

## **I. INTRODUCTION**

Disability Rights California, California's protection and advocacy agency, provides state-wide clients' rights advocacy services for regional center consumers pursuant to a five year contract, HD069010, with the Department of Developmental Services (DDS), through its Office of Clients' Rights Advocacy (OCRA). The current contract is effective through June 30, 2011.

OCRA takes great pride in its accomplishments. The statistics and work product for the past six months, which are discussed throughout this report, give ample evidence of continuing effective advocacy. During the past six months, OCRA resolved over 5,202 issues for consumers which represent a 12 per cent increase in the number of consumers served this past six months over the same time period last year. Additionally, OCRA participated in approximately 293 trainings presented to approximately 16,278 people. Though the number of trainings is less than this time period last year, the number of persons who attended the trainings increased by approximately 5,391 or approximately 30 per cent.

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

Disability Rights California greatly appreciates the support and efforts of DDS and the regional centers in OCRA's performance of this contract. Without support from those agencies serving people with developmental disabilities, OCRA's efforts to ensure the rights of people with developmental disabilities throughout the State of California would not be so successful.

## **II. PERFORMANCE OBJECTIVES**

Disability Rights California's contract with DDS requires performance outcomes, as established in Exhibit E, Paragraph 3, of the above-referenced contract. Each of the specific required outcomes is discussed in the following Sections A through F. The contract does not set specific

numbers for performance for the outcomes. OCRA is willing to establish specific numbers in conjunction with DDS, if it so desires.

**A. Services are provided in a manner that maximizes staff and operational resources.**

OCRA continues its tradition of serving a large number of people with developmental disabilities. OCRA handled 5,202 issues for regional center consumers during the first 6 months of the fiscal year. This represents a 12 per cent increase in intakes from this same period last fiscal year.

The breath of issues in these cases is staggering. With the numerous changes in regional center and public benefits law this year, OCRA staff was successful in staying knowledgeable about the current law in an effort to help consumers and parents understand the changes. The statistics, attached as Exhibit B, are discussed below and show the wide variety of issues and the large number of cases handled by OCRA staff.

**1) Advocacy Reports.**

Each advocate provides on a quarterly basis a summary of at least one administrative hearing or other case that has unique situations from which others can learn and that can be used as examples of the advocacy that OCRA accomplishes. The summaries for Summer, 2009, and Winter, 2009, are compiled and attached as Exhibit C. 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:

**Consumer Receives Fully Favorable Decision in SSI Case.**

A.O. is a regional center consumer with some significant deficits and was denied Supplemental Social Security (SSI). A.O. filed an appeal and OCRA provided direct representation at the hearing. The issue in the case was whether or not A.O. was unable to engage in any substantial gainful activity by reason of any impairment or combination of impairments.

Evidence was admitted and testimony was taken during the hearing. After review of the record, the ALJ determined that A.O. was disabled as of August 31, 2007, the date the application for SSI was filed and that A.O.'s

disability continued through the date of the decision. The ALJ issued a fully favorable decision.

### **Twins Found Eligible for IHSS.**

A.S. and A.S are 5-year-old twin girls diagnosed with autism. After applying for IHSS, they were denied eligibility because they did not meet the SSI disability criteria. OCRA filed for an IHSS hearing on behalf of the twins. Because the twins were not SSI recipients, IHSS needed to determine if the twins qualified for IHSS based on their disability. The twins had to be evaluated by the state disability determination process. The IHSS hearings were conditionally withdrawn reserving the initial application date of September 11, 2008, pending the outcome of the state disability determination. OCRA helped the mother fill out the lengthy disability determination paperwork. After a few months, one of the twins was found eligible by the disability determination unit. Because the other twin's paperwork was sent to a different disability determination office, she still remained ineligible. However, OCRA resolved the SSI eligibility for both of the twins and then contacted IHSS. The county IHSS office reflected the changes in its system and found the second twin eligible for IHSS. Together, the twins received 86.5 hours of IHSS and retroactive payments going back to September 11, 2008.

### **P.M. Regains His Mobility.**

In 2007, P.M. had undergone a long pre-authorization process to get the expensive specialized electric wheelchair he needed funded by Medicare. As time went on, the chair was in the shop for repairs nearly as much as it was being used by P.M. The local distributor could no longer make sufficient repairs to the chair. The distributor arranged to have the chair sent back to the manufacturer in Ohio for complex repairs. The local distributor then misplaced some of the records, moved locations, and ultimately stopped even trying to get P.M. a working wheelchair.

The regional center asked OCRA to intervene. OCRA contacted the manufacturer who claimed that P.M. was a "high-end user" and therefore a new chair would not be covered. OCRA then advised the manufacturer about the "lemon laws" regarding durable medical equipment and assistive technology. The manufacturer then agreed to fit P.M. for a new chair.

### **Housing Authority Agrees to Move J.M. to Downstairs Apartment.**

J.M. was denied his request for a reasonable accommodation to move from his upstairs apartment into an accessible downstairs apartment. J.M.'s upstairs apartment was unsafe for J.M. because a lip on the threshold made it difficult for him to enter unassisted; the hallway is treated with a resin that makes it difficult for J.M. to walk; and the elevator is periodically inoperative. For over a year, the Area Housing Authority failed to respond to J.M.'s requests and physician's letters stating that J.M. needed a downstairs apartment. OCRA was contacted by J.M.'s service coordinator. OCRA agreed to represent J.M. by making a written request for a downstairs apartment as a reasonable accommodation. The housing authority agreed to place J.M. on the waiting list for an accessible downstairs apartment.

### **Student Maintains Appropriate Placement.**

K.U. has always been integrated into general education classes. At the start of her junior year of high school, the district wanted to place her in a special day class (SDC) at a different school. K.U. wanted to remain in her current placement. The district filed for due process to require K.U. to change schools.

OCRA provided direct representation at a 4-day due process hearing and prevailed on all issues.

## **2) Analysis of Consumers Served.**

OCRA handled a total of 5,202 cases from July 1 through December 31, 2009. This represents a significant provision of advocacy service and an increase of 12 per cent from this period last year. The complete six-month compilation of data 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. Type of Problem (Problem Codes)

The majority of the OCRA statistics remain consistent with OCRA's previous statistics. For example, the largest number of consumers served by age, 1,616 during this time period, has consistently been the 4-to-17 years-old age group. The next largest is the 23-40 age group with 749 people served. The ratio of males to females served also remains consistent. For those cases where gender is recorded, OCRA has traditionally served more males than females, with 64 percent of the consumers served being male and 36 percent being female. This roughly corresponds to the percentage of regional center consumers who are female versus male. As of December 31, 2007, the most current date for which data is available from DDS, 61.30 percent of all regional center consumers were male and 38.70 percent were female.

The percentage of consumers residing in the parental or other family home remains by far the largest number of consumers served with 3,933 consumers in the family home or 76 percent of the cases handled. The next largest group served is those living independently, with OCRA serving 543 people or 10 percent with this living arrangement. The statistics on the percentages has changed from this time period last year when the percentages were 70 and 13 percent, respectively.

OCRA's statistics on the ethnicity of consumers served from July 1, 2008, through December 31, 2008, show OCRA's continuing commitment to serve underserved communities.

The percentage of consumers from various ethnicities served by OCRA is:

Ethnicity	% OCRA Clients 7/1/08 - 12/31/08	% OCRA Clients 7/1/09 - 12/31/09	% RC Clients Dec. 2007
African-American	10	9	10.35
Latino	33	35	31.92
American-Indian or Alaskan Indian	1	1	.41
Asian	4	4	5.90
Pacific Islander	2	1	2.46
White	45	45	41.74
Multicultural (Self-Identify)	4	4	Not listed

Refused to State/Other	3	4	7.21
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OCRA's statistics show that OCRA's service to various ethnic groups is close to parity or above the number of consumers of each ethnicity served by the regional center.

The types of problems which the offices handle changed during the period of this report, which would be expected given the significant changes in regional center law that occurred during the time period. OCRA handled, during the six-month period, 2,216 regional center matters, which is 46 per cent of the cases handled for this time period versus the same time period last year, which was 1,327 regional center matters or 29 per cent of the issues handled. Generally, these matters were handled as short-term advice to consumers and families about the changes and consumers' rights. This year, the offices handled 877 education matters versus last year for the six-month period, 1,054 special education cases. OCRA also handled this year approximately 797 cases dealing with income maintenance, which includes Social Security and In-Home Support Services versus 635 last year this time period, and over 100 cases each in conservatorship, health, housing, and personal autonomy. For the first time, OCRA handled fewer than 100 cases in the areas of abuse, family law, and consumer finance. Taken together, the problem codes show a pattern of change in response to changes in law, but also continue to relay the broad areas of law with which OCRA staff need to be familiar.

### **3) Outreach/Trainings.**

OCRA recognizes that outreach and training are an essential part of providing effective advocacy for regional center consumers and also recognizes that trainings are one of the best ways to maximize staff and operational resources. Therefore, OCRA offers training on a wide variety of issues to a large variety of participants, including consumers, parents, regional center staff, vendors, and other interested people. Topics covered include, but are not limited to, consumers' rights, abuse and neglect issues, special education, voting rights, Medi-Cal and Medicare issues, and conservatorships, among other topics.

During the past six months, OCRA presented at 293 trainings with a total attendance of approximately 16,278 people at the various trainings. This is an outstanding performance by OCRA staff and represents a decrease in

the total number of trainings but an increase in the number of people attending by 30 per cent.

OCRA understands the need to provide assistance to individuals from traditionally underserved communities. To further the goal of meeting this need, OCRA has each office target at least three outreaches per year to a specific group of persons who are underrepresented in the office catchment area. To help with this, OCRA appointed a statewide outreach coordinator, Anastasia Bacigalupo. The coordinator advises staff in implementation of their target outreach plans. Based upon an evaluation of the original outreach plans' results, and using new census data and updated figures from DDS regarding the ethnicity of consumers served by each regional center, the OCRA offices update their target outreach plans on an annual or bi-annual basis. A detailed report on target outreach and training is included as Exhibit D.

**B. Issues and complaints are resolved expeditiously and at the lowest level of appropriate intervention.**

From July 1, 2009, through December 31, 2009, OCRA resolved 5,202 issues for consumers. Of those served, all but 108 were resolved informally. This means that 98 percent of all the matters that OCRA handled were resolved informally. Only 75 cases involved direct representation at hearing. Data showing this is attached as Exhibit E.

**C. Collaborative and harmonious working relationships are fostered.**

If at all possible, OCRA staff attempts to foster collaborative and harmonious working relationships with the consumers and parents who OCRA serve, regional center staff, stakeholders, and members of the general community. This philosophy is not only incorporated into Disability Rights California's contract with DDS, but also represents an internalized recognition that some of the most effective advocacy takes place at the level of interpersonal relationships and informal advocacy. The success of this philosophy is demonstrated by the number of calls we receive, by OCRA's many successes, and by its recognition as an excellent resource for people with developmental disabilities. Specific examples of collaboration, in addition to those discussed in sections above, are discussed below.

## **1) Memorandums of Understanding.**

OCRA has established Memorandums of Understanding (MOUs) with each regional center that addresses that center's individual needs, concerns, and method of operation. MOUs are updated as needed. As part of the implementation of the current contract, the director of OCRA met with each of the regional center directors or designees to revise the existing MOUs. Copies of all MOUs have been forwarded to DDS. The status of each revised MOU is discussed in Exhibit F. All of the MOUs have been completed except one, which has been drafted and needs to be signed by the regional center executive director.

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

## **2) Meeting with Association of Regional Center Agencies (ARCA).**

Catherine Blakemore, Executive Director, Disability Rights California, Jeanne Molineaux, Director, OCRA, and Bob Baldo, Executive Director of the Association of Regional Center Directors, met on December 15, 2009. At that time, several outstanding issues were resolved and further meetings will be planned as needed.

### **D. Consumers and families are satisfied with the services provided.**

Disability Rights California recognizes that consumer satisfaction is a primary goal for the people whom it serves. OCRA is committed to reaching consumers and parents in a manner and with results that ensure consumer and family satisfaction with the services provided.

#### **1) Consumer Satisfaction Survey.**

OCRA measures consumer satisfaction by use of an instrument developed jointly by staff, the Consumer Advisory Committee, and DDS. From the results of the most recent survey, it is clear that OCRA consumers remain extremely satisfied with the services provided by OCRA.



Seven hundred and twenty-one surveys were mailed out. Eighty-three people returned the survey. Of those responding to the questions, 93 percent of the responders felt they were treated well by the staff, 93 percent understood the information they were provided, 94 percent believed their CRA listened to them, 87 percent believed they were helped by the CRA, and 89 percent would ask for help from OCRA again. See Exhibit G which discusses the results of OCRA's survey. These are excellent survey results, for which OCRA is justly proud.

## **2) Letters of Appreciation.**

OCRA staff receives many letters of appreciation from consumers and others. Below are quotes from a few of the letters<sup>1</sup>:

“Respectuosamente doy mis saludos a la a la agencia OCRA y Principal mente a las abogados Margaret Opiel y Kendra McWright y gracias portodos sus servicios.” (“I would like to respectfully greet the OCRA agency and especially the advocates Margaret Opiel and Kendra McWright and thank you for all your services.”)

“Thank you very much for the wonderful job you did in helping ... get out of her credit card problem. After over 2 months of no calls or letters from B & A, we can finally put this incident behind us. You're very good at what you do, And we appreciate your professionalism.”

“Thank you so much for all of your assistance. With your help...we were able to successfully advocate for our son with the Regional Center and ultimately attain the services that he needs as a person with autism. We are extremely grateful for your support, understanding, and expertise. We absolutely would not have been able to make progress in ... case without this assistance. We're extremely fortunate to have had your input.”

“Thank you from the bottom of my heart. Without your help, I don't know what we would do without your help we would be in jam with Social Security. Thank you for helping us with the court case. Thank you.”

“Thank you so much for the continued support and guidance and for keeping in touch...”

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<sup>1</sup> Quotations are repeated as stated in the letters, except for the deletion of names.

“Our family cannot thank you enough for the dedication, commitment and support that your office has offered our family. I feel very blessed that we were able to connect and throughout our process for assisting our daughters ... and ..., your office cared from the bottom of your hearts. It's rare to find people today that genuinely care and provide undivided and unconditional attention in doing the right thing. Our family is eternally grateful for the undying support and believing in us. Thank you immensely.”

“I think you did an amazing job yesterday.”

“Thank you for assisting in making the August 27<sup>th</sup> Community event a successful. Having a Spanish translator available added to the sharing of the important Early Start mediation and due process. Your collaboration is greatly appreciated.”

“...I wanted to sincerely, thank you on behalf of our family for your support and guidance. You are an inspiration and a pleasure to have involved in our lives. I'm confident that some \_\_\_ will be able to thank you for all that you do for us, but more importantly for him. \_\_\_'s future will be in a much better place due to your involvement in navigating us through what can be very overwhelming hurdles in our lives.”

“Thank you for making a difference for our children with special needs!”

“I want to Thank You for presenting your information...on September 21.... The responses I received from the parents that attended were very positive. They all want to know when you will return. Hopefully we can set another date at the 1<sup>st</sup> of the year. I look forward to continuing our collaboration as we try to navigate these trying economic times.”

“On behalf of the staff and Training Department....THANK YOU (again) for sharing your times and expertise on IHSS. Staff feedback was “outstanding” and “timely”!!!”

“I wanted to thank you for sharing yesterday at ..... As always you were insightful and on point. Your passion really comes through!

“I cannot express all of my appreciation for all that you have helped us out with, the time you have put into ... case, and for being so available. Thank you so much.”

“Thank you for your support and participation in the development of \_\_\_\_’s Early Start Transition Video. Your contribution to the development of this video will help families make the transition out of the California Early Start program into school-based and community services. We truly appreciate your time and commitment in this special project.”

“Thank you for your help and the speed with which you jumped into this fray. You had the least of all the stakes in this issue and yet you and your organization get the credit for making things happen.”

“Always remembering your efforts contributed to a successful outcome. My child obtained an NPS placement and recovering. Thank you and God Bless You.”

“Thank you for the extraordinary and thoughtful work you do year after year for the special needs families.”

“I wanted to just say how much everyone enjoyed your wonderful presentation on the 13<sup>th</sup>. I always look forward to outside trainings and information to help keep our employees up-to-date and aware of services which exist for those we support. Your presentation was very informative and contained valuable and useful information. I am certain I speak for everyone in attendance in saying it was clear and well presented. Your agency provides a valuable and necessary service to individuals. You are welcomed back anytime. Thank you again for taking the time out of your busy schedule to come to \_\_\_\_ and share your services with us.”

“We can’t tell you how much it means to us that you have expended the effort you did for\_\_\_\_ who, until just a few short weeks ago was a total stranger to you. It becomes apparent that what you have chosen to do with your life at this moment is the best choice you could make.”

### **3) Cases will be handled in a timely manner.**

It is important that advocacy services be provided in a timely manner. Consumers and families are frequently in emergency situations, in danger of losing their placement in the least restrictive environment, losing their source of income, unable to get their medical needs met and a myriad of other dangerous or difficult situations. For this reason, OCRA has, since its establishment, had a policy that all calls will be returned as soon as possible, but not later than closing of the next business day. OCRA

measures its performance in this area by use of its consumer satisfaction survey, see Exhibit G, discussed more fully above. OCRA statistics show that 89 percent of all callers to OCRA received a call back within two days during the first half of this fiscal year, which is particularly impressive given the 12 per cent increase in office volume. This level of performance provides verification that cases are resolved in a timely manner. OCRA will continue to train on this requirement to ensure that it provides exceptional services for all callers.

**E. The provision of clients' rights advocacy services is 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 works through the OCRA Advisory Committee to ensure that this performance outcome is achieved. The OCRA Advisory Committee, which is a standing committee of Disability Rights California's Board of Directors, meets twice a year at various locations throughout the state. Attached as Exhibit H is a list of the members of the Board OCRA Advisory Committee effective December 31, 2009.

Public members of the Advisory Committee are appointed by Disability Rights California's Board of Directors. In the selection process, the Board considers 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 Board 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. Minutes for the meeting held on September 11, 2009, are attached as Exhibit H.

DDS staff is invited and encouraged to participate in any of the meetings set for 2010. They are:

March 5, 2010	Sacramento
September 24, 2010	Bay Area

**F. Self-advocacy training is provided for consumers and families at least twice in each fiscal year.**

Welfare and Institutions Code, Section 4433 (d)(5), requires that the contractor providing advocacy services for consumers of regional center services provide at least two self-advocacy trainings for consumers and family members. Disability Rights California's contract with DDS mirrors this language. OCRA has been proactive in this matter and requires each of its offices to provide at least one self-advocacy training for consumers a year. Many offices provide more than one training.

To date, OCRA has developed five separate packets of information for OCRA staff to use in the mandated trainings. Samples of the packets were previously provided to DDS and are contained in OCRA's Annual Report provided to DDS on September 1, 2007. In December, 2008, DDS sponsored a training on consumer emergency preparedness for OCRA staff. Staff uses the materials from this training as an additional self-advocacy training. Additionally, as one of the stipulations in the *Capital People First* law suit, DDS developed materials for OCRA staff to use in a consumers' rights self-advocacy training. Self-Advocacy Trainings held to date this year are listed in Exhibit I.

**III. 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, punitively 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 last six months, the log for which is attached as Exhibit J.

**IV. 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 of each January, April, July, and October. OCRA is including the reports concurrently with the contractual date to provide OCRA's semi-annual report. If this is not acceptable to DDS, OCRA will submit duplicate reports as requested. Attached as Exhibit K is the current log of Denials of Rights from the OCRA Offices.

## **V. CONSUMER GRIEVANCES**

Exhibit A, Paragraph 12, of the contract between DDS and Disability Rights California 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 an office declines to provide the requested service to that person.

Six grievances were filed by consumers or their families against OCRA during the last two quarters. Findings by Disability Rights California and DDS upheld the actions of OCRA. Information concerning the grievances has previously been submitted to DDS. Attached as Exhibit L is a chart detailing the grievances filed against OCRA during this time period.

## **VI. CONCLUSION**

OCRA's statistics show its staff's continuing commitment to the protection of the rights of people with developmental disabilities. OCRA handled over 5,202 cases the last six months, a 12 percent increase in cases from this period last year. Additionally, OCRA provided 347 trainings to over 10,887 people, an increase of 30 percent in the number of people who attended OCRA trainings. OCRA continued to meet each of its performance objectives. OCRA remains dedicated to ensuring that the rights of all of California's citizens with developmental disabilities are enforced.