineaux met with Bob Baldo, the Executive Director of the Association of Regional Center Directors, on November 13, 2002. At that time, it was agreed that there were no

significant outstanding issues between OCRA and the regional center directors. 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 multi-cultural 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.

The vacancies on the committee are listed on PAI's website and in its quarterly 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 three consumer members and four family members who represent diverse geographical and ethnic backgrounds. Additionally, most of the members belong to several 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 in Los Angeles on October 12, 2002, were included as Exhibit C in OCRA's Semi-Annual report for this fiscal year. Minutes from the February 1, 2003, meeting in Sacramento and the June 21, 2003, meeting in San Diego are attached here as Exhibit F.

DDS staff is invited and encouraged to participate in any of the meetings. The remaining committee meeting for this calendar year is in Los Angeles on November 1, 2003.

#### **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 G. 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:

##### **CCS Refusal to Provide Proper Size Stroller Reversed.**

M.P. is a 2-year-old consumer for whom California Children's Services (CCS) agreed to provide a specialized stroller for positional support to assist in learning communication skills, self-care, and other essential activities. The CCS Physical Therapist ordered a stroller which was a size too large, stating the equipment would only be provided if it would have a useful life of at least three years.

The stroller was so large that no positional support was possible. When M.P.'s legal guardian demonstrated this at the next CCS clinic, the doctor stated she would have to accept the one provided and should store it until M.P. grows into it.

M.P.'s guardian contacted OCRA. After researching and determining no law exists to support CCS's position, OCRA drafted a letter for the guardian to submit to CCS requesting an appeal and, alternatively, a list of medical experts from which to choose, to obtain a second binding opinion, as required by law.

Three work days later, CCS contacted the guardian and arranged for her to return the over-sized stroller in exchange for a proper fitting stroller. Doug Harris, Associate CRA, Redwood Coast Regional Center, Lake County.

##### **Consumer Receives Significant Increase in IHSS Hours.**

A.A.'s mother contacted the CRA to obtain assistance with her IHSS hearing. IHSS had performed a re-evaluation. The consumer was 8 and had



autism. Her mother helped A.A. in every area of personal care. In addition, the consumer's mother vigilantly watched her because A.A. would open the door locks and run out of the house or play with dangerous objects. After its re-evaluation, the county awarded A.A. 13.75 hours per month. The parent believed that her daughter was entitled to more hours and appealed the IHSS decision. The mother calculated the time per task after she contacted the CRA. The CRA offered to assist her by writing a brief explaining the time per task that the parent had calculated and the reasons why the consumer needed protective supervision. The parent agreed to postpone the hearing and have the CRA write the brief. The CRA retrieved documents from IHSS and the regional center and prepared the parent for the hearing. The judge agreed to increase the hours from 13.75 to 195 per month. Bernadette Bautista, CRA, Inland Regional Center.

**Reunification Accomplished in Specialized Community Program for Mother's and Young Children.**

Y.M. is a 19-year-old who gave birth to her son in 2002. CPS removed the son at birth and requested that the regional center investigate possible placement in a specialized community program for mothers with developmental disabilities and their babies. This program is three years in duration and consists of intensive parent education and instruction.

The regional center and OCRA launched a collaborative effort to have Y.M. and her son reunited and for them to live in the group home CPS originally requested. OCRA attended many meetings, made many phone calls, did a great deal of research, and advocated in every way possible to ensure reunification.

In February, 2003, when the baby was eight months old, Y.M. and her son moved into the specialized community placement together. OCRA continues to be involved, as the final disposition will take place in April. Katy Lusson, CRA, Golden Gate Regional Center.

**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. The CRA must approve the procedure and submit a quarterly report to DDS by the last day of each January, April, July, and October. OCRA is including the reports concurrently with the contractual date to provide OCRA's semi-annual and annual report. If this is not acceptable to DDS, OCRA will submit duplicate reports as requested. Attached as Exhibit H 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 was one Title 17 complaint filed during the fiscal year which was against a facility located in the North Los Angeles County Regional Center catchment area regarding the facility's failure to provide adequate procedures in routine medical care. The complainants were satisfied with the outcome of the Title 17 investigation though the consumer ultimately moved to a different facility.

## **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 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. 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 I 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 included in all letters to consumers or others who contact OCRA, when a CRA declines to provide service requested by that person.

Nine 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 J is a chart detailing the grievances filed against OCRA.

### **IX. ANALYSIS OF CONSUMERS SERVED**

OCRA handled a total of 8,014 cases from July 1, 2002, through June 30, 2003. This represents a significant amount of advocacy assistance.

It is important to note that the statistics from OCRA's previous annual report cannot be directly compared to this report. OCRA's previous report showed the cases open during a particular quarter, so a case could show open during each of two consecutive quarters. With the new computer program, statistics are run for the entire year, so a case would show as one open case during the year even though the advocate may well have worked on the case for several quarters. This difference in reporting accounts for any apparent decline in the services provided by OCRA. In OCRA's last annual report, it was stated

that the performance objectives established in January, 2002, might not be appropriate with the statistics gathered with the new computer program. However, the performance objectives appear to continue to remain appropriate.

Included as Exhibit B is the complete compilation of data for the fiscal year. 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, 2,450, has consistently been the 3-to-17 years-old age group. The next largest is the 22-40 age group with 1,354 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. In one percent of the cases the sex was not identified by the OCRA office. This is consistent with the percentage of regional center consumers who are male versus female. As of July, 2003, 59 percent of all regional center consumers were male and 41 percent female.

Consumers residing in their parental or other family home remain by far the largest number of consumers served, with 4,692 consumers or 69 percent of those OCRA served living in their family home. The next largest group served is those living independently, with OCRA serving 774 people or 14 percent with this living arrangement. DDS statistics show that 67.66 percent of regional center consumers live in their parent's home and 9.69 percent live independently.

OCRA's statistics on the ethnicity of consumers served from July 1, 2002, through June 30, 2003, show OCRA's continuing commitment to serve

underserved communities. OCRA staff has also made concerted efforts to ensure that all statistics are accurately entered into its computer system. Previous years, OCRA had statistics for a category known as “unknown.” This year, the system was changed to indicate when callers refused to divulge their ethnicity. The percentage of consumers from various ethnicities served by OCRA was:

<b>Ethnicity</b>	<b>2002-2003 %</b>	<b>2001-2002 %</b>	<b>2000-2001 %</b>	<b>1999-2001 %</b>	<b>Regional Centers %(Current Year)</b>
Amer. Indian or Alaskan Native	1	1	1	1	.41
African American	10	9	9	8	10.59
Asian	4	3	5	4	5.23
Hispanic/Latino	27	24	24	24	27.8
Self-identified Multicultural	4	4	4	3	Not listed
Pacific Islander	1	1	1	1	2.14
White	49	47	48	56	44.98
Refused to Identify/Other (Formerly Unknown)	4	11	8	8	7.23

OCRA's statistics show improved service to Hispanic/Latino, African American, and Asian populations. There is also an increase in service to Whites. It is impossible to tell if OCRA served an increased number of each ethnicity or if its staff's effort to better record data resulted in the increases in each category.

The types of problems which OCRA handles remain fairly consistent. For the time period covered by this report, OCRA handled 1,817 Special Education cases, 1,932 Regional Center matters, and over 200 cases each in the following categories: alleged abuse; conservatorships; consumer finance; family law matters; health issues; housing matters; income maintenance which includes Social Security and In-Home Support Services;

and placement.

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.

OCRA's new data base has the capacity to collect information on the level of service provided which will offer new opportunities to compare services provided among the catchment areas. In developing the statistics for its semi-annual report, OCRA learned that there is significant discrepancy among employees as to the definition of each service category. In response to this information, OCRA immediately developed written definitions of each category and is training staff on the correct input by category. For this annual report, OCRA's statistics should be consistent among offices for the last six-month reporting period but statistics for the initial six months of the year may have some discrepancies among offices.

## **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 in spite of the fact 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. CONCLUSION**

OCRA's statistics show its staff's continuing commitment to the protection of the rights of people with developmental disabilities. OCRA handled over 8,014 cases last year, provided 234 trainings to over 9,802 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.

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