Department of Developmental Services

Purchase of Services Study II

Determination of Service Variation Across Regional Centers:

Implications for Clients and Policy

A Report to the Legislature

Report 2

The Co-Principal Investigators for this study were Jan Blacher, Ph.D., University of California, Riverside (jan.blacher@ucr.edu) and Keith Widaman, Ph.D., University of California, Davis (kfwidaman@ucd.edu). The investigators are grateful to DDS and to ARCA, and their representatives, for providing the opportunity and resources to conduct this study.

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POS II. Report #2

Executive Summary

Introduction

This is the second report of findings from the study, *"Determination of Service Variation Across Regional Centers: Implications for Clients and Policy,"* also known as POS II. By way of review, this study had one main goal and three objectives. The overall goal was **to understand further the variability in purchase of services per capita expenditures across Regional Centers**. The first objective, *to examine existing analyses of statewide data, and to conduct further analyses, in order to identify linkages between that work and our proposed workscope,* was addressed in Report #1. In that report, we provided results of statistical modeling of the variation in per capita purchase of services for persons with mental retardation and developmental disabilities served by the 21 regional centers across California.

Here, we address the second and third objectives of the POS II study. The second objective was *to address the issue of variability in purchase of services by obtaining new data, using a combination of survey and focus group methodologies.* Toward that end, we developed a survey measure that focused on Family Needs, Services, and Satisfaction (FNSS), which was administered to over 4,000 regional center parents/consumers and staff, including a sub sample of Latina and European American mothers for whom additional information was available. We also developed a focus group protocol and conducted 16 focus groups at eight regional centers, in order to obtain qualitative information on service needs and supports provided to regional center families/consumers.

The third objective was *to identify key variables that may affect variation in service utilization*. This involved the secondary analyses of existing longitudinal data gathered from the subsample in order to provide information about the relationship between service use and client variables (e.g., age, ethnicity, household income, adaptive behavior). Specifically, we planned to relate family service needs and satisfaction to family demographics and maternal well-being.

Statewide Survey

To review, the purpose of this survey was to learn, directly from consumer families (either the consumers themselves, their parents or their representatives) what services they need, what they were currently receiving, and whether or not they were satisfied with those services. All items on the survey itself (contained in the Appendix) are offerings at regional centers. By surveying individuals directly, we were able to get information above-and-beyond what was available on the statewide database, and as described in POS II, Report #1.

We also obtained survey data from each respondent's service coordinator. The purpose of administering a version of the survey to service coordinators at all participating regional centers

was to compare the service coordinator perception of a given family's needs, services received, and level of satisfaction with consumer perceptions.

Survey instruments were developed for the purpose of this study, and previewed by a group of Stakeholders invited by DDS for this purpose, as well as by colleagues in the field. [See Appendix for copies of measures.] Parent/guardian recipients of the survey were selected randomly from 19 regional centers; two regional centers were involved in pilot testing the survey so they were not included again in the final sample. We received 1,118 parent/guardian surveys, and 2,866 service coordinator surveys; obviously, many parents/guardians did not follow through with completed surveys.

The survey instrument is called the Family Needs and Support Survey (FNSS). There are three main sections: Information, Support, and Resources. Respondents indicate: (1) whether they need this type of service, and (2) if they are receiving it, how satisfied they are.

Details of the survey procedure are contained in the body of this Report #2. Here, we summarize some of the key survey findings:

Receipt of Services

- In general, service coordinators and parents/guardians agreed with regard to the general levels of *information* received across the 10 categories of content asked about. That is, service coordinators and parents/guardians agreed that (a) the vast majority of consumers and their families or caregivers received information about Regional Center services; (b) clear majorities received information about the consumer's disability and about recreational services; (c) about half of the families or caregivers received information about the consumer's disability, behavior, social development, recreational services, and learning; and (d) that relatively few received information about the consumer's sexual development or about residential services.

- With regard to the types of *supports* received, parents/guardians reported that: (a) many parents/guardians had regular meetings with a service coordinator; (b) a moderate percent received support for behavior management and financial matters; and (c) relatively fewer received support related to handling stress or support from other with similar consumers. In the broadest strokes, these results were similar to those reported by service coordinators. The only major departure was that service coordinators reported families receiving more support for handling stress and less for behavior management.

- With regard to the types of *resources* received, parents/guardians reported somewhat higher rates than service providers of receiving resources in categories that were rarely received, but somewhat lower rates in the most common categories. However, the overall pattern of receipt of resources was quite similar across service coordinators and parents/guardians. For example, the four most common forms of resources received, as reported by both types of respondents, were: (a) access to Medi-Cal; (b) access to SSI or other federal relief programs; (c) medical services; and (d) transportation.

- Across all three categories (receipt of information, support, and resources), service coordinators and parents/guardians tended to show modest levels of agreement with regard to specific consumer families who were, or were not, receiving services. There was only modest level of agreement on a case-by-case receipt of services, which was surprising, given the rather high levels of agreement between service coordinators and parents/guardians on the general levels of service received across categories of service. That is, service coordinators and parents/ guardians agreed rather well with regard to which services were received by many consumers and which were received by few consumers. But, despite these high levels of agreement on general receipt of services by category of services, service coordinators and parents/guardians did not exhibit notable agreement on which consumers are receiving which services.

Satisfaction with Services

- With regard to satisfaction with *information,* parents/guardians tended to report smaller, but significantly lower levels of satisfaction with information received regarding: (a) consumer's social development; (b) recreational services; (c) vocational services; (d) residential placement; and (e) regional center services.

- With regard to satisfaction with *support* received, parents/guardians again reported smaller, but significantly lower satisfaction with support provided to: (a) handling stress, (b) support from others who have children with similar disabilities; (c) financial assistance for obtaining services or equipment. As with information, these differences represented fairly small effect sizes.

- With regard to satisfaction with *resources* received, there were no significant differences in mean ratings between parents/guardians and service coordinators.

- Finally, with regard to parent/guardian and service coordinator agreement on a case by case basis, there were quite high levels of agreement in satisfaction ratings within one scale point.

Predictors of Total Scores:
Services Received, Services Needed, Satisfaction with Services

- We determined how five consumer variables predicted total scale scores in the areas of *services received*, *services needed* (or *unmet service needs*) and *satisfaction with services*. The demographic variables considered were also considered in POS II Report #1, and included: consumer age, level of mental retardation, ethnicity, gender, and regional center. Here we also included respondent, as we considered both parent/guardian and service coordinator survey responses.

- With regard to *age group*, receipt of information and resources varied positively with age, i.e., more services were received as consumer age increased. However, the need for additional services in all categories varied inversely with age, i.e., parents/guardians of younger consumers wanted more information.

- Not surprisingly, *level of mental retardation* had an effect on receipt of services, with consumers having more severe mental retardation receiving higher levels of resources than consumers with milder levels of mental retardation.

- There were few significant relationships of *gender* with receipt of services.

- With regard to *ethnicity*, however, there were some interesting findings: (a) African American consumers received somewhat fewer resources than did European American consumers, but consumers from the remaining identified minority ethnic groups (Asian American and Hispanic) received about the same number of services as European American consumers; (b) relative to the remaining groups, Asian American consumers had lower levels of satisfaction with support, and Hispanic consumers somewhat higher levels of satisfaction with support; (c) consumers from all identified minority groups (African American, Asian American, and Hispanic) had higher reported levels of need for additional resources than did European American consumers.

- Finally, with regard to *respondent*, service coordinators uniformly reported higher levels of two services received – support and resources – than did parents/guardians, and service coordinators reported substantially lower needs for additional services in all three categories – information, support, and resources. The consistency of the effects and their direction should be a cause for concern. At present, we cannot determine whether service coordinators or parents/guardians were more accurate in their estimates of number of services received. Moreover, service coordinators and parents/guardians appear to differ in important ways on perceived need for additional services, with parents/guardians perceiving much higher needs for additional services.

Are these findings consistent with those from Report #1?

It is important to remember that analyses of the statewide data and of these newly gathered surveys vary widely in scope and purpose. The former (Report #1) was an attempt to see if there was any systematic bias in service delivery variables or purchase of services; overall, we were unable to detect such systematic effects, of sufficient magnitude, either at one time, or across the five years. The survey analyses presented here, in Report #2, represent "real" data (meaning they reflect responses given from actual individuals rather than numbers entered onto a computer database) from a much smaller, though more random, sampling pool (roughly 1000 vs. over 100,000). Furthermore, survey data are not causative, that is, they cannot tell us *why*, just *what is*. We feel confident in stating that, overall, consumer families are satisfied with services received, but they indicated more areas of service need than service coordinators did. And while all minority groups (African-American, Asian-American, Hispanic) indicated more need for additional resources, Hispanics reported comparable services and higher satisfaction with support services relative to other ethnic groups.

Survey Data from Subsample

This section of the POS II project involved a "mini-study" within the larger study. We had available to us a rather unique intact sample of Hispanic families who had sons or daughters with developmental disabilities. These families had already been involved as subjects in the University of California- Riverside, Families Project. They participated in home interviews, and completed a variety of measures pertaining to aspects of their own functioning. Thus, we had measures of family well-being not available for the larger sample. What we hoped to gain from the inclusion of this sample is further understanding of how family needs, services received, and satisfaction with services relate to one another, and how these domains relate to young adult age, ethnicity, family socioeconomic status, family well-being, and family decisions about out-of-home placement.

It is important to note some unique aspects of this sample relative to the larger one, and why we elected to conduct these additional analyses. First, the sub sample allowed us to gather survey data from close to 100 Spanish-speaking families; we couldn't be sure that the random selection used in the larger survey study would result in this many Spanish-speaking families (even though the survey was available in Spanish.) Second, these families completed the survey instrument during an in-person interview in their own home, thus allowing the interviewers to clarify questions or concerns, and to note any useful comments. Too, the respondents had worked with the researchers at UCR for a number of years, and a bond of trust and understanding had been established, allowing these mothers to be quite candid. Third, the "children" of these families were all young adults, between the ages of 18 and 28. Thus, this sample was more homogeneous and more narrow in scope on some of the key variables examined in POS II Report #1 (e.g., regional center, age of consumer, ethnicity, level of mental retardation). However, this homogeneity should make findings more readily interpretable and easy to generalize to this particular group. The sub sample contained 95 Hispanic families and 40 European American families.

Summary of findings:

- Overall, looking at the total sample of 135 families, the average family reported a total of 18.6 needs, and received services that met 43.2% of these needs, or a mean of 8.0 services. Their expressed satisfaction with these services received was high, with a mean satisfaction score of 4.60 on a scale of 1 to 6 (where 4=somewhat satisfied and 5=satisfied).

- Looking by sample, however, Hispanics expressed significantly greater needs than European Americans for information and resources, though not support.

- Hispanics received significantly fewer services than European Americans in areas of support and resources, though not information.

- The two samples were identical on a mean satisfaction score (Hispanic = 4.60; European American = 4.60.) This finding is of interest, given that the two samples differed quite significantly on the number of perceived service needs and services received.

- Among the scales of the FNSS within this sample, parents who received more services were more satisfied, and expressed needs did not relate to the number of services received.

- Unmet needs were twice as high for Hispanics (61%) as for European Americans (31%); this is a highly significant difference.

- Hispanic mothers who expressed more total service needs were less acculturated, had sons or daughters with more severe behavior problems, were of lower education/income. These mothers expressing greater needs were experiencing more parenting stress and more depressive symptoms.

- On average, about half of the expressed needs within each sample were not being addressed. Regional Center services were most responsive to the most commonly expressed needs, however.

- Overall, Hispanic families expressed significantly greater needs than European American families, and they also received significantly fewer services. The percentage of unmet service needs was twice as high for Hispanic families.

In summary, the respondents to the FNSS expressed a high number of needs they would like regional centers to meet. They were satisfied with the services they were receiving, but only about half of their expressed needs were being met. Hispanic families expressed significantly greater needs than European American families, and also received significantly fewer services. Thus, the percentage of unmet service needs was twice as high for Hispanic families in this sub-sample. Two of highest support needs identified by Hispanic mothers were regular meetings with regional center service coordinators, and help for purchasing services such as speech therapy for the young adult. The Hispanic and European American samples differed on a number of demographic and well-being variables that related to unmet service needs; however, when these were controlled in statistical analyses, Hispanic status still accounted for significant variance in unmet service needs.

There are implications for the regional center system from these findings. First, it is clear that the Hispanic families in this sample desired more interaction with their service coordinators. Obviously, these meetings should involve staff who are sensitive to the cultural context and who themselves are bilingual. That, in itself, may resolve several other areas of unmet needs because parents are likely to feel more comfortable requesting specific services, or participating in the prioritizing of existing services. Even in lean fiscal times, having some direct input and involvement in setting priorities can be empowering.

Second, it is important to note that most of the sons and daughters of these mothers were going through "transition," the process of leaving public high school, a stressful time for parents. This volatile period can elicit new worries for families and challenges for their young adult consumers, such as finding work or day programs in the community, developing new friends or socialization opportunities. This may have

caused respondents to perceive more "unmet needs," and to less often want "what's on the menu" of services provided by regional centers.

Focus Groups

We supplemented the quantitative findings from the FNSS with qualitative results from our focus groups. While quantitative results are often deemed the most trustworthy outcomes of scientific research studies, they are limited by the structure of the instruments on which the data were gathered. Thus, the more open-ended consumer-driven qualitative portion of our study design should help us determine what service needs or delivery issues are paramount for this smaller sample of consumer families, as reported by parents/consumers and service coordinators.

We selected eight regional centers to participate in the focus groups, four from relatively low per capita expenditure centers (Inland; San Diego; Central Valley; East Los Angeles), and four from high per capita expenditure centers (Redwood Coast; Golden Gate; San Andreas; Kern). There were 16 focus groups conducted, 8 for parents or consumers and 8 for staff. In all, a total of 61parents/consumers participated; of these, 5 were consumers and 4 spoke only Spanish. A total of 69 regional center (RC) staff participated.

The majority of the focus group questions addressed, and thus included in this report, pertained specifically to aspects of service delivery, such as service availability and service accessibility. Detailed reports of focus group comments are contained in this Report #2, with a brief summary here.

- *With regard to equity in service delivery*, there was an impressive level of consistency, across staff and parents/consumers, in terms of how families found out about regional center services, regardless of ethnicity or location or regional center. Typical sources were physicians, teachers, Early Start programs at regional centers, and the "grapevine" of friends and neighbors.

- However, the perceptions of both parents/consumers and staff is that services are not the same everywhere and for everyone. For parents, this often meant that the "squeaky wheel" gets the attention and the services.

- Parents also noted that having a "good caseworker" (i.e., service coordinator) made all the difference. Staff, on the other hand, expressed frustration that they did not always have the resources at hand to distribute out as they saw fit. There was consistent mention of differential access to services, with urban areas perceived as having greater access than rural ones. One staff participant mentioned that at times the service coordinator has to be "creative" (in terms of cost categories) in order to serve a given family.

- *With regard to cultural differences*, there was some evidence that cultural differences do affect access to services. However, cultural differences were likely correlated with education, income and general knowledge about the service system. In general, staff felt that families with more education and income were more likely to get services.

- There was a general feeling that Hispanic families, in particular, were reluctant to ask for services, in part because they were easily intimidated by language barriers, and in part because they perceived a stigmatizing aspect to making such requests.

- Language barriers likely had an alienating effect. Some staff expressed the need for true translators who could really talk to families and address these issues, rather than ones that can "only translate words." This lack of language knowledge may be related to the expressed frustration that service coordinators may not have had the cultural sensitivity to know what was really going on in the families.

- There may be some service provider bias in the belief that Hispanic families wish to "take care of their own" and that they don't want services. Even though families, too, mentioned the desire to have family or extended family care for their son or daughter, they still expressed the need for more services. One mother pointedly wished that the service coordinator would recognize her [the mother's] fatigue and stress.

- *With regard to concerns about service accessibility,* parents/consumers and staff generally felt that services were provided on the basis of need whenever possible.

- Staff members at times felt hindered by a lack of services, such as transportation, which forced them to provide services on the basis of availability rather than need.

- Physical accessibility was a looming factor in accessing services, whereby consumers in more rural areas might wait longer, have fewer provider choices and have more difficulty finding specialized services.

- Overall, transportation needs, in particular, were recognized as key to service access by both parents/consumers and staff.

- Some staff highlighted the problem of having to fight with school districts to assure that their consumers have access to and receive appropriate services.

- Both parent and service coordinator focus group members mentioned that parents of higher income and educational background seemed to get more and better services. Of concern was the parental fear that their children would be better off if only they had more money, expressed by one by the statement: "…autism is a rich man's disease."

- For the most part, though, both the staff and parents/consumers felt that services were provided on the basis of need whenever possible, and opinions expressed indicated that participants found the process of service delivery to be equitable.

Summary

Overall, the participants in the focus groups expressed a number of concerns that reflected some of the issues addressed in POS Report #1 regarding ethnicity, consumer characteristics, and regional center. However, most sentiments were expressed by only a handful of participants and

cannot be interpreted as widely representative. The affect expressed during the groups was generally upbeat -- neutral to positive; negative comments were relatively rare. For the most part, both the staff and parents/consumers felt that services were provided on the basis of need whenever possible, and opinions expressed indicated that participants found the process of service delivery to be equitable.

However, the constant reference to services unique to autism spectrum disorder (which was not a focus of this particular study) indicates how concerned consumer families and service coordinators were about the fiscal implications of meeting this particular need. Indeed, parents of children with other types of disorders were not as confident that their (and their consumers') needs would be adequately met.

Finally, there are implications for Spanish-speaking families and for some Asian, non-English-speaking families as well. As in the survey findings from the Hispanic subsample, these concerns might readily be dealt with by increasing the use of bilingual service coordinators who spend additional time assessing family needs and prioritizing their concerns.

The final integration and synthesis of these survey and focus group findings can found in the Final Report for POS II.

A. Survey Data: Statewide

Introduction

This is the second report of findings from the study, *"Determination of Service Variation Across Regional Centers: Implications for Clients and Policy,"* also known as POS II. By way of review, this study had one main goal and three objectives, reviewed here. The overall goal was to **further understand the variability in purchase of services per capita expenditures across Regional Centers**. The first objective, *to examine existing analyses of statewide data, and to conduct further analyses, in order to identify linkages between that work and our proposed workscope,* was addressed in Report #1. In that report, we provided results of statistical modeling of the variation in per capita purchase of services for persons with mental retardation and developmental disabilities served by the 21 regional centers across California.

Here, we address the second and third objectives of the POS II study. The second objective was to *address the issue of variability in purchase of services by obtaining new data, using a combination of survey and focus group methodologies.* Toward that end, we developed a survey measure that focused on Family Needs, Services, and Satisfaction (FNSS), which was administered to regional center parents/consumers and staff, as well as to a subsample of Latina and Anglo mothers. [Details provided below.] We also developed a focus group protocol and conducted 16 focus groups at eight regional centers, in order to obtain qualitative information on service needs and supports provided to regional center families/consumers.

The third object was *to identify key variables that may affect variation in service utilization*. This involved the secondary analyses of existing longitudinal data gathered from Regional Center families in order to provide information about the relationship between service use and client variables (e.g., age, ethnicity, household income, adaptive behavior). Specifically, we planned to relate family service needs and satisfaction to family demographics and maternal well-being.

Rationale and Background for the Survey Analyses

In order to provide a context for understanding the data gathered as part of the POS II project, we have included a review of literature, that is contained in full in Appendix A. Clearly, researchers have been interested in the relationship between service delivery and caregiver well-being for some time. Most of the studies that appeared in the literature have been conducted with small samples (unlike this POS II study with over 1,000 parents/consumers as respondents) and typically with less diverse populations. We included studies containing non-English speaking populations whenever possible.

The following contains a summary of the review, as it pertains directly to the rationale for this portion of the POS II study. Appendix A contains the full text of the review, including references to the sources consulted.

Do the supports that consumer families receive from regional centers matter?

The answer to this question is likely yes, particularly when one considers the types of challenges, concerns, and needs expressed by parents of children with intellectual disabilities in the past. ***First,*** parents of children with physical or intellectual disabilities have reported worse

physical and mental health than parents of nondisabled children, including more general fatigue from caregiving. Feelings of being overwhelmed, depressed, and financially distressed (more so than "typical families") are not uncommon. ***Second***, parents have also reported experiencing interpersonal distress ranging from social isolation to generalized family stress. Relative to parents of typically developing children, research suggests that parents of children with developmental disabilities experienced frequent disruptions in family routines and more marital adjustment problems. ***Third***, mothers of children with developmental disabilities may experience a variety of role adjustments including lower expectations from careers, and a feeling that they lack freedom.

Parents of children of children and young adults with intellectual disabilities have also reported that the three most anxiety-provoking areas of caregiving involved surveillance, long-term support, and behavior. They worry about their children's abilities to function independently in the future and express concerns about the need for ongoing care throughout adulthood. In addition to concerns about their children's futures, many parents struggle with their children's ongoing psychiatric and/or behavioral challenges. According to Hoare, Harris, Jackson, and Kerley (1998), 38% of children with severe disabilities have significant psychiatric morbidity. In a sample of children with intellectual disabilities, 75% of the caregivers reported problem behaviors, and more than one third reported at least three areas of difficulty (Grant and McGrath, 1990). Among families who have children with developmental disabilities, challenging behavior is a common predictor of parenting stress and/or burden, and is a better predictor than the type of disorder or cognitive level (Baker et al., 2003; Floyd & Gallagher, 1997).

Regional center services address many of the needs noted above (e.g., respite, behavioral intervention, adult services) and items to reflect these areas of need have been included on our survey.

Do regional center consumer families have specific support needs?

Again, the answer is, "yes." The fairly extensive body of literature on this topic indicates the importance of both formal and informal supports. Formal supports include, most notably, respite care. The need for respite care is common among caregivers of children with intellectual disabilities. Parents request respite care for a variety of reasons, including increasing community integration, developing their children's interests, and preparing their children for other living environments. However, the most common reason is providing the caregivers with a break.

Interestingly, some studies indicate large discrepancies between actually wanting respite care – or a break – and actually utilization of respite care. The top three reasons for **non-use** of respite care by parents were 1) they did not end up needing it, 2) they used family members instead, and 3) they were not able to obtain providers when needed. A number of studies have examined predictors of who actually uses respite care, though we did not find any that examined ethnicity carefully in this regard.

Regional centers provide respite care hours to many consumer families. Consequently, this formal service – conceptualized as either in-home or out-of-home, was examined in the following survey. We note that we also assessed consumer families' knowledge and use of

financial supports such as government benefit programs (SSI, Social Security, Medi-Cal, and so on).

Informal supports also comprise a major area of interest by researchers, and are included in the attached review. Informal supports tend to include spouse, and immediate social networks made up of other relatives, friends, or neighbors. The use of informal supports correlates highly with parental well-being in several studies. However, these sources of information or support were **not** included in our survey, because they are not under the purview of regional centers.

Are there specific service needs for families who have children or adults with developmental disabilities?

Again, the answer is, "yes." Many studies highlight commonly cited needs for families. These include the need for information about services or developmental issues, information about respite care, strategies for interacting with children (or parent training), and behavioral intervention. Indeed, studies show quite clearly that severe behavioral challenges seem to impinge most on mothers' well-being or mental health.

Nearly all of the service needs cited in the literature are provided through regional centers, and have been included as items on our Family Needs and Support Service.

Are there any identified barriers to service utilization?

Unfortunately, "yes," the literature indicates some clear-cut barriers to service utilization. Among these are lack of coordination among agencies, and parents' or caregivers' lack of knowledge about how to access services. Interestingly, the literature suggests that these two barriers might exist, even in the presence of adequate funding.

The other barrier cited in the literature, of particular interest here, concerns language. For example, Spanish-speaking Hispanics have been shown, in some studies, to have high service need but low service use. Some have written about clashes between cultural contexts and the service delivery system. Thus, it would be helpful to better understand the needs of non-English-speaking (and other) minorities, and to appreciate how culture impacts service needs and utilization.

The survey and statistical procedures designed for use in this study allowed us to examine findings by ethnicity, which here is a proxy for cultural context. Variables that truly represent "culture" cannot be contained on a statewide database of over 100,000 individuals, of course, but the ethnicity variable was one of several biasing variables that we did examine.

Is measuring family or consumer satisfaction important?

Obviously, we think it is! Yet, the literature does not contain many studies that assess both family or consumer *use of services* and their *satisfaction*. As expected, few include non-English speaking groups. Researchers should thus continue to assess specific areas of service

need, and to evaluate parent/consumer satisfaction with services received. The following portion of the POS II study is one such effort.

Method of Study

Overall design of the current project

Results from two sets of data are presented in this report. The first pertains to the survey data gathered statewide, and the second involves the administration of the same survey, and incorporating those findings within an existing dataset. The latter includes more in-depth analyses of caregiver well-being in relation to service needs and satisfaction in a subsample of Hispanic families, and is described in the next section of this report. Here, we include findings from the statewide administration of the survey.

To review, the purpose of this survey was to learn, directly from consumer families (either the consumers themselves, their parents or their representatives) what services they think they need, what they were currently receiving, and whether or not they were satisfied with those services. All items on the survey itself (contained in the Appendix) are offerings at regional centers. By surveying individuals directly, we are able to get information above-and-beyond what was available on the statewide database, and as described in POS II, Report #1.

We also obtained survey data from each respondent's service coordinator. The purpose of administering a version of the survey to service coordinators at all participating regional centers was to compare the service coordinator perception of a given family's needs and level of satisfaction with perceptions obtained directly from parents.

<u>The Statewide Data</u>

To study the relations among client characteristics, family perceived needs, and services received, we gathered data from a random sample of clients served by Regional Centers. We sought a sample large enough to adequately represent each Regional Center and to be diverse on important dimensions (e.g. client age and functioning; family race/ethnicity and socioeconomic status). One caveat is that we only had the capability to provide measures in English or Spanish, so we were limited to respondents who speak one of these languages.

Survey instruments were developed for the purpose of this study, and previewed by a group of Stakeholders invited by DDS for this purpose, as well as by colleagues in the field. [See Appendix for copies of measures.] In addition, we pretested a preliminary form of our survey questionnaire in two Regional Centers (Alta and North Los Angeles County), but did so with a complete data collection, so that we could both identify any problems with the survey instrument and determine (a) any difficulties encountered by service coordinators and parents/guardians when completing the survey, and (b) if our on-line survey was adequate for the task. Because we changed our survey instrument in key ways after our pretest in Alta and North Los Angeles County Regional Centers, data from these two centers were not comparable to those from the statewide survey, so are not reported further in this report.

Our survey procedures were as follows: We notified each of the 19 remaining Regional Centers that they should identify the next 200 clients whose cases were up for annual review. According to DDS guidelines, each client served by a Regional Center is to be reviewed once per year, at which time the Client Development Evaluation Report (CDER) is completed on the client. Taking 200 consecutive clients from each Regional Center led to a projected sample of size 3,800 participants across the 19 Regional Centers, an adequate sample on which to determine variation across Regional Centers on key variables related to study goals (socioeconomic status of families, age of client, disability, ethnicity, and so forth). Of course, practical considerations prevailed, and we did not obtain the desired 3,800 participant surveys. The final sample of parents/consumer surveys returned was 1,118; of these returned surveys, 1,073 surveys contained usable data.

Each of the 3,800 clients and their families selected received a targeted mailing. This mailing included all appropriate consent forms for participants in the research, as well as the survey, which contained several demographic questions along with those specifically addressing family needs, services received, and satisfaction. We refer to this instrument as the FNSS (standing for Family Needs, Services, and Satisfaction). Families had the option of either mailing the survey and materials back to UC Davis (in the stamped envelope provided) or completing the survey on-line. Only 117 of the 1,118 family respondents selected the on-line option.

The person completing the survey from the consumer's perspective could have been any of a number of persons. If the consumer was young and living at home, then a parent was the most common person to fill out the survey instrument. If the consumer was living in a community placement, a person who functioned as the consumer's guardian was the most common respondent. In addition, consumers themselves completed some surveys. Thus, we did not restrict the identity of the person completing the survey from the consumer's point of view: If the consumer was able to complete the survey, then s/he was perhaps the most appropriate person to do so. If the consumer was unable to complete the survey, we asked that a person who knew the consumer well to complete the survey instrument. For ease of reference, in the remainder of this report we will refer to the respondent from the consumer's point of view as the "parent/ guardian," because parents and guardians were the most common persons completing the surveys. However, we acknowledge that this fails to capture all persons who completed the survey from the consumer's point of view.

In addition to the mailed survey from each family, we also designed a short survey to be filled out by the service coordinator for each of the 200 clients per Regional Center. This included a series of questions related to perceived family and client needs, the availability of services for all needs, and the adaptability of the family in the scheduling of services. We also incorporated several questions pertaining to the service coordinator's years of experience and language proficiency. All service coordinators completed surveys on-line, and the data were compiled immediately on a computer at UC Davis. The structure of the service coordinator questionnaire closely followed certain parts of the FNSS completed by families. The parallel structure enabled us to determine the extent to which family respondents and service coordinators agreed on the family's and client's needs and the services to meet those needs. In addition, we were able to determine whether family satisfaction with services, and with interactions with Regional Center

personnel, are consistent with perceived family satisfaction on the part of service coordinators. The final number of surveys received from service coordinators was 2,866.

Data from the participating clients, their families, and their service coordinators were entered into a computerized database. This database contained identifiers for Regional Center (numbers from 1-21) as well as client within Regional Center (participant identification numbers ranging from 1-200 per center), yielding a unique identifier for each participating client and his/her family.

Results of Statewide Survey

In this section, we will provide a descriptive analysis of data collected in the statewide survey from service coordinators and from parents/guardians. The first matter to report is the number of service coordinators and parents/guardians who participated from each Regional Center. The number of service coordinators is reported in the first data column of Table 1; the percentage this constitutes of the total of 2,866 is reported in the next column. In the third and fourth columns of Table 1, the number of parents/guardians completing surveys from each Regional Center and then the percent of the total sample of 1,118 parent/guardian surveys are reported.

Table 1

Numbers of Service Coordinators and Parents/Guardians Participating in Statewide Survey

	Service Coordinators		Parents/Guardians	
Regional Center	Number	Percent	Number	Percent
Central Valley	171	5.97	80	7.16
East Bay	86	3.00	30	2.68
East Los Angeles	217	7.57	82	7.33
Far Northern	174	6.07	79	7.07
Golden Gate	155	5.41	48	4.29
Harbor	176	6.14	40	3.58
Inland	169	5.90	64	5.72
Kern	159	5.55	62	5.55
Lanterman	142	4.95	61	5.46
North Bay	197	6.87	63	5.64
Orange	218	7.61	72	6.44
Redwood Coast	152	5.30	75	6.71
San Andreas	226	7.89	111	9.93
San Diego	83	2.90	20	1.79
San Gabriel/Pomona	145	5.06	36	3.22
Tri-Counties	100	3.49	55	4.92
Valley Mountain	180	6.28	78	6.98
Westside	116	4.05	62	5.55
Total	2,866	100.00	1,118	100.00

As can easily be seen from Table 1, between 83 and 226 service coordinators completed the survey from the 18 Regional Centers that participated in the study. Service coordinators from three Regional Centers (San Andreas, Orange, and East Los Angeles) provided an extraordinary number of surveys. One of these centers (San Andreas) also had a very large proportion of parents/guardians returning surveys. Also, despite numerous contacts by project personnel, the South Central Los Angeles Regional Center returned no service coordinator or family surveys.

Perceived Receipt of Information, Support, and Resources

Receipt of Information. The first part of our survey inquired about whether the consumer and his or her family or guardian was receiving information on a number of topics. We will first report on perceived receipt of information from both the service coordinator and parent/guardian viewpoints. Our results, presented in Tables 2 and 3, cover the 10 types of information about

which we inquired. For each item, we asked whether the consumer was or was not receiving the information and if more information than now received were desired.

Table 2

Service Coordinator Perceptions of Consumer Receipt of Information

	Not receiving		Receiving	
Item	Don't Need it	Need it	Yes	Need more
1. Consumer's disability	948 (34.0)	116 (4.2)	1546 (55.5)	178 (6.4)
2. Consumer's development	1386 (50.1)	141 (5.1)	1131 (40.9)	110 (4.0)
3. Teaching the consumer	1197 (43.2)	225 (8.1)	1227 (44.3)	119 (4.3)
4. Managing consumer's behavior	1327 (48.0)	190 (6.9)	1097 (39.7)	150 (5.4)
5. Social development	1029 (37.2)	242 (8.8)	1366 (49.4)	127 (4.6)
6. Sexual development	1850 (67.2)	378 (13.7)	470 (17.1)	57 (2.1)
7. Recreational services	777 (28.1)	217 (7.8)	1638 (59.2)	137 (4.9)
8. Vocational services	1468 (53.1)	109 (3.9)	1122 (40.5)	68 (2.5)
9. Residential placements	1944 (70.3)	35 (1.3)	744 (26.9)	41 (1.5)
10. Regional Center services	208 (7.5)	20 (.7)	2468 (89.0)	78 (2.8)

As shown in Table 2, service coordinators reported that consumers or their family (or guardians) received information about a range of topics. The most commonly received type of information dealt with Regional Center services (Item 10), with over 90 percent of consumers receiving this form of information (note: to obtain the percentage of consumers receiving information, sum the "Receiving – Yes" and "Receiving – Need more" numbers). Service coordinators also reported that over 50 percent of consumers received information about the consumer's disability (Item 1), social development (Item 5), and recreational services (Item 7). Service coordinators reported that between 40 and 50 percent of consumers and/or their families/guardians received information on the consumer's development (Item 2), teaching (Item 3), managing behavior

(Item 4), and vocational services (Item 8). Fewer consumers received information about sexual development (Item 6; 19 percent) or residential placements (Item 9; 28 percent).

The preceding results can be compared with the parent/guardian reports of receipt of information from the Regional Center, data presented in Table 3. Once again, information about Regional Center services was the most common type of information received (Item 10; 82 percent). Furthermore, the next highest forms of information received were identical to those for the service coordinators. Specifically, a large percentage of parents/guardians reported receiving information about the consumer's disability (Item 1; 73 percent) and recreational services (Item 7; 60 percent). About one half of the parents/guardians also reported receiving information about most other topics, with between 48 and 58 percent reporting receiving information about the consumer's development, teaching the consumer, the consumer's behavior, social development, and vocational services. Consistent with the service coordinator reports, parents/guardians reported receiving less information about the consumer's sexual development (Item 6; 27 percent) and residential placements (Item 9; 33 percent).

Thus, in general, service coordinators and parents/guardians agreed with regard to the general levels of information received across the 10 categories of content. That is, both service coordinators and parents/guardians agreed that (a) the vast majority of consumers and their families or caregivers received information about Regional Center services; (b) clear majorities received information about the consumer's disability and about recreational services; (c) about half of the families or caregivers received information about the consumer's disability, behavior, social development, recreational services, and learning; and (d) that relatively few received information about the consumer's sexual development or about residential services.

Unanswered by the preceding similarities in percentages for service coordinators and parents/ guardians is the question about whether the data support a conjunction between viewpoints. That is, we have not yet asked whether the parents/guardians who report receiving information on a certain topic are the same parents/guardians who service coordinators report receive information on that topic. That is, do service coordinators and parents/guardians agree on these ratings. This will be a topic of a later section.

Table 3

Parent/Guardian Perceptions of Receipt of Information

	Not receiving		Receiving	
Item	Don't Need it	Need it	Yes	Need more
1. Consumer's disability	180 (17.1)	101 (9.6)	611 (58.0)	161 (15.3)
2. Consumer's development	273 (26.5)	162 (15.7)	488 (47.4)	107 (10.4)
3. Teaching the consumer	295 (28.8)	213 (20.8)	435 (42.4)	83 (8.1)
4. Consumer's behavior	306 (29.4)	199 (19.1)	437 (42.0)	99 (9.5)
5. Social development	237 (23.0)	235 (22.8)	460 (44.7)	97 (9.4)
6. Sexual development	500 (48.4)	251 (24.3)	246 (23.8)	35 (3.4)
7. Recreational services	151 (14.5)	260 (25.0)	529 (51.0)	98 (9.4)
8. Vocational services	330 (31.8)	214 (20.6)	425 (41.0)	68 (6.6)
9. Residential placements	536 (52.6)	151 (14.8)	287 (28.2)	45 (4.4)
10. Regional Center services	63 (6.0)	119 (11.4)	728 (69.5)	138 (13.2)

Receipt of Support. The next section of the survey inquired about receipt of support of various types. As shown in Table 4, service coordinators reported that approximately 71 percent of parents/guardians had regular meetings with the service coordinator (Item 3). Support in handling stress (46 percent) and financial help with services and equipment (also 46 percent) were also common forms of support received. Service coordinators reported somewhat lower levels of receipt of support in the categories of behavior management (31 percent) or support from others with similar children or consumers (24 percent).

Thus, these results suggest that service coordinators report that (a) many parents/guardians have regular meetings with a service coordinator; (b) a moderate percent receive support for handling

stress and financial matters; and (c) relatively fewer receive support related to behavior management or support from other with similar consumers.

Table 4

Service Coordinator Perceptions of Consumer Receipt of Support

	Not receiving		Receiving	
Item	Don't Need it	Need it	Yes	Need more
1. Handling stress	1188 (42.8)	314 (11.3)	1159 (41.7)	116 (4.2)
2. Support from others with similar children/consumers	1655 (60.2)	448 (16.3)	607 (22.1)	41 (1.5)
3. Regular meetings with service coordinator	717 (28.5)	100 (3.6)	1916 (68.9)	47 (1.7)
4. Behavior management	1681 (60.7)	218 (7.9)	792 (28.6)	77 (2.8)
5. Financial help with services or equipment	1397 (50.3)	103 (3.7)	1210 (43.6)	68 (2.4)

The reports by parents/guardians with regard to types of support received are shown in Table 5, displayed in the same categories as for service coordinators. Parents/guardians reported that a high proportion, approximately 84 percent, had regular meetings with a service coordinator (Item 3). Support in behavior management (43 percent) and financial help with services and equipment (52 percent) were the next most common forms of support received. Parents/guardians reported somewhat lower levels of receipt of support in the categories of handling stress (38 percent) or support from others with similar children or consumers (33 percent).

Thus, these results suggest that parents/guardians report that (a) many parents/guardians have regular meetings with a service coordinator; (b) a moderate percent receive support for behavior management and financial matters; and (c) relatively fewer receive support related to handling stress or support from other with similar consumers.

In the broadest strokes, these results are similar to those reported by service coordinators (see Table 4). The only major switch was that service coordinators reported more support for handling stress and less for behavior management. Aside from this small difference, the reported levels of support were quite similar across service coordinators and parents/guardians.

Table 5

Parent/Guardian Perceptions of Receipt of Support

	Not receiving		Receiving	
Item	Don't Need it	Need it	Yes	Need more
1. Handling stress	378 (36.2)	272 (26.1)	339 (32.5)	54 (5.2)
2. Support from others with similar children/consumers	438 (43.6)	239 (23.8)	285 (28.4)	43 (4.3)
3. Regular meetings with service coordinator	84 (8.0)	86 (8.2)	817 (78.2)	58 (5.6)
4. Behavior management	381 (37.3)	200 (19.6)	362 (35.4)	79 (7.7)
5. Financial help with services or equipment	313 (30.4)	179 (17.4)	461 (44.8)	76 (7.4)

Receipt of Resources. The third section inquired about receipt of various kinds of resources. Reports by service coordinators and parent/guardians are provided in Tables 6 and 7.

Table 6

Service Coordinator Perceptions of Consumer Receipt of Resources

Item	Not receiving		Receiving	
	Don't Need it	Need it	Yes	Need more
1. Infant development program	2695 (97.6)	12 (.4)	51 (1.8)	2 (.1)
2. Infant development specialist	2688 (98.0)	11 (.4)	43 (1.6)	0 (0)
3. Home health agency	2553 (92.4)	66 (2.4)	135 (4.9)	9 (.3)
4. Respite care: In-home	1589 (57.4)	132 (4.8)	994 (35.9)	52 (1.9)
5. Respite care: out-of-home	2497 (90.5)	116 (4.2)	138 (5.0)	8 (.3)
6. Day care or child development program	2392 (86.8)	95 (3.4)	251 (9.1)	19 (.7)
7. Occupational therapy	2097 (76.1)	133 (4.8)	483 (17.5)	42 (1.5)
8. Speech therapy	1829 (66.3)	186 (6.7)	657 (23.8)	88 (3.2)
9. Physical therapy or physical development program	2133 (77.3)	154 (5.6)	431 (15.6)	40 (1.5)
10. Transportation	1227 (44.5)	71 (2.6)	1413 (51.2)	47 (1.7)
11. Vocational or habilitation program	1763 (63.8)	145 (5.2)	813 (29.4)	44 (1.6)
12. Behavioral intervention or behavioral adjustment program	1884 (68.2)	208 (7.5)	618 (22.4)	53 (1.9)
13. Specialized autism program	2446 (89.1)	145 (5.3)	136 (5.0)	17 (.6)
14. Social skills or social development program	1265 (45.8)	453 (16.4)	960 (34.7)	87 (3.1)

Table 6 (continued)

Item	Not receiving		Receiving	
	Don't Need it	Need it	Yes	Need more
15. Medical services	801 (29.1)	65 (2.4)	1808 (65.6)	82 (3.0)
16. Access to Medi-Cal	544 (19.7)	144 (5.20	2024 (73.2)	52 (1.9)
17. Access to SSI or other federal relief program	608 (22.1)	219 (7.9)	1882 (68.3)	48 (1.7)
18. Community living option	1989 (72.2)	75 (2.7)	666 (24.2)	24 (.9)
19. Day program option	1731 (62.6)	92 (3.3)	918 (33.2)	24 (.9)

Results for receipt of resources as reported by service coordinators are shown in Table 6. The four most common forms of resources received, as reported by service coordinators, were for (a) access to Medi-Cal (Item 16; 75 percent), (b) access to SSI or other federal relief program (Item 17; 70 percent); (c) medical services (Item 15; 69 percent; and (d) transportation (Item 10; 53 percent). Of the 19 types of resources, these were the four types of service that were most commonly reported as having been received, and these were the only four with over 50 percent of the consumers receiving the resource.

The next most prevalent types of resources received were received by between 24 and 38 percent of consumers. These seven categories were: (a) in-home respite (Item 4; 38 percent); (b) social skills or social development program (Item 14; 38 percent); (c) day program options (Item 19; 34 percent); (d) vocational or habilitation program (Item 11; 31 percent); (e) speech therapy (Item 8; 27 percent); (f) community living options (Item 18, 25 percent); and (g) behavior intervention or behavior adjustment programs (Item 12; 24 percent).

The remaining eight forms of service (see Items 1, 2, 3, 5, 6, 7, 9, and 13) were received by considerably fewer consumers, with rates of receipt ranging between 2 and 19 percent. Of these forms of resources, only (a) occupational therapy (Item 7; 19 percent) and (b) physical therapy (Item 9; 17 percent) were received by more than 10 percent of consumers.

The reports of resources received from the parent/guardian perspective are reported in Table 7, again in the same categories as for service coordinators. Interestingly, relative to service coordinators, parents/guardians reported somewhat higher rates of receiving resources in

Table 7

Parent/Guardian Perceptions of Receipt of Resources

Item	Not receiving		Receiving	
	Don't Need it	Need it	Yes	Need more
1. Infant development program	825 (85.5)	84 (8.7)	49 (5.1)	7 (.7)
2. Infant development specialist	805 (85.9)	80 (8.5)	43 (4.6)	9 (1.0)
3. Home health agency	745 (75.2)	122 (12.3)	103 (10.4)	21 (2.1)
4. Respite care: In-home	504 (51.3)	97 (9.9)	307 (31.3)	74 (7.5)
5. Respite care: out-of-home	673 (68.8)	140 (14.3)	133 (13.6)	32 (3.3)
6. Day care or child development program	732 (74.9)	120 (12.3)	112 (11.5)	13 (1.3)
7. Occupational therapy	572 (57.5)	200 (20.1)	173 (17.4)	49 (4.9)
8. Speech therapy	534 (53.2)	253 (25.2)	154 (15.3)	63 (6.3)
9. Physical therapy or physical development program	601 (59.6)	212 (21.0)	158 (15.7)	37 (3.7)
10. Transportation	445 (42.9)	111 (10.7)	436 (42.0)	45 (4.3)
11.Vocational or habilitation program	518 (51.9)	178 (17.8)	258 (25.9)	44 (4.4)
12. Behavioral intervention or behavioral adjustment program	540 (53.7)	204 (20.3)	203 (20.2)	59 (5.9)
13. Specialized autism program	755 (77.0)	167 (17.0)	40 (4.1)	18 (1.8)
14. Social skills or social development program	398 (39.3)	299 (29.5)	252 (24.9)	63 (6.2)

Table 7 (continued)

Item	Not receiving		Receiving	
	Don't Need it	Need it	Yes	Need more
15. Medical services	401 (39.1)	99 (9.6)	471 (45.9)	55 (5.4)
16. Access to Medi-Cal	253 (24.8)	74 (7.3)	634 (62.2)	58 (5.7)
17. Access to SSI or other federal relief program	250 (24.4)	139 (13.6)	579 (56.5)	56 (5.5)
18. Community living option	635 (63.4)	129 (12.9)	218 (21.8)	20 (2.0)
19. Day program option	519 (50.9)	163 (16.0)	309 (30.3)	29 (2.8)

the categories of resources that were rarely received, but somewhat lower rates of receiving resources in the most common categories. However, the overall pattern of receipt of resources, with regard to which categories of resources were most commonly received, were quite similar across service coordinators and parents/guardians.

Specifically, the four most common forms of resources received, as reported by parents/ guardians, were for (a) access to Medi-Cal (Item 16; 68 percent vs. 75 percent for service coordinators), (b) access to SSI or other federal relief program (Item 17; 62 percent vs. 70 percent for service coordinators); (c) medical services (Item 15; 51 percent vs. 69 percent for service coordinators); and (d) transportation (Item 10; 46 percent vs. 53 percent for service coordinators). Of the 19 types of resources, these were the four types of service that were most commonly reported by parents/guardians as having been received, and these were the only four with over 45 percent of the consumers receiving the resource.

The next most prevalent types of resources received were received by between 24 and 39 percent of consumers. These six categories were: (a) in-home respite (Item 4; 39 percent); (b) social skills or social development program (Item 14; 31 percent); (c) day program options (Item 19; 33 percent); (d) vocational or habilitation program (Item 11; 30 percent); (e) community living options (Item 18, 24 percent); and (f) behavior intervention or behavior adjustment programs (Item 12; 26 percent). These six types of resources constitute 6 of the 7 types of moderate levels of resources reported by service coordinators; moreover, parents/guardians and service coordinators reported similar levels of receipt of these resources.

The remaining nine forms of service (see Items 1, 2, 3, 5, 6, 7, 8, 9, and 13) were received by fewer consumers, with rates of receipt ranging between 6 and 22 percent. Of these forms of resources, four were reportedly received by more than 15 percent of consumers. These four were (a) occupational therapy (Item 7; 22 percent); (b) speech therapy (Item 8; 22 percent); (c) physical therapy (Item 9; 17 percent); and (d) out-of-home respite care (Item 5; 17 percent). The remaining five categories of resources were received by fewer than 15 percent of consumers.

Respondent Agreement on Perceived Receipt of Information, Support, and Resources

We next sought to answer the following question: Do service coordinators and parents/guardians agree on their reports of receipt of information, support, and resources? That is, we saw that service coordinators and parents/guardians reported similar percentages of consumers receiving various sorts of information, support, and resources. But, we have no information regarding whether the consumers identified by service coordinators as receiving a particular kind of information are the same consumers identified by parents/guardians as receiving that kind of information. To answer this sort of question, we need to evaluate the congruence between the answers given by service coordinators and parents/guardians on a consumer-by-consumer basis.

Agreement on Receipt of Information. For receipt of information, we did the following: (a) first, we determined whether the service coordinator stated that a consumer was receiving a form of information (i.e., the service coordinator indicated either that the consumer was receiving the information or was receiving it but needed more) or was not receiving the information (i.e., the service coordinator indicated the consumer was not receiving or was not receiving but wanted to receive); (b) next, we determined whether the parent/guardian stated that a consumer was receiving a form of information (i.e., the parent/guardian indicated either that the consumer was receiving the information or was receiving it but needed more) or was not receiving the information (i.e., the parent/guardian indicated the consumer was not receiving or was not receiving but wanted to receive); (c) then, we cross-classified these two judgments; and (d) calculated the rate of agreement in judgments with regard to receipt or non-receipt of information. These values for agreement between ratings made by service coordinators and parents/guardians are provided in Tables 8, 9, and 10 for receipt of information, support, and resources, respectively.

Consider the first row of Table 8, which reports whether a consumer (or his parent/guardian) has received information about the consumer's disability. For a total of 1,016 consumers, both the service coordinator and parent/guardian responded to this question. For 370 consumers, the service coordinators stated that the consumer was not receiving this information; for these 370 consumers, 95 parents/guardians agreed that they had not received the information, but 275 parents/guardians stated that they had received this information. Thus, 95 parents/guardians agreed with the service coordinator that information on the consumer's disability had not been received, but 275 parents/guardians disagreed and stated that they had received this information. Conversely, for 646 consumers, the service coordinators stated that the consumer or family/guardian had received information on the consumer's disability; for these 646 consumers, the parents/guardians agreed in 475 cases that such information had been received, but 171 parents/guardians disagreed and stated that the information had not been received.

Given these results, overall agreement and disagreement can be calculated in the following fashion: (a) for overall agreement, service coordinator and parent/guardian agree if (1) both say that the information was not received (i.e., both say No to this question; N = 95) or (2) both say that the information was received (i.e., both say Yes to this question; N = 475); and (b) for overall disagreement, service coordinator and parent/guardian disagree if (1) service coordinator says the information was not received, but parent/guardian says it was (i.e., service coordinator says No, parent/guardian says Yes; N = 275) or (2) service coordinator says the information was received, but parent/guardian says it was not (i.e., service coordinator says Yes, parent/guardian says No; N = 171). Therefore, on receipt of information about the consumer's disability, a total of 570 (or 75 + 475) of 1,016 cases, or 56 percent of cases, reveal agreement between service coordinator and parent/guardian, and 446 cases, or 44 percent of cases, reveal disagreement between service coordinator and parent/guardian. Because receipt vs. nonreceipt of information is simply a dichotomous judgment, one should expect agreement about 50 percent of the time by chance alone. Therefore, agreement on 56 percent of cases is not evidence of substantial "better than chance" agreement between service coordinators and parents/guardians.

On six of the remaining nine types of information, even poorer levels of agreement are shown, agreement nearing the "chance level" of 50 percent agreement between service coordinators and parents/guardians. We refer specifically here to the following items: information regarding (a) consumer's development (Item 2; 52 percent agreement); (b) teaching the consumer (Item 3; 52 percent agreement); (c) consumer's behavior (Item 4; 51 percent agreement); (d) social development (Item 5; 51 percent agreement); (e) recreation services (Item 7; 54 percent agreement); and (f) vocational services (Item 8; 48 percent agreement).

On three forms of information, service coordinators and parents/guardians had higher levels of agreement: concerning information regarding (a) consumer sexual development (Item 6; 63 percent agreement); (b) residential placements (Item 9; 57 percent agreement); and (c) Regional Center services (78 percent agreement). But, even these levels of agreement between service coordinators and parents/guardians do not represent strong concordance between these reporters.

Agreement on Receipt of Support. Results on agreement between service coordinators and parents/guardians with regard to receipt of support are reported in Table 9. As shown in Table 9, service coordinators and parents/guardians showed approximately chance levels of agreement for three of the five forms of support: support for (a) handling stress (Item 1; 49 percent agreement); (b) behavior management (Item 4; 51 percent agreement); and (c) financial help (Item 5; 52 percent agreement).

For the remaining two categories, service coordinators and parents/guardians showed higher levels of agreement, reaching 57 percent agreement on support from others with similar children or consumers, and 64 percent agreement on whether the parent/guardian had regular meetings with the service coordinator. As with receipt of information, these levels of agreement do not represent strong concordance between reports by service coordinators and parents/guardians.

Table 8

Comparison between Service Coordinator and Parent/Guardian Perceptions of Receipt of Information

Item	Sample size	Service Coord. No		Service Coord. Yes		Overall	
		P/G No	P/G Yes	P/G No	P/G Yes	Disagree-ment	Agree-ment
1. Consumer's disability	1016	95 (9.4)	275 (27.1)	171 (16.8)	475 (46.8)	446 (43.9)	570 (56.1)
2. Consumer's development	990	230 (23.2)	288 (29.1)	190 (19.2)	282 (28.5)	478 (48.3)	512 (51.7)
3. Teaching the consumer	981	242 (24.7)	233 (23.8)	242 (24.7)	264 (26.9)	475 (48.4)	506 (51.6)
4. Consumer's behavior	994	272 (27.4)	278 (28.0)	209 (21.0)	235 (23.6)	487 (49.0)	507 (51.0)
5. Social development	980	191 (19.5)	227 (23.2)	255 (26.0)	307 (31.3)	482 (49.2)	498 50.8)
6. Sexual development	983	562 (57.2)	213 (21.7)	154 (15.7)	54 (5.5)	367 (37.3)	616 (62.7)
7. Recreational services	997	138 (13.8)	207 (20.8)	257 (25.8)	395 (39.6)	464 (46.5)	533 (53.5)
8. Vocational services	990	273 (27.6)	268 (27.1)	247 (24.9)	202 (20.4)	515 (52.0)	475 (48.0)
9. Residential placements	970	444 (45.8)	210 (21.6)	207 (21.3)	109 (11.2)	417 (43.0)	553 (57.0)
10. Regional Center services	1002	6 (.6)	51 (5.1)	170 (17.0)	775 (77.3)	221 (22.1)	781 (77.9)

Table 9

Comparison between Service Coordinator and Parent/Guardian Perceptions of Receipt of Support

Item	Sample size	Service Coord. No		Service Coord. Yes		Overall	
		P/G No	P/G Yes	P/G No	P/G Yes	Disagree-ment	Agree-ment
1. Help handling stress	1000	315 (31.5)	207 (20.7)	306 (30.6)	172 (17.2)	513 (51.3)	487 (48.7)
2. Support from other's who have similar children/consumers	962	490 (50.9)	249 (25.9)	161 (16.7)	62 (6.4)	410 (42.6)	552 (57.4)
3. Regular meetings with service coordinator	1007	40 (4.0)	245 (24.3)	123 (12.2)	599 (59.5)	368 (36.5)	639 (63.5)
4. Behavior management help	983	389 (39.6)	307 (31.2)	171 (17.4)	116 (11.8)	478 (48.6)	505 (51.4)
5. Financial asst. with services or equipment	991	273 (27.5)	280 (28.3)	201 (20.3)	237 (23.9)	481 (48.5)	510 (51.5)

Agreement on Receipt of Resources. Agreement between service coordinators and parents/guardians with regard to receipt of resources is reported in Table 10. Here, much more impressive levels of agreement were exhibited for certain categories of resources. Six of the types of resources showed agreement over 75 percent. Specifically, these were for receipt of the following kinds of resources: (a) infant development programs (Item 1; 92 percent agreement); (b) infant development specialist (Item 2; 92 percent agreement); (c) home health agency (Item 3; 84 percent agreement); (d) out-of-home respite (Item 5; 79 percent agreement); (e) day care or child development program (Item 6; 80 percent agreement); and (f) specialized autism program (Item 13; 89 percent agreement). Not surprisingly, these high levels of agreement between service coordinators and parents/guardians occurred for types of resources that very few consumers received. Therefore, the high levels of agreement stemmed almost completely from agreement by service coordinator and parent/guardian that the consumer did not receive the services under consideration. Moreover, most of this agreement should stem from categorical constraints on the receipt of services. That is, only infants can attend infant development programs and have the services of an infant development specialist, so consumers who were children, adolescents, or adults would be excluded from receiving such services.

For an additional four categories of resources, service coordinators and parents/guardians had moderate levels of agreement, between 60 and 70 percent agreement. This moderate agreement was exhibited for receipt of the following kinds of resources: (a) occupational therapy (Item 7; 66 percent agreement); (b) physical therapy or physical development program (Item 9; 69 percent agreement); (c) behavioral intervention or adjustment program (Item 12; 62 percent agreement); and (d) community living options (Item 18; 63 percent agreement). Once again, relatively high levels of agreement between service coordinators and parents/guardians were achieved for these categories of resources because the relatively few persons received these resources.

For the remaining nine categories, service coordinators and parents/guardians exhibited lower levels of agreement, ranging from 49 to 59 percent agreement. These levels of agreement are not evidence of any notable concordance between the ratings by service coordinators and parents/guardians.

Summary. Across all three categories (receipt of information, support, and resources), service coordinators and parents/guardians tended to show modest levels of agreement with regard to who was receiving services and who was not. High levels of agreement were achieved only for categories of service for which extremely low levels of receipt of services were reported. For all categories of service for which a moderate proportion of the population received services, agreement between service coordinators and parents/guardians was modest at best. These modest levels of agreement on case-by-case receipt of services is all the more surprising, given the rather high levels of agreement between service coordinators and parents/guardians on the general levels of service received across categories of service. That is, service coordinators and parents/guardians agree rather well with regard to which services are received by many consumers and which are received by few consumers. But, despite these high levels of agreement on general receipt of services by category of services, service coordinators and parents/guardians do not exhibit notable agreement on which consumers are receiving which services.

Table 10

Comparison between Service Coordinator and Parent/Guardian Perceptions of Receipt of Resources

Item	Sample size	Service Coord. No		Service Coord. Yes		Overall	
		P/G No	P/G Yes	P/G No	P/G Yes	Disagree-ment	Agree-ment
1. Infant development program	923	843 (91.3)	54 (5.9)	24 (2.6)	2 (.2)	78 (8.5)	845 (91.5)
2. Infant development specialist	889	817 (91.9)	51 (5.7)	20 (2.2)	1 (.1)	71 (8)	818 (92)
3. Home health agency	944	780 (82.6)	110 (11.7)	46 (4.9)	8 (.8)	156 (16.5)	788 (83.5)
4. In-home respite	941	356 (37.8)	242 (25.7)	216 (23.0)	127 (13.5)	458 (48.7)	483 (51.3)
5. Out-of-home respite	935	725 (77.5)	150 (16.0)	51 (5.5)	9 (1)	201 (21.5)	734 (78.5)
6. Day care or child development program	931	728 (78.2)	108 (11.6)	82 (8.80	13 (1.4)	190 (20.4)	741 (79.6)
7. Occupational therapy	945	587 (62.1)	176 (18.6)	147 (15.6)	35 (3.7)	323 (34.2)	622 (65.8)
8. Speech therapy	957	510 (53.3)	147 (15.4)	242 (25.3)	58 96.1)	389 (40.6)	568 (59.4)
9. Physical therapy or physical development program	964	630 (65.4)	154 (16.0)	149 (15.5)	31 (3.2)	303 (31.4)	661 (68.6)
10. Transportation	990	268 (27.1)	241 (24.3)	265 (26.8)	216 (21.8)	506 (51.1)	484 (48.9)
11. Vocational or habilitation program	956	453 (47.4)	202 (21.1)	212 (22.2)	89 (9.3)	414 (43.3)	542 (56.7)

Table 10 (continued)

Item	Sample size	Service Coord. No		Service Coord. Yes		Overall	
		P/G No	P/G Yes	P/G No	P/G Yes	Disagree-ment	Agree-ment
12. Behavioral intervention or adjustment program	959	547 (57.0)	200 (20.9)	165 (17.2)	47 (4.9)	365 (38.0)	594 (62.0)
13. Specialized autism program	936	830 (88.7)	52 (5.6)	51 (5.4)	3 (.3)	103 (11.0)	833 (89.0)
14. Social skills or social development program	968	397 (41.0)	195 (20.1)	270 (27.9)	106 (11.0)	465 (48.0)	503 (52.0)
15. Medical services	981	151 (15.4)	151 (15.4)	323 (32.9)	356 (36.3)	474 (48.3)	507 (51.7)
16. Access to Medi-Cal	976	71 (7.3)	152 (15.6)	242 (24.8)	511 (52.4)	394 (40.4)	582 (59.6)
17. Access to SSI or other federal relief program	975	96 (9.8)	151 (15.5)	273 (28.0)	455 (46.7)	424 (43.5)	551 (56.5)
18. Community living option	953	543 (57.0)	164 (17.2)	186 (19.5)	60 (6.3)	350 (36.7)	603 (63.3)
19. Day program option	969	422 (43.6)	219 (22.6)	227 (23.4)	101 (10.4)	446 (46.0)	523 (54.0)

Satisfaction with Information, Support, and Resources

In addition to inquiring about receipt of information, support, and resources, we asked both service coordinators and parents/guardians to report on satisfaction with information, support, and resources if they received these. This question asked (a) service coordinators to rate how satisfied the consumer and his/her parent/guardian were with information, support, and resources received, and (b) parents/guardians to rate how satisfied they were with information, support, and resources received. Moreover, only consumers who were reported to have received information, support, or resources should have information concerning satisfaction with these services. For all items, satisfaction was assessed on a 1-to-6 scale, where 1 = extremely dissatisfied and 6 = extremely satisfied.

Satisfaction with Information Received. Levels of perceived satisfaction with information received are reported in Table 11 for both service coordinators and parents/guardians. In Table 11, we present (a) the number of consumers for whom both service coordinator and parent/guardian reported satisfaction, (b) the mean and standard deviation of scores provided by both service coordinators and parents/guardians, (c) the difference between the means for the two groups, and (d) the *t* test value and its degrees of freedom, along with an indication of whether the mean difference was statistically significant. The *t* test used was the dependent *t* test, because we were comparing ratings by service coordinator and parent/guardian on the same consumer.

As shown in Table 11, service coordinators and parents/guardians reported fairly high overall levels of satisfaction, with means ranging between 4.79 and 5.04 for service coordinators and between 4.56 and 4.96 for parents. In addition, they reported similar, nonsignficantly different levels of satisfaction for 5 of the 10 types of information. For these five types of information – information on consumer's disability, consumer's development, teaching the consumer, consumer's behavior, and sexual development – parents/guardians tended to report somewhat, but nonsignificantly lower levels of satisfaction with information received relative to service coordinators.

But, for the remaining five types of information, parents/guardians reported significantly lower levels of satisfaction. That is, significant differences in mean satisfaction, with parents/guardians reporting lower levels of satisfaction, were found for satisfaction with information regarding (a) social development, (b) recreational services, (c) vocational services, (d) residential placement, and (e) Regional Center services.

One way to gauge the magnitude of a difference is to calculate Cohen's *d*, where *d* is obtained by dividing the difference between means by the reference group (i.e., parents/guardians) standard deviation. The *d* values for the five significant differences were: (a) social development, $d = 0.12$; (b) recreational services, $d = 0.19$; (c) vocational services, $d = 0.21$; (d) residential placement, $d = 0.23$; and (e) Regional Center services, $d = 0.17$. In the behavioral sciences, researchers often use *d* values of 0.20, 0.50, and 0.80 to identify mean differences as representing small, medium, and large effect sizes, respectively. Thus, all five of these statistically significant differences represent effect sizes that would be considered, in the behavioral sciences, small effect sizes. However, in a service agency, any significant differences should provide indicators of places for needed improvements.

Table 11

Levels of Perceived Satisfaction by Service Coordinators and Parents/Guardians with Information Received

Item	Sample size	Mean (SD) Service Coordinator	Mean (SD) Parent/ Guardian	Mean Difference	t (df)
1. Consumer disability	560	4.94 (0.70)	4.96 (0.96)	-0.02	-0.40 (559)
2. Consumer's development	354	4.92 (0.58)	4.91 (0.98)	0.01	0.09 (353)
3. Teaching the consumer	344	4.88 (0.56)	4.75 (1.06)	0.13	1.88 (343)
4. Consumer's behavior	342	4.87 (0.67)	4.79 (1.04)	0.08	1.20 (341)
5. Social development	386	4.91 (0.62)	4.80 (0.98)	0.12	2.01* (385)
6. Sexual development	163	4.79 (0.82)	4.56 (1.02)	0.22	1.95 (162)
7. Recreational services	487	4.93 (0.70)	4.73 (1.01)	0.19	3.23** (486)
8. Vocational services	303	4.93 (0.67)	4.69 (1.09)	0.23	3.19** (302)
9. Residential placements	213	5.00 (0.73)	4.74 (1.13)	0.26	2.95** (212)
10. Regional Center services	746	5.04 (0.59)	4.88 (0.96)	0.16	4.14*** (745)

Note. * $p < .05$ ** $p < .01$ *** $p < .001$

Satisfaction with Support Received. Levels of perceived satisfaction with support received are reported in Table 12. The format of Table 12 is identical to that for Table 11, with information on the number of participants with data on each item, the mean and standard deviation of ratings by service coordinators and parents/guardians, the mean difference, and the *t* test statistic testing whether the means differed across reporters.

Once again, both service coordinators and parents/guardians reported rather high overall levels of satisfaction with support received, with means ranging from 4.82 to 5.06 for service coordinators and from 4.52 to 4.82 for parents/guardians. And, parents/guardians tended to provide consistently somewhat lower ratings of satisfaction relative to service coordinators. For two of the five types of support, parent/guardian and service coordinator mean levels did not differ significantly.

But, for the remaining three types of support, significant differences in mean ratings were obtained. Parents/guardians reported significantly lower levels of satisfaction with support with regard to: (a) handling stress, (b) support from others who have similar children or consumers, and (c) financial assistance with services or equipment.

We again computed Cohen's *d* values to represent the magnitude of the differences in mean ratings. These *d* values were as follows: (a) handling stress, $d = 0.21$; (b) support from others who have similar children or consumers, $d = 0.28$; and (c) financial assistance with services or equipment, $d = 0.15$. So, as with satisfaction with information, these results with regard to satisfaction with support represent, in a behavioral science rendering, fairly small effect sizes. However, any differences between groups should give pause to consider how to improve levels of parent/guardian satisfaction with support provided by Regional Centers.

Satisfaction with Resources Received. Levels of satisfaction with resources received are reported in Table 13 in a fashion identical to that for the preceding types of services. Service coordinators reported very high parent/guardian satisfaction with resources received, with means ranging from 4.64 to 5.17 across the 19 categories of resources. Parents/guardians, while evidencing overall reasonably high levels of satisfaction, had rather lower mean ratings, ranging between 4.17 and 4.91.

Service coordinators and parents/guardians did not differ significantly in mean level in their satisfaction ratings for 11 of the 19 categories of resources. On the positive side, this means that, on over one half of the resource categories, service coordinators and parents/guardians generally differed little in mean levels of satisfaction. On a more negative note, the failure to find significant differences was, at times, due to the rather small sample sizes involved and resulting low levels of power to detect a significant difference (see, for example, Items 1 [N = 33], 3 [N = 51], 5 [N = 58], and 6 [N = 61]).

Table 12

Levels of Perceived Satisfaction by Service Coordinators and Parents/Guardians with Support Received

Item	Sample size	Mean (SD) Service Coordinator	Mean (SD) Parent/ Guardian	Mean Difference	t (df)
1. Help handling stress	290	4.82 (0.65)	4.57 (1.24)	0.26	3.00** (289)
2. Support from others who have similar children/Consumers	161	4.85 (0.70)	4.52 (1.18)	0.33	3.03** (160)
3. Regular meetings with Regional Center SC	645	5.06 (0.65)	5.06 (0.94)	0.00	-0.04 (644)
4. Behavior management help	222	4.92 (0.60)	4.82 (1.03)	0.10	1.31 (221)
5. Financial assistance with services or equipment	343	4.99 (0.72)	4.82 (1.10)	0.17	2.35* (342)

Note. * $p < .05$ ** $p < .01$ *** $p < .001$

Table 13

Levels of Perceived Satisfaction by Service Coordinators and Parents/Guardians with Resources Needed

Item	Sample size	Mean (SD) Service Coordinator	Mean (SD) Parent/ Guardian	Mean Difference	t (df)
1. Infant development program	33	5.06 (0.35)	4.73 (1.04)	0.33	1.77 (32)
2. Infant development specialist	29	5.17 (0.38)	4.17 (1.51)	1.00	3.36* (28)
3. Home health agency	51	5.00 (0.49)	4.71 (1.19)	0.29	1.68 (50)
4. In-home respite	187	4.99 (0.72)	4.80 (1.21)	0.20	1.89 (186)
5. Out-of-home respite	58	5.00 (0.56)	4.62 (1.30)	0.38	1.95 (57)
6. Day care or child development program	61	5.03 (0.55)	4.69 (1.29)	0.34	1.86 (60)
7. Occupational therapy	95	4.87 (0.64)	4.59 (1.23)	0.28	1.91 (94)
8. Speech therapy	137	4.64 (0.83)	4.50 (1.42)	0.14	0.98 (136)
9. Physical therapy or physical development program	94	4.99 (0.43)	4.41 (1.24)	0.57	4.23*** (93)
10. Transportation	283	4.96 (0.65)	4.80 (1.22)	0.16	1.90 (282)

Table 13 (continued)

Item	Sample size	Mean (SD) Service Coordinator	Mean (SD) Parent/ Guardian	Mean Difference	t (df)
11. Vocational or habilitation program	161	4.92 (0.83)	4.65 (1.15)	0.27	2.25* (160)
12. Behavioral intervention or adjustment prog.	126	4.96 (0.64)	4.52 (1.13)	0.44	3.65*** (125)
13. Specialized autism program	35	4.83 (0.82)	4.26 (1.36)	0.57	2.20* (34)
14. Social skills or social development program	179	4.96 (0.69)	4.56 (1.25)	0.39	3.60*** (178)
15. Medical services	391	4.92 (0.62)	4.91 (1.01)	0.02	0.25 (390)
16. Access to Medi-Cal	518	4.85 (0.71)	4.79 (1.11)	0.06	0.99 (517)
17. Access to SSI or other federal relief program	465	4.87 (0.77)	4.86 (1.04)	0.01	0.15 (464)
18. Community living option	123	5.13 (0.42)	4.80 (1.08)	0.33	3.34** (122)
19. Day program option	169	5.08 (0.60)	4.83 (1.10)	0.25	2.59* (168)

Note.
* $p < .05$ ** $p < .01$ *** $p < .001$

On the remaining eight categories of service, service coordinators and parents/guardians had mean satisfaction ratings that differed significantly. These eight categories involved satisfaction with (a) infant development expert, (b) physical therapy or physical development program, (c) vocational or habilitation program, (d) behavioral intervention or adjustment program, (e) specialized autism program, (f) social skills or social development program, (g) community living options, and (h) day program options.

To provide an index of the magnitude of these differences in mean ratings, we calculated Cohen's *d* values for each of the significant test statistics. The *d* values for these eight categories of resources were: (a) infant development expert, $d = 0.66$; (b) physical therapy or physical development program, $d = 0.46$; (c) vocational or habilitation program, $d = 0.23$; (d) behavioral intervention or adjustment program, $d = 0.39$; (e) specialized autism program, $d = 0.42$; (f) social skills or social development program, $d = 0.31$; (g) community living options, $d = 0.31$; and (h) day program options, $d = 0.23$.

The raw mean difference in mean ratings and the Cohen's *d* values for certain of these comparisons reflect differences in satisfaction to which attention must be paid. Here, we refer specifically to (a) infant development expert, mean difference = 1.00, $d = .66$; (b) physical therapy or physical development program, mean difference = 0.57, $d = .46$; (d) behavioral intervention or adjustment program, mean difference = 0.44, $d = .39$; and (e) specialized autism program, mean difference = 0.57, $d = .42$. For each of these four categories, the difference between mean ratings neared or exceeded one-half scale point, and the *d* values indicated that these were effects in the medium-to-large range. Interestingly, the category for which service coordinators indicated that consumers and parents/guardians were *most* satisfied – infant development specialist, mean = 5.17 – was the same category for which parents/guardians registered their *lowest* level of satisfaction – mean = 4.17. There is a clear disconnect here with regard to satisfaction perceived by service coordinators and satisfaction expressed by parents/guardians.

For the remaining four categories of resources for which significant differences emerged, the mean differences were consistent with fairly small effect sizes, at least with regard to standards in the behavioral sciences. But, as with information and support, any differences in satisfaction with resources should be noted and efforts should be expended to improve levels of parent/guardian satisfaction with resources offered through the Regional Centers.

Agreement on Ratings of Satisfaction with Information, Support, and Resources

Paralleling earlier sections of this report, we turned next to agreement – on a case-by-case basis – between ratings made by service coordinators and parents/guardians. In the immediately preceding section, we found that the two types of respondents – service coordinators and parents/guardians – exhibited significant mean differences on about one-half of the categories of information, support, and resources, and these mean difference often were rather small in magnitude. These results suggested that service coordinators and parents/guardians have high overall levels of agreement with regard to satisfaction with information, support, and resources, albeit with several notable exceptions.

However, the similarities in mean levels of satisfaction across respondents does not speak to whether service coordinators and parents/guardians agree in their satisfaction ratings on a case-by-case basis. Therefore, we calculated correlations – both Pearson product moment and Spearman's rank correlations – between the ratings provided by service coordinators and parents/guardians. These values are presented for satisfaction with information, support, and resources in Tables 14, 15, and 16, respectively.

The results reported in Tables 14, 15, and 16 are so similar and uniform that we will discuss them together. In short, the correlations in these tables range between $r = -0.145$ and $r = +0.144$, and appear to average very close to zero. One would hope that service coordinators and parents/guardians would show high levels of agreement, with correlations of .60 and higher. This would show that the two types of respondents agree on which parents/guardians are highly satisfied with services and, perhaps more importantly, which parents/guardians are extremely dissatisfied with services. The low levels of concordance shown in Tables 14, 15, and 16 indicate that service coordinators have almost no idea at all which parents/guardians are very dissatisfied with services. Given these low levels of concordance with parent/guardian-reported satisfaction, perhaps Regional Centers should take special pains to monitor parent/guardian satisfaction with services in a more vigilant fashion.

We acknowledge that part of the reason for the low levels of correlation between service coordinators and parents/guardians in their ratings of satisfaction with services could be the high mean levels of satisfaction overall. That is, if everyone were completely satisfied and gave ratings of 6 on all items, then ratings made by service coordinators and parents/guardians would correlate 0, even though complete agreement in all ratings held. Correlations would be zero because there would be no variance at all in ratings; as variance in ratings decreases, limits on correlations increase. In the present study, with all mean satisfaction ratings at the high end of the scale (i.e., means around 4.8 to 5.0), there was little room to distinguish among high levels of satisfaction for service coordinators and parents/guardians.

Therefore, we calculated one more statistic to index interrater agreement – the percentage of ratings by service coordinator and parent/guardian that were within one scale point. That is, if the service coordinator rated the parent/guardian as a '5' on a given scale and the parent/guardian reported a value of '4,' '5,' or '6,' the two ratings were within one scale point and were thus fairly congruent. Inspection of Tables 14, 15, and 16 indicates that, by and large, the percentage of ratings within one scale point tended to vary between 75 percent and 89 percent, and percentages for 22 of the 34 categories of information, support, and resources fell about 80 percent. Thus, despite the low levels of correlational concordance between service coordinators and parents/guardians, the high percentages of ratings within one scale point indicate that low variance in ratings is partly, if not mostly, responsible for the low levels of correlation between ratings by service coordinators and parents/guardians.

Table 14

Agreement between Service Coordinators and Parents/Guardians on Satisfaction with Information

Item	Sample size	Pearson r	Spearman r	Percent within 1 scale point
1. Consumer's disability	560	0.057	0.063	87.5%
2. Consumer's development	354	-0.058	-0.021	87.6%
3. Teaching the Consumer	344	-0.054	-0.034	82.8%
4. Consumer's behavior	342	-0.036	-0.045	80.4%
5. Social development	386	0.047	0.064	85.2%
6. Sexual development	163	-0.002	0.001	77.9%
7. Recreational services	487	-0.026	-0.065	81.1%
8. Vocational services	303	0.001	0.052	81.8%
9. Residential placements	213	0.108	0.047	81.2%
10. RC services	746	0.092	0.084	88.3%

Table 15

Agreement between Service Coordinators and Parents/Guardians on Satisfaction with Support

Item	Sample size	Pearson r	Spearman r	Percent within 1 scale point
1. Handling stress	290	-0.089	-0.063	76.9%
2. Others with similar children	161	-0.004	0.013	77.6%
3. Regular meetings with service coordinator	645	0.001	-0.009	88.5%
4. Behavior management	222	0.012	0.005	84.2%
5. Financial help with services or equipment	343	-0.069	-0.084	80.8%

Table 16

Agreement between Service Coordinators and Parents/Guardians on Satisfaction with Resources

Item	Sample size	Pearson r	Spearman r	Percent within 1 scale point
1. Infant development program	33	0.047	0.035	87.9%
2. Infant development specialist	29	-0.114	-0.018	75.9%
3. Home health agency	51	0.069	0.144	86.3%
4. In-home respite	187	-0.051	0.025	82.4%
5. Out-of-home respite	58	-0.145	-0.101	77.6%
6. Day care or child development program	61	-0.104	-0.046	80.3%
7. Occupational therapy	95	-0.107	-0.050	74.7%
8. Speech therapy	137	-0.014	0.017	70.8%
9. Physical therapy or physical development program	94	-0.012	0.010	76.6%
10. Transportation	283	-0.002	0.078	84.5%

Table 16 (continued)

Item	Sample size	Pearson r	Spearman r	Percent within 1 scale point
11. Vocational or habilitation prog.	161	-0.187	-0.124	68.1%
12. Behavioral interv. or adj. prog.	126	-0.082	-0.109	74.6%
13. Specialized autism program	35	0.067	0.040	71.4%
14. Social skills or social dev prog.	179	-0.042	-0.025	76.5%
15. Medical services	391	-0.007	-0.008	86.2%
16. Access to Medi-Cal	518	-0.029	-0.024	82.2%
17. Access to SSI or other federal relief program	465	0.028	0.032	84.5%
18. Community living option	123	0.130	0.108	87.0%
19. Day program option	169	0.003	0.011	84.6%

Analyses of Scale Scores

All preceding analyses were performed at the item level, to give the richest portrayal of the data. In this section of the report, we discuss results on a series of scales computed from items in each section of the report. These scales were computed in the following fashion:

> **Services Received**. Scales of information, support, and resources received: For each section of the survey (i.e., information, support, and resources), we counted up the number of items for which the respondent indicated that the consumer either "received" or "received, but needed more" of the service. This led to scales that could potentially vary from 0-10 for information received, 0-5 for support received, and 0-19 for resources received.
>
> **Services Needed (or Unmet Service Needs)**. Scales of information, support, and resources needed: For each section of the survey (i.e., information, support, and resources), we counted up the number of items for which the respondent indicated that the consumer either "did not receive, but needed" or "received, but needed more" of the service. This led to scales that could potentially vary from 0-10 for information needed, 0-5 for support needed, and 0-19 for resources needed.
>
> **Satisfaction with Services**. Scales of satisfaction with information, support, and resources received: For each section of the survey, we averaged the satisfaction ratings for all items in the section for which the respondent indicated that the consumer received the service. This led to scales that could potentially vary from 1-6 for satisfaction with information, support, and resources.

These procedures listed above resulted in the construction of 18 scale scores: (a) three for services received (information, support, and resources) as rated by service coordinators, (b) three for services received as rated by parents/guardians, (c) three for services needed (information, support, and resources) as rated by service coordinators, (d) three for services needed as rated by parents/guardians, (e) three for satisfaction with services received (information, support, and resources) as rated by service coordinators, and (f) three for satisfaction with services received as rated by parents/guardians.

We performed a series of analyses of these scale scores. We will concentrate here on results from application of the general linear model that incorporated five consumer demographic variables. Specifically, we used the following as predictors of scale scores:

> **Consumer Age Group**: 4 groups, categorized as (a) infants and children (age 11 years or younger); (b) adolescents (aged 12-22 years); (c) younger adults (aged 23-44 years); and older adults (aged 45 years or older). These age categories were utilized in this report to retain comparability to age categories employed in Report #1 of the POS II study. In this survey study, the parents/guardians of too few infants were included in the sample to allow infants to be considered as a separate group.

Level of Mental Retardation: 5 levels, categorized as (a) mild mental retardation; (b) moderate mental retardation; (c) severe mental retardation; (d) profound mental retardation; and (e) unknown.

Ethnicity: 5 groups, categorized as (a) African American; (b) Asian American; (c) Hispanic; (d) Other; and (e) White.

Gender: 2 groups, in the traditional categories of (a) female and (b) male.

Regional Center: 3 groups, in the categories of (a) low expenditure centers, (b) medium expenditure centers, and (c) high expenditure centers. The four low expenditure centers were Central Valley, East Los Angeles, Inland, and San Diego; the four high expenditure centers were Golden Gate, Kern, Redwood Coast, and San Andreas. The remaining 10 participating centers were deemed medium expenditure centers. We used this categorization of Regional Centers to maintain comparability with the focus group materials contained later in this report. In the later section of the report, we discuss focus group information obtained from the four low expenditure and four high expenditure centers identified above.

In addition to the above five person-level factors, we compared judgments made by service coordinators and parents/guardians. Thus, the "respondent" factor comparing service coordinators and parents/guardians was a sixth factor in the analyses

Regression Modeling. The initial regression model fitted to data was a model with five between-subjects factors (Age Group, Level of Mental Retardation, Ethnicity, Gender, Regional Center) and one within-subjects factor (Respondent). We fit all six main effects and all possible two-way interactions among the main effects; the sample size was too small to support higher-way interactions. In this initial model, we also estimated two error terms: a between-subjects error term, and a within-subjects error term.

The final regression model was identical to the initial model with one exception: we pooled the between-subjects and within-subjects error terms. In each of our analyses, we tested whether the two error terms differed significantly. In each of our analyses, the two error terms differed nonsignificantly. This outcome was expected, given the low levels of correlation between reports or ratings by service coordinators and parents/guardians.

Finally, we discuss here only effects that were significant at the $\forall = .01$ level or beyond. The sample size was rather large, leading to relatively high power to reject null hypotheses even if they explained very little variance. In addition, across the nine analyses, over 150 a priori tests of significance were computed. To reduce the likelihood of committing a Type I error, we therefore report only significance tests that met the .01 level of significance.

Receipt of Services

Receipt of Information. The first scale analyzed was the scale for receipt of information. The only statistically significant effects involved Age Group, and three effects were significant: the

main effect of Age Group, F (3, 1287) = 4.14, $p < .01$, and the interactions of Age Group with Level of Mental Retardation, F (12, 1287) = 2.30, $p < .01$, and Respondent, F (3, 1287) = 9.96, $p < .001$. For the main effect, adolescents received fewer forms of information (M = 5.18) than did infants/children, younger adults, and older adults (M = 5.49, 5.62, and 5.49, respectively). The pooled standard deviation was 2.94, so the Cohen's *d* for the difference between adolescents and the other age groups was only about 0.10, which represented a rather small effect. Importantly, no significant effects involving Regional Center or Ethnicity were found.

The two interactions moderated the general trend for Age Group. The interaction of Age Group and Level of Mental Retardation was not a simple interaction, but tended to show that infants or children received the largest number of types of information if they had profound mental retardation (M = 6.37) than if they had less severe levels of mental retardation (M = 5.13); that adolescents received the largest number of types of information if they had moderate or severe mental retardation (M = 6.18) than if they had mild or profound retardation (M = 5.17); that young adults received the highest number of types of information if they had profound retardation (M = 6.46) than other levels of mental retardation (M = 5.37); and older adults received the largest number of types of information if they had mild, moderate, or severe mental retardation (M = 5.91) than if they had profound mental retardation (M = 4.96).

The interaction of Age Group and Respondent was simpler to characterize. Service coordinators reported that infants/children received more types of information (M = 6.13) than adolescents, younger adults, and older adults (M = 5.16, 5.17, and 5.10, respectively), whereas parents/ guardians reported that infants/children and adolescents received relatively fewer types of information (M = 4.83 and 5.20, respectively) than did younger and older adults (M = 6.07 and 5.89, respectively). The largest mean difference contrast had a Cohen's *d* of 0.44, a medium-sized effect.

Receipt of Support. For receipt of support, the only significant effect was the effect of Respondent, F (1, 1271) = 8.53, $p < .005$. Service coordinators reported that consumers received an average of 2.38 types of support, whereas parents/guardians reported an average of 2.52 types of support. The pooled estimate of the within-group standard deviation was 1.41, so the Cohen's *d* value for this difference was only $d = 0.10$, a rather small effect.

Receipt of Resources. As for receipt of resources, five main effects and two two-way interactions were significant. The main effect of Age Group was significant, F (3, 1271) = 5.61, $p < .001$. This main effect revealed that respondents reported that infants/children, adolescents, and younger adults tended to receive more types of resources (M = 5.79, 5.57, and 6.03, respectively) than did older adults (M = 5.25). The pooled standard deviation for this outcome variable was 2.99, so the largest difference between means had a Cohen's *d* of 0.26, a fairly small effect.

The main effect of Level of Mental Retardation was significant, F (4, 1271) = 6.26, $p < .001$. The means indicated that persons with severe or profound mental retardation tended to receive larger numbers of resources (M = 6.66 and 6.36, respectively) than persons with mild, moderate, or unknown levels of mental retardation (M = 5.18, 5.53, and 4.57, respectively). The Cohen's *d* for the largest contrast between means was 0.70, a fairly large effect. However, this was likely a

reasonable outcome, as persons with severe or profound mental retardation probably require more services, on average, than persons with unknown level of mental retardation.

The main effect of Ethnicity was also significant, F (4, 1271) = 3.84, $p < .005$. Means showed that consumers in the Other category reportedly received the highest number of types of resources (M = 6.66), that consumers in European American (M = 5.63), Hispanic (M = 5.54), and Asian American groups (M = 5.47) receiving middling levels of types of services, and that African American consumers reportedly received the lowest levels of number of resources (M = 4.98). The Cohen's d for the largest contrast between means was 0.56, a medium-sized effect, which deserves further study.

The main effect of Regional Center was significant, F (2, 1271) = 4.14, $p < .001$. As one might expect, results showed that consumers at high expenditure centers reportedly receiving a larger number of types of resources (M = 6.22) than did consumers at low expenditure (M = 5.43) or medium expenditure (M = 5.32) centers. The Cohen's d for this effect was 0.30, a small effect.

The main effect of respondent was also significant, F (1, 1271) = 21.22, $p < .001$. Service coordinators reported that consumers received a higher number of types of resources (M = 6.16) than did parents/guardians (M = 5.16). Although the mean difference was exactly 1.0 additional types of service reported by service coordinators, the effect was only small-to-medium in magnitude, $d = 0.33$.

Two interactions moderated the main effect of respondent. The first of these was the Age Group by Respondent interaction, F (3, 1271) = 13.50, $p < .001$. Means here showed that service coordinators and parents/guardians agreed fairly well on number of types of services received by younger adults (M = 6.17 and 5.94, respectively) and older adults (M = 5.05 and 5.44, respectively). However, service coordinators reported substantially higher levels of number of resources received than did parents/guardians for consumers who were infants/children (M = 6.58 and 4.73, respectively) and adolescents (M = 6.61 and 4.53, respectively). The effect size for the largest of these contrasts between means was $d = 0.69$, a fairly large effect that deserves further study.

The second significant interaction with respondent was the Level of Mental Retardation by Respondent interaction, F (4, 1271) = 5.30, $p < .001$. Service coordinators and parents/guardians agreed fairly well on the number of types of resources received by persons with mild (M = 5.18 and 5.17, respectively), moderate (M = 5.76 and 5.29, respectively), or unknown (M = 4.62 and 4.51, respectively) levels of mental retardation. But, service coordinators reported much higher levels of number of resources than did parents/guardians for consumers at the severe (M = 7.47 and 5.86, respectively) and profound (M = 7.74 and 4.98, respectively) levels of mental retardation. The Cohen's d for the largest contrast between means was 0.92, a rather large difference that deserves further study.

Need for Services

Need for Information. With regard to need for information, analyses revealed two significant main effects and three significant interactions. The first main effect was that of Age Group, F (3,

1287) = 8.15, $p < .001$. This main effect revealed that infants/children and adolescents (M = 1.93 and 2.26, respectively) had higher needs for additional information than did younger adults and older adults (M = 1.53 and 1.03, respectively). Given the pooled estimate of standard deviation of 2.39, the largest difference between means was associated with a Cohen's *d* of 0.51, so was a medium-sized effect.

The Gender by Level of Mental Retardation interaction was also significant, F (4, 1287) = 3.61, $p < .01$. At four of the five levels of mental retardation, males and females had similar levels of rated need for information. Specifically, females tended to have slightly higher needs for information than did males for consumers with mild (M = 2.00 and 1.73, respectively), moderate (M = 2.19 and 1.93, respectively), severe (M = 1.92 and 2.03, respectively), and unknown (M = 1.21 and 0.77, respectively) levels of mental retardation. But, for consumers at the profound level of mental retardation, males (M = 2.53) had much higher reported needs for information than did females (M = 0.57). The latter difference was the largest difference between means and was consistent with a Cohen's *d* of 0.82, a relatively large effect.

Respondent was a significant main effect, F (1, 1287) = 197.69, $p < .001$. Service coordinators perceived a much lower level of need for information (M = 0.64) than reported by parents/guardians (M = 2.73). The difference between these means had a Cohen's *d* of 0.87, a large effect that should be the object of further study.

Two interactions moderated the main effect of respondent. The first of these interactions was the Age Group by Respondent interaction, which was significant, F (3, 1287) = 15.46, $p < .001$. The means for this interaction showed an interesting pattern: service coordinators reported low need for information for infants/children (M = 0.41) and then higher needs for adolescents, younger adults, and older adults (M = 0.76, 0.71, and 0.70, respectively). In contrast, parents/guardians reported the highest levels of need for information for infants/children and adolescents (M = 3.44 and 3.72, respectively) and lower levels for younger adults and older adults (M = 2.35 and 1.36, respectively). The largest contrast between mean differences was associated with a Cohen's *d* of 0.99, a large effect that should be followed up by further research.

The second interaction with Respondent was the Regional Center by Respondent interaction, F (2, 1287) = 4.82, $p < .01$. Service coordinators reported a lower level of need for information in low expenditure centers (M = 0.57) and than at medium and high expenditure centers (M = 0.70 and 0.66, respectively). In contrast, parents/guardians reported the highest level of need for information at low expenditure centers (M = 3.19) and lower levels for medium expenditure (M = 2.89) and especially high expenditure centers (M = 2.11). The largest contrast between mean differences had a Cohen's *d* of 0.49, a medium-sized difference.

Need for Support. The analyses of need for support revealed similar trends as those for need for information, with two significant main effects and three significant two-way interactions. The first significant main effect was for Age Group, F (3, 1271) = 7.27, $p < .001$. Respondents reported the highest levels of need for support for consumers who were infants/children or adolescents (M = 0.89 and 0.99, respectively), and lower levels for younger adults and older adults (M = 0.81 and 0.82, respectively). The largest contrast between means had a Cohen's *d* of 0.15, a very small effect.

Mirroring analyses for need for information, the Gender by Level of Mental Retardation was significant for need for support, F (4, 1271) = 3.58, $p < .01$. Respondents reported only modestly different levels of need for support for female and male consumers if those consumers were at the mild (M = 0.87 and 0.82, respectively), moderate (M = 0.93 and 0.85, respectively), severe (M = 0.68 and 0.90, respectively), or unknown (M = 0.87 and 0.54, respectively) levels of mental retardation. However, for consumers with profound mental retardation, respondents indicated that male consumers required much higher levels of support (M = 1.67) than did female consumers (M = 0.68). The largest contrast between mean differences had a Cohen's d of 1.11, a rather large effect. If replicated, the effect is worthy of additional study.

The main effect of Respondent was also statistically significant, F (1, 1271) = 156.61, $p < .001$. Service coordinators once again reported much lower levels of perceived need for support (M = 0.51) than did parents/guardians (M = 1.25). The contrast between means had a Cohen's d of 0.62, a medium-to-large sized effect.

The main effect of Respondent was moderated by two two-way interactions. The first of these was the Age Group by Respondent interaction, which was significant, F (3, 1271) = 7.27, $p < .001$. Across the four age groups (infants/children, adolescents, younger adults, and older adults), ratings showed a largely linear increase in perceived need for support by service coordinators (M = 0.26, 0.47, 0.55, and 0.77, respectively), but a largely linear decrease in perceived need for support by parents/guardians (M = 1.53, 1.51, 1.08, and 0.87, respectively). The largest contrast between means had a Cohen's d of 0.98, a large effect deserving further study.

The second interaction with Respondent was the Ethnicity by Respondent interaction, which was significant, F (4, 1271) = 5.80, $p < .001$. The mean ratings by service coordinators were approximately a full point lower than ratings by parents/guardian for consumers who were African American (M = 0.90 and 1.80, respectively), Asian American (M = 0.31 and 1.30, respectively), or Hispanic (M = 0.42 and 1.41, respectively), but only about 0.4 points lower for consumers from the Other (M = 0.30 and 0.67, respectively) and European American groups (M = 0.64 and 1.06, respectively). This interaction can be interpreted in several ways. For example, one might argue that service coordinators pay more attention to certain groups and therefore tend to agree more closely with European American or Other ratings than with those from other ethnic groups. Or, one might argue that the effect arises because parents/guardians with consumers who are European American or Other have lower levels of need for support than do parents/guardians with consumers from other ethnicities. Regardless, the largest mean contrast has a Cohen's d of 0.55, a medium-sized effect.

Need for Resources. The need for additional resources outcome variable was predicted significantly by three main effects and two two-way interactions. The first main effect was the effect of Age Group, which was significant, F (3, 1271) = 17.27, $p < .001$. Means showed higher levels of perceived need for consumers who were infants/children or adolescents (M = 2.79 and 3.49, respectively) and lower levels of need for additional resources for consumers who were younger or older adults (M = 1.67 and 1.55, respectively). Given the pooled estimate of residual standard deviation of 2.96, the largest mean difference was associated with a Cohen's d of 0.66, an effect of medium-to-large magnitude.

The second main effect was the effect of Ethnicity, F (4, 1271) = 5.50, $p < .001$. Consumers who were African American or Asian American had higher levels of need for additional resources (M = 3.49 and 3.26, respectively) than consumers who were Hispanic, Other, or European American (M = 2.52, 0.56, and 2.06, respectively). The largest mean contrast had a Cohen's d of 0.99, a rather large effect that deserves additional study.

The third main effect was that of Respondent, F (1, 1271) = 216.87, $p < .001$. Service coordinators perceived a much lower need for additional resources (M = 0.99) than did parents/guardians (M = 3.77). This mean difference was associated with a Cohen's d of 0.94, a large effect that should be the object of further study.

Two interactions once again moderated the main effect of Respondent. The first of these interactions was the Age Group by Respondent interaction, F (3, 1271) = 20.67, $p < .001$. Across the four age groups (infants/children, adolescents, younger adults, and older adults), service coordinators had an approximately constant level of perceived need for additional resources (M = 0.77, 1.39, 0.79, and 0.99, respectively). In contrast, parents/guardians perceived much higher need for additional resources if consumers were infants/children or adolescents (M = 4.82 and 5.59, respectively), than if consumers were younger or older adults (M = 2.55 and 2.10, respectively). The largest contrast between mean differences had a Cohen's d of 0.91, a relatively large effect.

The second interaction was the Ethnicity by Respondent interaction, F (4, 1271) = 8.47, $p < .001$. Parents/guardians had much higher levels of need for additional resources than perceived by service coordinators if consumers were African American (M = 4.99 and 1.99 for parents/guardians and service coordinators, respectively), Asian American (M = 5.25 and 1.27, respectively), or Hispanic (M = 4.26 and 0.78, respectively). Respondent differences were not as pronounced if consumers were Other ethnicity (M = 1.60 and 0.10 for parents/guardians and service coordinators, respectively) or European American (M = 2.74 and 1.37, respectively). Whether this difference is the result of service coordinators paying closer attention to needs of parents/guardians of consumers who were European American and Other ethnicities or if the latter parents/guardians simply had lower levels of need for additional resources is deserving of further study. The largest contrast between mean differences had a Cohen's d of 0.88, a rather large effect.

Satisfaction with Services

Satisfaction with Information. The analyses of satisfaction with information yielded a single significant effect, the interaction of Respondent and Level of Mental Retardation, F (4, 1181) = 4.03, $p < .01$. The means revealed that service coordinators and parents/guardians agreed closely on satisfaction for consumers with mild (M = 4.85 and 4.85, respectively), moderate (M = 5.03 and 4.97, respectively), and severe mental retardation (M = 4.85 and 4.86, respectively). The respondents differed, and in different directions, for the remaining two groups. Specifically, for consumers with profound mental retardation, service coordinators perceived higher satisfaction (M = 5.22) than parents/guardians reported (M = 4.61). For consumers with unknown level of mental retardation, service coordinators reported somewhat lower satisfaction (M = 4.87) than

did parents/guardians (M = 5.07). Because the pooled standard deviation was 0.68, the largest contrast between means represented an effect size, in Cohen's *d* metric, of $d = 0.90$, so represents a relatively large effect. However, the overall levels of satisfaction with information were rather high, resulting in a small standard deviation. Because a large difference appeared for only one of five levels of mental retardation and effect sizes at three of the levels were essentially zero, the difference here is of minor importance, although it deserves attention.

Satisfaction with Support. Analyses of satisfaction with support also resulted in a single statistically significant effect, the effect of Ethnicity, $F(4, 1053) = 3.58$, $p < .01$. Hispanic (M = 5.14) and Other (M = 5.16) reported the highest levels of satisfaction with support, Asian Americans the lowest (M = 4.87), and African American (M = 4.96) and European Americans (M = 4.98) had middling levels of satisfaction. The largest difference between groups had a Cohen's *d* of 0.42, so it was of small-to-medium size.

Satisfaction with Resources. Finally, satisfaction with resources led to a single statistically significant effect, the effect of Regional Center, $F(2, 1157) = 5.70$, $p < .01$. The means showed that respondents at high expenditure centers reported somewhat higher satisfaction with resources (M = 5.05) than did respondents at low or medium expenditure centers (M = 4.89 and 4.90, respectively). Given the pooled standard deviation of 0.65, the difference between means constituted a Cohen's *d* of 0.24, a rather small effect. This was only the second significant effect involving Regional Center in any of the nine analyses reported here. In particular, as reported in an earlier section, respondents at high expenditure centers reported receiving a higher number of services than did respondents at low or medium expenditure centers, a relatively small effect ($d = 0.30$), mirroring the relatively small difference in satisfaction shown here. Interestingly but not surprisingly, respondents receiving more types of resources report somewhat higher levels of satisfaction with those services, although both effects were rather small.

Summary of Results for Scale Scores

As a summary of the foregoing analyses, we note several trends. First, Age Group was frequently a significant effect, both as main effect (in 5 of 9 analyses) and in two-way interactions (in 8 two-way interactions). The potency of Age Group was expected, as receipt of information and resources are likely to vary positively with age, and need for additional information, support, and resources are likely to vary inversely with age. These effects were largely borne out.

The consumer's Level of Mental Retardation was also expected to have effects on the various outcome variables. Level of mental retardation had a significant main effect on only a single variable, but this was the one expected. That is, consumers with more severe levels of mental retardation received higher levels of resources than consumers with more mild levels of mental retardation. Level of mental retardation appeared in five significant two-way interactions, serving to moderate the relations of other variables – usually gender and respondent – on outcomes, but again these outcomes were largely expected.

Two variables that could help identify bias in service delivery are Gender and Ethnicity. The main effect of Gender was nonsignificant in all nine analyses, and Gender was involved in only two significant two-way interactions. Thus, the results with regard to Gender suggest that few

issues related to Gender are associated with notable differential receipt of services, need for additional services, or satisfaction with services received.

With regard to Ethnicity, the main effect of Ethnicity was significant in three analyses, and Ethnicity was involved in two two-way interactions. The three analyses with significant main effects of Ethnicity were (a) receipt of resources, (b) need for additional resources, and (c) satisfaction with support. These results revealed the following: (a) African American consumers received somewhat lower numbers of resources than did European American consumers, but consumers from the remaining identified minority ethnic groups (Asian American and Hispanic) received about the same number of services as European American consumers; (b) consumers from all identified minority groups (African American, Asian American, and Hispanic) had higher reported levels of need for additional resources than did European American consumers; and (c) relative to the remaining groups, Asian American consumers had lower levels of satisfaction with support, and Hispanic consumers somewhat higher levels of satisfaction with support. These discrepancies among groups may arise from several sources, such as socioeconomic status. For example, despite receiving about the same number of resources as European American consumers, consumers from the identified minority groups (African American, Asian American, and Hispanic) may have a higher reported need for additional resources because they are poorer and rely on DDS for a larger proportion of their service needs. Or, perhaps these higher perceived needs for additional resources arise from receipt of slightly smaller dollar amounts of service, as documented in our POS II Report #1. Regardless of the basis, these differences should be the topic of further research.

The main effect of Regional Center was significant in two analyses, and Regional Center was involved in only one two-way interaction. Interestingly, but not surprisingly, high expenditure Regional Centers had higher mean levels of number of resources provided and slightly higher levels of satisfaction with those resources received. Both of these effects were of rather small magnitude, suggesting that the differences revealed should be noted but are not of major concern.

The final effect was that of Respondent, which was a significant main effect in 5 of the 9 analyses and contributed to 10 two-way interactions. Uniformly, service coordinators reported higher levels of two types of service – support and resources – than did parents/guardians, and service coordinators reported substantially lower needs for additional services in all three categories – information, support, and resources. The 5 main effects were of notable magnitude, and the 10 two-way interactions served to magnify many of these differences for certain groups. The consistency of the effects and their direction should be a cause for considerable concern. At present, we cannot determine whether service coordinators or parents/guardians are more accurate in their estimates of number of services received. Moreover, service coordinators and parents/guardians appear to differ in important ways on perceived need for additional services, with parents/guardians perceiving much higher needs for additional services. Clearly, additional work must be done to understand the differences associated with the differing viewpoints of service coordinators and parents/guardians in order to bring perceptions and expectations into closer agreement.

B. Survey Data: Subsample

Introduction

This section of the POS II project involved a "mini-study" within the larger study. We had available to us a rather unique intact sample of Hispanic or Hispanic families who all had sons or daughters with developmental disabilities. These families had already been involved as subjects in the University of California- Riverside, Families Project. As part of that project, they participated in home interviews, and completed a variety of measures pertaining to aspects of their own well-being. The focus of the broader investigation was on the transition to adulthood (Blacher, 2001; Kramer & Blacher, 2001; Kraemer, Blacher, & Marshal, 1997). Thus, we had measures of family well-being not available for the larger sample. What we hoped to gain from the inclusion of this sample is further understanding of how family needs, services received, and satisfaction with services relate to one another, and how these domains relate to young adult age, ethnicity, family socioeconomic status, family well-being, and family decisions about out-of-home placement.

Although our last wave of interviews of Families Project families was nearly completed before the survey instrument was completed and approved, we still had 95 Latino families (and 40 Anglo families) awaiting interviews. While these sample sizes were small, they were still of adequate size for looking within the Hispanic group, and for making some limited comparisons between groups.

It is important to note some unique aspects of this sample relative to the larger one, and why we elected to conduct these additional analyses. First, the subsample allowed us to gather survey data from close 100 Spanish-speaking families; we couldn't be sure that the random selection used in the larger survey study would result in this many Spanish-speaking families (even though the survey was available in Spanish.) Second, these families completed the survey instrument during an in-person interview in their own home, thus allowing the interviewers to clarify questions or concerns, and to note any useful comments. Third, the "children" of these families were all young adults, between the ages of 18 and 28. Thus, this sample is more homogeneous and more narrow in scope on some of the key variables examined in POS II Report #1 (e.g., regional center, age of consumer, ethnicity, level of mental retardation). However, this homogeneity should make findings more readily interpretable and easy to generalize to this particular group.

Previous Analyses Relevant to the Current Study

We have conducted previous analyses using our Latino sample that bear some relationship to the current POS II study. As noted above, we have data on Hispanic families (most monolingual, Spanish speaking), as well as on comparison families (all English speaking) of diverse ethnicity, though primarily Anglo. These families live in Southern California and are served by 7 Regional Centers. Over the years we have focused on the impact of a child with severe disabilities on the family, with particular emphasis on supports that mitigate stresses and decrease the likelihood of out-of-home placement. We have monitored the use of informal and formal supports (that include state-provided respite care, support from Regional Center case managers, government subsidies and so on.). We have in this database more family and environmental process variables than could ever be gathered in one calendar year (it takes

approximately two years to gather one full wave, and we have from two to seven waves on these families).

In a preliminary way we have examined how the services these families received related to their perceived needs and well being, in addition to the more obvious demographics derived from surveys (e.g. child age, ethnicity). As one illustration, consider a survey finding relating expenditures to ethnicity – for example, lower service expenditures for Latino families. We know that costs vary widely depending upon where a client or consumer lives – in her own home or in a community residence. We also know, from previous studies, that Hispanic families are much less likely to seek community placement than Anglo families. Direct interviews, however, help us determine whether the inclination to keep the son or daughter at home is because Hispanic families know less about residential options (an access issue) or because cultural values such as familism make placement unthinkable (a cultural issue). Thus the non-equivalence in spending may result indirectly from responsiveness to parental desires, rather than from some type of ethnic bias.

Another construct in which we have abiding interest is family well-being. We have been particularly concerned about this in our Hispanic sample, as some previously published papers Blacher, Lopez, Shapiro, & Fusco, 1997; Blacher Shapiro, Lopez Diaz & Fusco, 1997) have suggested high rates of depressive symptomatology reported by Latina mothers of children with severe disabilities. With high depression often comes low morale and high stress. Here, we have an opportunity to see whether service needs and supports, as assessed by the survey developed for the POS II study, relate to any indices of family well-being.

We believe that further examination of our existing interview data and the collection of new information from these families will help us to determine the relevance of relationships derived in broader surveys. We were able to incorporate the survey instrument developed for use as part of this POS II study (The Family Needs & Support Survey) into the interviews remaining in this phase of the UC Riverside Families Project. Ninety-five Latina and 40 Anglo mothers completed the survey during the DDS timeframe. The findings reported here are from these interviews.

The aim here was twofold: (1) to assess service needs, actual services received, and satisfaction with services as perceived by parents in this subsample; and (2) to contrast the service needs and experiences of the subsample of Latino and Anglo families in Southern California.

Method of Study

Samples

The samples consisted of 95 Hispanic families and 40 Anglo families. The family ethnic designation was determined by the ethnicity reported for the young adult. It should be noted here that all of the target subjects in this subsample were young adults, and all had significant intellectual disabilities; hence, there was a restricted age-range and level of functioning.

Survey Instrument

An earlier version of the same survey that was administered to the regional center sample of parents/consumers was given to the parents in this Families Project. There were three, probably nonsignificant differences: 1) this survey was not available in an on-line version; 2) it was administered as part of an in-person interview, and not mailed; 3) the response categories were slighted different than in the final version; however, two regional centers that served as "pilots" for the larger study received this same version; both versions yielded equivalent information, but in a slightly different format.

Because this entire sample of families had sons or daughters with developmental disabilities who were young adults, we omitted two items from the Resources section of the survey pertaining to infants (Infant Development Program and Infant Development Specialist.)

Additional Instruments Administered to Families

Information on these instruments is contained as a note at the end of this section. This report focuses more on their overall relationship to family support needs and satisfaction. [a]

Demographics: Overall

The mean age for the young adults in this sample, Hispanic and Anglo combined, was 22.7 years (range: 18 to 28), and 59% were males. Adaptive behavior was quite low, with a mean standard score of 23.9 on the Vineland, which has a floor of 20 points.

Respondents' mean age was 51.6, and 65% were married. Fifty- eight % were high school graduates, and 38% had incomes of $35,000 or more.

Demographics: By Sample

Table 1 shows the child and parent demographic variables by sample (Anglo vs Hispanic). It also shows scores on five measures of parent well-being.

In contrasting the Anglo and Hispanic samples, child (young adult) variables were quite similar. Young adults in the Anglo sample were slightly, but significantly, older, and accordingly, a higher percent had exited from school. The samples did not differ on young adult adaptive or maladaptive behavior.

Parent demographics differed on socioeconomic indicators, with the Anglo sample scoring significantly higher than the Hispanic sample on years of education and family income.

Parent well-being was mixed, with Hispanic parents scoring higher on depression but also higher on a measure of the positive impact of the child on the family. This finding is consistent with other analyses we have done, indicating that Latina mothers report more positive impact of their young adult on the family than Anglo mothers; however, they report nearly the same negative impact as the Anglo mothers.

Table 1

Demographic and Well-being Variables (Hispanic n= 95 vs Anglo n=40)

	Anglo	Hispanic	t or Chi Square
Child variables:			
Child Age	23.7	22.4	t = 2.75**
Child Gender (% male)	57	60	Chi Sq = 0.01
Exited from School (%)	86	59	Chi Sq = 5.69*
Adaptive Behavior	28.0	22.6	t = 1.94
Reiss Total	8.1	6.5	t = 0.94
SIB-R Total	-12.9	-13.2	t = 0.09
Parent demographics:			
Respondent Age	50.3	52.2	t = 1.30
Marital Status (% married)	78	60	Chi Sq = 3.07
Education	4.7	2.5	t = 8.23***
Family Income	5.3	2.7	t = 9.14***
Well-Being variables:			
Positive Impact	11.2	15.6	t = 4.77***
Negative Impact	19.1	16.3	t = 1.50
Morale	12.8	11.7	t = 1.12
Depression	9.1	13.3	t = 2.60*
Marital Adjustment	112.0	112.4	t = 0.11

*p<.05; **p<.01; ***p<.001

Needs, Services, and Satisfaction: Overall

Table 2 shows scores for the total sample on information, support, and resource needs. It also shows the satisfaction with services received, and unmet service needs. The average family reported a total of 18.58 needs, and received services that met 43.2% of these needs, or a mean of 8.02 services. Their expressed satisfaction with these services received was high, with a mean satisfaction score of 4.60 on a scale of 1 to 6.

Table 2

Total Needs, Services, and Satisfaction

	Information	**Support**	**Resources**	**Total**
Number of items	10	5	17	32
Mean needs indicated	6.11	2.61	9.86	18.58
Mean services received	1.93	0.96	5.13	8.02
Mean satisfaction with services received	4.53	4.71	4.64	4.60
Percent of needs that are unmet	68.4	63.2	48.0	56.8

*p<.05; **p<.01; ***p<.001

Needs: By Sample

The two samples were compared on a total needs score, as well as on the expressed needs in the domains of information, support, and resources. The samples differed significantly on total needs (Hispanic = 19.9; Anglo = 15.4, t = 3.93, p <.001). *Within domains, Hispanics expressed significantly greater needs for information and resources, though not support, than Anglos*.

Services Received: By Sample

The two samples were compared on a total services received score, as well as on services received in the domains of information, support, and resources. The samples differed significantly on total services received (Hispanic = 7.1; Anglo = 10.2, t = 4.14, p <.001). *Within domains, Hispanics received significantly fewer support and resource services, though not information services, than Anglos.*

Satisfaction with Services Received: By Sample

The two samples did not differ on a mean satisfaction score (Hispanic = 4.60; Anglo = 4.60.) This finding is of interest, given that the two samples differed quite significantly on the number of perceived service needs and services received.

Relationship among Needs, Services, and Satisfaction

Parents with greater expressed needs did not receive more services; the correlation (r = .15) was not significant.

Parents with greater expressed needs were significantly less satisfied with the services they did receive (r = -.24, p = .006).

Parents who received more services expressed greater satisfaction with them (r = .27,

p =.001).

These findings indicate that, at least within this sample, parents who receive more services are more satisfied, and that expressed need does not relate to the number of services received.

Unmet Service Needs

We created a variable called "unmet service needs" that combines parents' perceived needs and the extent of services received to address those needs. *Met service needs* is represented by a ratio of services received divided by needs. *Unmet service needs* is a proportion (1 – met service needs). Unmet service needs for the families studied ranged from .00 (all needs met) to .95 (almost all needs not met). The average was .52, indicating that about half of the parents' expressed needs were not met.

Further correlational analyses indicated that:

(a) Respondents with higher unmet needs had higher total needs, $r = .52$, $p < .001$.

(b) Respondents with higher unmet needs received fewer services, $r = -.69$, $p < .001$.

(c) Respondents with higher unmet needs expressed less satisfaction with the services that they did receive, $r = -.39$, $p < .001$.

When considered by sample, unmet needs were twice as high for Hispanics (61%) as for Anglos (31%); this is a highly significant difference, $t = 7.01$, $p < .001$.

Hispanics and Unmet Needs: An Artifact of Demographic Differences*?*

Hispanics reported significantly greater unmet needs than Anglos. In attempting to understand this difference, we must first consider the other ways that these samples differed. As indicated above, the samples differed significantly on child age, whether or not the young adult had exited from high school already, respondent's education, family income, respondent's depression, and respondent's perceived positive impact. All but the last of these variables also correlated significantly with the "unmet needs" variable. Thus, the sample differences might be accounted for entirely by these demographic differences.

To test this, we conducted a hierarchical regression on "unmet needs." In the first step, we entered the two child demographics on which the samples differed: age and school status; these accounted for 3.8% of the variance, which was not significant. On the second step, we added the family socioeconomic variables, education and income; these accounted for an additional, significant 18.2% of variance (F change = 13.42, df 2,115, $p < .001$). On the third step, we added the well-being variable of depression; this did not account for additional variance. On the fourth and final step we added "sample," which accounted for an additional 6.4% of variance, which was also significant (F change = 10.16, df 1,113, $p = .002$). Thus, Hispanic ethnic status accounted for significant variance in "unmet needs" even after other sample differences were accounted for. *In other words, in this particular sample of Latina mothers, there clearly are unmet perceived service needs, and moreso in this group than in their Anglo counterparts.*

Within Hispanic Sample Analyses

To further understand service needs within the Hispanic sample, we ran correlations between three FNSS total scores (needs, services received, and unmet needs) and all of the child and parent variables in Table 1. In addition, an acculturation measure was available for the Hispanic sample. Total unmet needs and total services received were not related to any of these

measures. However, the total needs score was significantly related to a number of child and parent variables. Total needs was predicted by level of acculturation (r = -.31), child behavior problems (Reiss total, r = .48; SIB-R r = -.45), socioeconomic variables (respondent education, r = -.22; income, r = -.28) and respondent well-being (negative impact r = .35; morale r = -.29; depression r = .21). *What these correlations mean, is that Latina mothers who expressed more total service needs were less acculturated, had sons or daughters with more severe behavior problems, were of lower education/income, and experienced more negative impact on parenting and more depressive symptoms.* However, correlational analyses are ***not*** causal, i.e., we can't say whether these mothers would have higher well-being if all of their service needs were met or not.

In a further attempt to determine the independent contributions of these variables in predicting Latina mothers' expressed service needs, we conducted a regression analysis, accounting for 29% of the variance. Step 1 included behavior problems (Reiss total score), and this accounted for 22.8% of the variance, F = 26.90, p = .001. Step 2 included acculturation to English, and accounted for an additional 5.4% of the variance, R = 6.74, p = .01. When income was entered in Step 2 instead of acculturation, the result was virtually identical, as these two variables were highly correlated. Step 3 included the well-being variables, and these did not account for significant additional variance. *In sum, then, the extent of Latina mothers' need for service is best predicted by knowing the extent of her child's behavior problems (more problems, more needs) and her degree of acculturation (less acculturation, more needs) or family income (lower income, more needs).*

Further Analysis of Individual Needs

Tables 3a, 4a, and 5a show the individual items in the need for information, support, and resources domains, rank ordered highest to lowest by the proportion of respondents expressing each need. The highest needs for information expressed by at least ¾ of the combined sample were in the following areas: Information about regional center services, and information about recreational services. The highest needs for resources that were expressed by at least ¾ of the combined sample were help in finding: Access to SSI, access to Medi-Cal, medical services for the young adult, in-home respite care, and transportation. Tables 3a, 4a, and 5a also show the percentage of Anglo and Hispanic parents expressing each need. *In almost all cases where there was a significant difference (indicated by an asterisk next to the Chi square value shown in the last column), Hispanic parents expressed greater need.*

Table 3b, 4b, and 5b also show these same items, but rank ordered according to "unmet needs," – the proportion of families expressing each need who were not receiving services to address the need. *The highest expressed needs (Tables 3a, 4a, 5a) tended to be among the lowest with unmet needs, indicating that Regional Center services are responsive to the most commonly expressed needs. Yet many of the other service needs were being met for a remarkably low percent of families. Among the greatest unmet needs, for the combined sample, were information about sexual development (84.5% of those who expressed these needs did not receive the service), information about recreational services (74.8%), help in behavior management (80%) or in handling stress (78.6%) and help in finding the following resources: home health agency (90.2%), specialized autism programs (85.7%), behavioral intervention (82.7%) and social skills program (82.1%). As noted above, on average about half of the expressed needs were not being addressed, in either sample.*

Table 3a

NEED FOR INFORMATION: ANGLO and HISPANIC

Ranked From Highest to Lowest % expressing Need in combined sample

	Combined	Anglo	Hispanic	Chi Square
Need for information about:				
1. Regional Center services	96.3	88	100	9.08**
2. Recreational services	76.3	68	80	1.79
3. Child's disability	63.0	30	77	24.51***
4. Sexual development	62.2	45	70	6.17-
5. Vocational services	60.7	35	72	14.30***
6. Development	59.0	28	73	21.92***
7. How to teach my young adult	56.3	38	64	7.11**
8.5 Social development	53.3	35	61	6.66*
8.5 How to manage behavior	53.3	38	60	4.86*
10. Residential placements	30.3	32	30	0.02

*p<.05; **p<.01; ***p<.001

Table 3b

UNMET NEED FOR INFORMATION: ANGLO and HISPANIC

Ranked from Highest to Lowest Unmet Needs in combined sample
(Unmet Need = 1 – Service received/Need Indicated)

	Combined	Anglo	Hispanic	Chi Square
Need for information about:				
1. Sexual development	84.5	66.7	89.4	3.98*
2. How to teach my young adult	84.2	73.3	86.9	0.80
3.5 How to manage behavior	81.9	73.3	84.2	0.36
3.5 Social development	81.9	71.4	84.5	0.57
5. Vocational services	81.7	50.0	88.2	8.94**
6. Development	76.3	54.5	79.7	2.07
7. Recreational services	74.8	44.4	85.5	15.71***
8. Child's disability	55.3	33.3	58.9	1.79
9. Residential placements	48.8	30.8	57.1	1.53
10. Regional Center services	30.0	25.7	31.6	0.19

*p<.05; **p<.01; ***p<.001

Table 4a

NEED FOR SUPPORT: ANGLO and HISPANIC

Ranked From Highest to Lowest % expressing Need in combined sample

	Combined	Anglo	Hispanic	Chi Square
I Need:				
1. Financial help to purchase services or equipment	65.5	58	68	0.05
2. To meet more regularly with my RC service coordinators	60.7	80	53	7.73**
3. Support from other parents/ providers	49.6	42	53	0.79
4. Help behavior management	44.4	32	50	2.63
5. Help handling stress	41.5	40	42	0.05

*p<.05; **p<.01; ***p<.001

Table 4b

UNMET NEED FOR SUPPORT: ANGLO and HISPANIC

Ranked from Highest to Lowest Unmet Needs in combined sample
(Unmet Need = 1 – Service received/Need Indicated)

	Combined	Anglo	Hispanic	Chi Square
I Need:				
1. Help in behavior management	80.0	62	85	2.22
2. Help handling stress	78.6	53	88	4.90*
3. Support from other parents/ providers	68.7	41	78	6.37*
4. Financial help to purchase services or equipment	60.2	26	72	13.28***
5. To meet more regularly with my RC service coordinator	39.0	6	60	21.48***

*p<.05; **p<.01; ***p<.001

Table 5a

NEED FOR RESOURCES: ANGLO and HISPANIC

Ranked From Highest to Lowest % expressing Need in combined sample

	Combined	Anglo	Hispanic	Chi Square
I Need Help Finding:				
1. Access to SSI, other relief	89.6	88	90	0.05
2. Access to Medi-Cal	87.4	78	92	3.87*
3. Medical services: consumer	79.3	80	79	0.00
4. Respite care: In-home	77.8	60	86	8.98**
5. Transportation	77.0	82	75	0.57
6. Day program option	70.4	62	74	1.20
7. Speech therapy	65.2	35	78	20.97***
8. Vocational, habilitation program	62.2	52	66	1.74
9. Medical services for self:	60.0	62	59	0.04
10. Social skills program	57.8	45	63	3.10
11.5 Occupational therapy	50.4	35	57	4.53*
11.5 Physical therapy	50.4	38	56	3.07
13. Respite care: Out-of-home	42.2	30	47	2.80
14. Behavioral intervention	38.5	28	43	2.29
15. Home health agency	37.8	12	48	13.96***
16. Community living option	22.2	38	16	6.47*
17. Specialized autism program	10.4	8	12	0.16

*p<.05; **p<.01; ***p<.001

Table 5b

UNMET NEED FOR RESOURCES: ANGLO and HISPANIC

Ranked from Highest to Lowest Unmet Needs in combined sample
(Unmet Need = 1 – Service received/Need Indicated)

	Combined	Anglo	Hispanic	Chi Square
I Need Help Finding:				
1. Home health agency	90.2	80	91	0.00
2. Specialized autism program	85.7	67	90	0.02
3. Behavioral intervention	82.7	54	90	5.43*
4. Social skills program	82.1	39	95	25.91***
5. Respite care: Out-of-home	75.4	67	78	0.17
6. Vocational, habilitation	73.8	38	86	16.09***
7. Occupational therapy	73.5	57	78	1.49
8. Physical therapy	69.1	40	77	5.99**
9. Speech therapy	67.0	43	72	3.20
10. Day program	54.7	24	66	11.31**
11. Community living options	53.3	33	73	3.35
12. Medical services: consumer	38.3	16	48	8.62*
13. Medical services: self	34.6	4	48	13.05***
14. Transportation	26.0	12	32	3.82
15. Respite care: In-home	21.0	21	21	0.00
16. Access to SSI, other federal relief	10.7	0	15	4.46*
17. Access to Medi-Cal	6.8	0	9	1.78

*p<.05; **p<.01; ***p<.001

Comparing Anglo and Hispanic families, Hispanics had greater needs in every case where the difference was significant, and there were some striking differences in unmet needs. Among the highest, in the domain of support needs, were: meeting regularly with Regional Center service coordinators, and financial help to purchase services speech therapy for the young adult. *We note that Latina mothers reported higher unmet needs than Anglo mothers in every category of support*. Latina mothers also expressed higher unmet need for information about recreational services, and high unmet resource need in the area of speech therapy. We note that

in every category but one (#15, in-home respite care) Latina mothers had higher unmet resource needs.

Summary

In summary, the Hispanic and Anglo samples differed on a number of variables that related to unmet service needs; these included variables such as child age, respondent's education, family income, mother's symptoms of depression, and mother's perception of positive impact of the child on the family. All but the last of these variables also correlated significantly with the "unmet needs" variable. When these differences between samples were controlled in statistical analyses, Hispanic status still accounted for significant variance in unmet service needs.

In conclusion, Hispanic families expressed significantly greater needs than Anglo families, and they also received significantly fewer services. The percentage of unmet service needs was twice as high for Hispanic families. Thus, it is clear that these Latina mothers at least perceived that they had a number of unmet needs. However, we did not have service coordinator data for each of these families, so it is difficult to determine the validity of these perceptions. Overall, the Latina respondents to this survey were quite satisfied with the services they were receiving, despite the fact that only about half of their expressed needs were being met.

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[a] Measures included young adult demographics, including adaptive and maladaptive behavior, family demographics, and questionnaires about family well-being. All of the instruments, except the family well-being measures for some families, were collected in a face-to-face session with the caregivers. A few families preferred to fill these out privately.

The Family Data Sheet. This demographic questionnaire has been used previously in this research program (e.g., Blacher, 1985; Blacher, Hanneman, & Rousey, 1992).

Acculturation Measure. The acculturation scale utilized was *The Bidimensional Acculturation Scale for Hispanics, BAS* (Marin & Gamba, 1996). This scale that yields scores for two major cultural dimensions (Hispanic and non-Hispanic.) There are 12 items for each cultural domain that measure three language-related areas. Individuals can score high on either domain, or both (indicating biculturalism.) The authors report reliability and validity indices that are comparable or higher than those found with other published acculturation scales.

Vineland Adaptive Behavior Scales (VABS; Sparrow et al., 1984). The Vineland was administered to mothers as a structured interview. This measure yields four domain scores (communication, daily living skills, socialization, and motor skills), and an overall adaptive behavior composite (m = 100; sd = 15).

Scales of Independent Behavior - Revised, Problem Behavior Scale (SIB-R; Bruininks et al, 1996). The Problem Behavior Scale of the SIB-R provides a general maladaptive index, comprised of eight problem items organized into three broad maladaptive behavior indexes (Internalized (3 items), Externalized (3 items), and Asocial (2 items). Each item is rated according to frequency of occurrence and severity. Total scores can range from +10 (good) to –74 (extremely serious). The mean for "normal" samples is 0 (SD = 10). A cut-off score of –21 and below was used to classify maladaptive behavior as moderately serious to serious.

Reiss Screen for Maladaptive Behavior (2nd ed.). The Reiss Screen (Reiss, 1994) is a 38-item screening tool used to identify mental health problems in adolescents and adults across the full range of mental retardation. Items describe discrete behavior categories with a three-point response scale of "No problem" , "Problem", and "Major Problem". Operational definitions of each point take into consideration the frequency, intensity, and social impact of the behavior. The Reiss Screen contains eight sub-scales (5 items each) with eight of the items double loading on subscales: aggressive behavior; autistic symptoms; psychosis; paranoia; depression behavioral symptoms; depression physical symptoms; dependent personality disorder; and avoidant behavior. In addition to these subscales, six single-item maladaptive behaviors are included: drug abuse; over activity; self-injury; sexual problems; stealing; and suicidal tendencies. The Reiss Screen manual (1994) suggests using a 26-item total score and a cut-off score of 9 or above to indicate clinically significant risk of mental illness.

Family Impact Questionnaire (FIQ). The FIQ (Donenberg & Baker, 1993) is a 50-item Likert-type questionnaire assessing the perceived impact that a child has on the family relative to the impact that other children have on their families. The FIQ has six sub-scales, three of which were used in the present study, yielding two composite scores. The Negative Impact score is essentially a measure of parenting stress; it is comprised of the Negative Feelings Toward Parenting subscale (11 items) and

the Negative Impact on Relationships (9 items) subscale, with an alpha of .90 in this sample. The Positive Impact on Parenting score is a subscale (7 items), with an alpha of .85. Not included were the subscales on Financial Impact and the two subscales pertaining to marriage and siblings, because there is inevitably missing data on these.

Center for Epidemiologic Studies-Depression (CES-D). The CES-D (Radloff, 1977) is a 20-item Likert-type questionnaire assessing the respondent's depressive symptoms of mood, perceptions, and outlook in the general population. A total score of 16 or greater designates the clinical range for depressive symptomatology. While some researchers suggest that Hispanics may report elevated scores on the CES-D, it has been used frequently in cross-cultural research (Blacher, Lopez, et al., 1997; Blacher, Shapiro, et al., 1997; Magana, 1999).

Philadelphia Geriatric Center Morale Scale (PGC). The PGC (Lawton, 1972) is a 14-item self-administered yes/no questionnaire used to assess the respondent's general morale/mood and attitude toward life. The range of scores is 0 to 18 (including three summary questions that can total four points). Lawton reported Kuder-Richardson-21 reliability coefficient = .81.

C. Focus Groups

Focus Group Component of the DDS Study

We have supplemented the quantitative findings from the service needs and support survey with qualitative results from our focus groups. Quantitative results are often deemed the most trustworthy outcomes of scientific research studies. However, quantitative results are limited by the structure of the instruments on which the data were gathered. Thus, the qualitative portion of our study design should help us determine what service needs or delivery issues are paramount for this smaller sample of consumer families, as reported by parents/consumers and service coordinators.

Background and Rationale for Focus Groups

As noted previously, one of the key concerns inherent in the POS II study was equity in service delivery, particularly with respect to non-English speaking constituents of regional centers. Recently, one of the authors of this report (Blacher) completed a study with monolingual and bilingual Spanish-speaking mothers of young adults with severe disabilities.[a] The following remarks have been adapted from that publication and are provided here to set the stage for understanding the new focus group data gathered as part of POS II.

Hispanic/minority family concerns about their relationships with service delivery/early education systems. Many minority families come to view the service delivery and/or educational system as a bureaucracy controlled by educated, monolingual, monocultural individuals whom they have no power to question (Nicolau & Ramos, 1990). These families often have not acquired the cultural capital – i.e., the deep understanding of implicit and/or explicit values, knowledge, practices, and ways of understanding and interacting that are rewarded in a given context (Apple & Beane, 1995; Bourdieu & Champagne, 1999; Portes, 1998) - with respect to U.S. institutions to understand what service delivery systems are there for and how they work. These concerns have been raised by a number of researchers, and have a great deal of face validity.

Minority family concerns with respect to the educational systems are relevant to our understanding of service delivery issues. Early studies of intervention programs generally reported high satisfaction among Hispanic parents (Lynch & Stein, 1987; McNaughton, 1994). However, an in-depth, qualitative study of five Hispanic families noted parental feelings of mistrust for teachers and other school personnel, and perceptions of school personnel as unfriendly or indifferent (Zetlin, Padron, & Wilson, 1996). A more recent study of Hispanic families similarly found that their degree of satisfaction with the educational and service delivery systems was only moderate, and that 17% were either mostly or entirely dissatisfied (Bailey, Skinner, Rodriguez, Gut, & Correa, 1999). Even more disturbing was the finding that greater awareness of programs and greater use of services were both associated with *greater* parental dissatisfaction. The most dissatisfied parents in this study cited teachers whom they felt were not committed; complained of feeling discriminated against because of their ethnic background by certain agencies; and were upset at not being able to find the services or information they needed. However, parents often confound public school and other and service delivery systems

in their remarks, making it difficult to determine if one institution is more satisfying than the other.

Hall (1977) argued that high context cultures, such as those of many Latin American countries, emphasize interpersonal networking and relationships based on personal knowledge, trust, warmth, and caring. This stands in contrast to low context cultures, such as that of the United States, which highlight criteria of objectivity and rationality in professional dealings. For example, Harry (1992a) reported findings from Puerto Rican mothers of children and adolescents with disabilities, who stated that they preferred Puerto Rican schools that wielded unquestioned authority, but also provided safety and love for students, to the more technical, less affectionate approach they encountered in the U.S. Other scholars have also commented on the importance of a professional interaction style with Hispanic parents that is personalized and characterized by a close and caring relationship (Cazden, Carrasco, Maldonado-Guzman, & Erikson, 1985). Confronted by professionals whose demeanor appears officious and indifferent, parents from high context cultures often feel mistrustful and ineffectual, although they may continue to "present the face of *respeto* (respect)" to authorities (Bennett, 1988, p. 150). The clash between the directive, quick fix, problem-solving American approach (McGowan, 1988) and the more indirect approach based on personal relationship may lead to many parent-professional misunderstandings.

Successful professional interactions with Hispanic parents of children with developmental disabilities. Drawing on both the early mental health literature of the 1970s and more recent special education literature regarding provision of services to Spanish-speaking and Spanish-surnamed individuals, we can identify certain general themes that have been recommended, although much less frequently adopted, to promote effective parent-professional relationships. These include treating family members and their cultural patterns with respect and cultivating interpersonal relations based on trust between families and representatives of formal institutions or organizations (personalismo) (Padilla, Ruiz, & Alvarez, 1976).

Harry (1992b) also made several suggestions for developing successful special education programs to serve culturally diverse populations. These included forming personalized, individual relationships with families rather than large-group structured interactions, as well as the use of parent advocates as mediators between parents and professionals from different cultural and socioeconomic backgrounds. Other authors similarly confirm the importance of being more person- than task-centered (Kalyanpur & Rao, 1991). A case study of community schools serving Hispanic and Southeast Asian children concluded that staff should function in a warm, caring, and respectful manner, not dissimilar to an extended family (Zetlin, Ramos, & Chen, 2001). An ideal parent-professional relationship should avoid formalism, proceed at an unhurried pace, incorporate humor, and encourage service providers to convey an attitude that is nonjudgmental, supportive, warm, friendly and caring (Salend & Taylor, 1993; Summers, Dell-Oliver, Turnbull, Benson, Santelli, Campbell, & Siegel-Causey, 1990). One recent study reported parents valuing teamwork, cooperation, partnership, shared responsibility, having a trusted group of people to use as a sounding-board, flexibility in the planning process that is tailored to the individual needs of the child, and collaboration and support (Blue-Banning, Turnbull, & Pereira, 2000). It is critical to recognize that, without exception, all of these recommendations, challenge

professional privilege, acknowledge multiple, coexisting, and equally valuable worldviews, and respect the cultural capital of both parents and professionals.

Relevance to the Regional Center System

Previous study involving family consumers of regional center. Our own study (Shapiro et al, in press) involved three focus groups comprised of 16 low-income Latina mothers of young adults with developmental disabilities. All parents were monolingual or bilingual Spanish-speaking; facilitators were bilingual. Of importance here is the fact that, while all mothers had sons or daughters who were clients of regional center, all were recruited explicity by Fiesta Educativa, an advocacy organization in East Los Angeles. This recruitment strategy likely yielded mothers who were more activist, more confrontational and more vocal than Latina mothers in general. On the other hand, they may have been more knowledgeable and aware of services to which they were entitled, and thus more able to articulate insights and perceptions than other more shy or less involved mothers.

These groups were conducted using strict focus group methodology and techniques. We utilized a content analysis approach that was initially descriptive, then interpretive. The unit of analysis was primarily each focus group, rather than individual comments, but data were compared both within group and across groups. In analyzing the data, we paid attention to disconfirming evidence and outliers. We also took into account elements of frequency, extensiveness, and intensity in the analysis. The goal of analysis was to identify patterns, make comparisons, and contrast one set of data with another. It is important to note here that these groups took many hours to conduct, involved literally hundreds of pages of transcript and took almost two years to analyze fully.

The primary concerns identified in the data were: a) Poor communication between professionals and parents; b) Low professional effort in providing services; c) Negative attitudes of professionals toward client children; d) Negative treatment of parents by professionals; e) The mother's role as central to the well-being of their children. These themes are elaborated in the manuscript, but of particular relevance here is that mothers tended to adopt a position of ***alienated advocacy*** in relation to their son's or daughter's educational and service needs. Alienated advocacy refers to how these mothers experienced the service delivery system – as cold, uncaring, and disrespectful of their own expertise with their children. This construct often led to interactions with school and service agency personnel marked by conflict and adversary.

> ***Group, 3 Rina*:** Le voy a decir una cosa, señora. Ellos tienen como 300 clientes. El que le de más lata, esa es a la que le van hacer caso. Yo a mi trabajadora le digo el lunes, "Okay, mi hija necesita estos servicios, el vienes quiero la respuesta." Y el viernes yo le hablo por teléfono, "Qué pasó?" "O, no, que mire," "Ok, el lunes arreglamos esto." Así se hacen las cosas… Es que a ellos no les interesan nuestros hijos. (I'm going to tell you something, mam. They have around 300 clients. The one who complains most is the one who they're going to give their attention to. I tell my worker on Monday, "Okay, my daughter needs these services, I want the response on Friday." And I call her on Friday by telephone, "What happened?" "Oh, but look," 'Okay, on Monday we'll fix this.' That's how these things are done…. It's that our children do not interest them.)

> ***Marta**:* Tienen que exigir, exigir sus derechos como quien dice. Por que ellos le dan la larga y si usted no habla…(You have to demand, demand your rights, as one would say. They'll give you the run around and if you don't speak up…)
> ***Ana*:** Mire, yo he peliado por el niño mio, yo he peliado mucho y yo me he metido donde quiera me metido. (Look, I have fought for my son, I have fought a lot and I have entered wherever I have entered.) [from: Shapiro et al, in press]

Rationale for the Selection of Focus Group Methodology, POS II

This study used focus group methodology to explore attitudes and beliefs of parents about services for their sons and daughters with developmental disabilities. Conducting focus groups involves the facilitation of informal discussion among a small group of people, selected according to a predetermined set of criteria. Each focus group is comprised of new individuals, and generally 3-5 such groups are conducted, or until the data achieve theoretical saturation (Morgan, 1998). Focus group members are asked to express their viewpoints or opinions on a particular topic about which they have special expertise or life experience. The objective of focus groups is to explore experiences and beliefs rather than to reach consensus (Carney et al., 1998). They are particularly useful in encouraging participants to provide candid, complete, and in-depth responses. Their dialogue creates a synergistic effect, allowing a wider range of insight and information than is possible with an individual interview (Stewart & Shamdasani, 1990). They are also particularly useful when working with individuals who have a history of limited power and influence (Morgan, 1993).

Recruitment and Participants

Since focus group participants are not intended to represent the entire population, there is no need for random selection. Rather, focus group participants are often selected instead on the basis of demographics, their established activism in the area, or on the basis of their experience or informed status. Focus groups are often recruited through recommendations of key informants, though volunteers are also welcomed.

Based on data provided in POS I and from our own analyses, we selected eight regional centers to participate in the focus groups, four from relatively low expenditure centers (Inland RC; San Diego RC; Central Valley RC; East Los Angeles RC), and four from high expenditure centers (Redwood Coast RC; Golden Gate RC; San Andreas RC; Kern RC). There was some variability in how each regional center recruited focus group participants, but in general, the recruitment was done in-house to preserve confidentiality. Once groups were assembled, confirmation letters were sent, and reminder phonecalls were made one day in advance of each group. Parents and staff were asked to sign a consent form at the beginning of each group that allowed them to participate, and that also allowed audio or videotaping for later coding. Parent or consumer participants received a small honorarium ($40.00) for their time.

All focus groups were moderated by Ms. Susan Berman of ImpactResearch [b]; bilingual Spanish-speaking translators were provided as needed.

There were 16 focus groups conducted, 8 for parents/consumers and 8 for staff. In all, a total of 61parents/consumers participated; of these, only 5 were consumers and only 4 spoke only Spanish. Groups ranged from 5 to 13 participants. These participants represented 58 consumers, of whom 32 were males. Consumers ranged in age from 10 months to 51 years, and had a range of disabilities described by parents as including: mental retardation, developmental delay, cerebral palsy, epilepsy, autism spectrum disorder, a variety of specific syndromes (e.g., Down, Charge, Noonan's), learning disability, speech delays, and orthopedic impairments.

A total of 69 regional center (RC) staff participated; groups ranged from 6 to 13 staff members. Staff had been employed from 1 month to 30 years. The job areas represented included: Early Start, Assessment Coordinator, Children and Adult Services, Children and Adult Residential, Case Management (for both Spanish and English speaking families), Program Manager, High Risk Infants, Transition Unit, Nurse and Prevention Coordinator, Resource Developer, Community Services Unit, In-Home Units, Developmental Center, and Floater.

Procedures

Due to the large number of focus groups carried out for this project (16), and the relatively short timeline (less than a year), a modified version of focus group techniques was employed. The facilitator or moderator followed a standard questioning route (provided below) but time constraints prevented full elaboration of every theme raised. Focus groups generally lasted about two hours. There were variations across groups, of course, where some groups were able to address all questions and others spent more time on only a sampling of questions.

- **Questioning Route: Parents/Consumers**
    - To what extent were you able to obtain the services you wanted/needed?
    - Are the same services available everywhere and to everyone? (Were you told or made aware of services available elsewhere, but not in your community? Were services offered to other consumers, but not to your family?
    - Do the costs of services influence the services made available by the Regional Center to its consumers?
    - Does the frequency of a particular disorder (or service need) influence the local availability of services for that type of disorder?
    - How does physical accessibility influence the choice of services? (How does distance, poor transit system, long waits for appointments, etc. influence what services the consumers obtain?)
    - Did you come in knowing the services you wanted, or did you arrive wanting to find out what was available and whether you could/should seek those services? That is, to what degree do the consumers and their families influence the choice of services?
    - Are consumers and their families directed to the services they need or to the services that are available?

- **Questioning Route: Staff**
    - How do consumers find out about services? Do the costs of services influence the services made available by the Regional Center to its consumers?

- To what extent are you limited in the services that you can provide to consumers and their families? Are the same services available everywhere and to everyone?
- Does the frequency of a particular disorder (or service need) influence the local availability of services for that type of disorder?
- How does physical accessibility influence the choice of services?
- Do consumers and their families come in knowing the services they want and asking for them, or do they arrive wanting to find out what is available and whether they can/should seek those services? That is, to what degree do the consumers and their families influence the choice of services?
- Are consumers and their families directed to the services they need or to the services that are available?
- What percentage of your caseload has multiple disabilities?
- Are there cultural differences in obtaining services?
- Anything else you would like to add?

Transcriptions and Analysis

Focus group research generates qualitative data in the form of rich verbal information. Focus groups are not composed of representative samples, and the opinions expressed by focus group participants should not be interpreted as representative of the entire population. The information provided by focus group participants is often more explanatory than that obtained in standardized surveys. People are encouraged to speak about their personal experiences and provide anecdotes to support their statements.

Focus groups were professionally transcribed by a local secretarial service in Davis, California, and also by ImpactResearch due to numerous errors in the transcription process. Some tapes were difficult to hear because participants spoke softly or all at the same time.

Information in the transcripts was screened and highlighted relevant to its importance in answering the specific focus group questions. Quotes were drawn out that exemplified a point.

Findings (themes)

The 16 focus groups generated a large volume of data; complete notes, with transcriptions and quotes, were, provided by ImpactResearch. In this section, we have highlighted some key themes that emerged. They are arranged below by question, respondent (parent/consumer vs. staff) and by regional center (low vs. high expenditure).[c]

Are there cultural differences in obtaining services?

Parents

- Parents feel that they know what is best for their child and they themselves are the best advocates for their child.
    - *We came here a couple for years ago. Sometimes we have a different philosophy as the case manager. We can understand our own child's needs and we can approach it more.*
    - *I mean you kind of become strong in your own advocate. Your gut feeling is you know what is right for your own child. I feel like I am in a battle every single day and what this child is entitled to. It is not just it is the schools, it is the regional center, the state, and it is every day living.*
- Some parents feel that service coordinators do not have the cultural sensitivity needed to help deal with culturally diverse families.
    - *And many times the service coordinators may not have the cultural sensitivity to say, "Are you tired? Do you have time for yourself?" They assume the natural support system of grandparents, etc. will take care of the child.*
- Parents feel the RC is against them if they do not have the right coordinator. The solution for this is to switch coordinators.
- Some parents feel alienated from others, such as family, including fathers and consumer's siblings, and friends.

Staff

- Hispanic consumers do not ask for services because they are afraid of being reported to immigration officials or that it will affect their residency status.
- For Hispanics and Asians, cultural stigmas associated with a disabled child inhibit families from seeking help.
- If the family has a language barrier and are poor they tend to be satisfied with less whereas more vocal and higher income families fight until the get what they want.
- Those with a language and economic limitations are hesitant to ask for services and thus underutilize services.
- Staff: Spanish-speaking families are more timid or are intimidated which may be due to the language barrier.
    - *You are trying to direct them because either they're very, very hard working people who don't want to ask you for nothing, don't ever call you, sometimes you have to check up on them because they're afraid to ask for any help or voice concerns, and the language barriers make them very intimidated.*
- Staff: The Hispanic population is more passive and resistant to services they prefer to take care of their own.
- Parents look at Regional Center and staff members as a government agency overseeing the family, and the family feels threatened by them.
    - *This is based on the families I work with. I think there is a feeling that if the family can't take care of their child their child might be taken away from them. The Regional Center is looked at like a government agency that is coming in to make sure everything is okay.*

Low Expenditure RC-Parents

- Parents have a different philosophy than staff regarding their child, they know what is best and they are the best advocates for their child.
- Language barriers inhibit parents from asking for services, others don't ask because of the stigma associated with Hispanics coming to the US and taking advantage of the system.
    - *I didn't want to find myself in trouble, and that usually it's also that people sort of construct Hispanic families are seeking money and coming to this country to, you know, get advantage of services and stuff like that, so for that reason many times I feel like Hispanics don't like to, you know, ask, because it's been something that, you know, Hispanics have been stigmatized with. And it doesn't have to do with the fact that I have papers or not, because I have papers as citizen, but it is just because of the idea that Hispanics are here to, you know, money seekers or to take advantage.*
    -

High Expenditure RC-Parents

- Parent relates experience of not using services because when he first arrived to the US he was told by immigration officials that he could not get services for 7-years, so he did not ask for services because he though he would have to pay for them.
- There is a stigma associated with a child with a disability in the Asian culture, whereby others usually shun the child, including the family.
    - *In the Asian culture, my son went to the high school, almost all of the children were shunned basically.*
    -

Low Expenditure RC-Staff

- Staff feel that ethnic parents do not ask for services because they are afraid of being reported to immigration officials or that receiving services will interfere with the process of becoming legal residents.
    - *One of the reasons that some of my families kind of take a break, and I've had a couple of them, is 'cause they are going through the INS process and for some reason they're just afraid that if they use our services the INS process is going to stop, and that's very important to them that it continue, and sometimes it drags on for years. So I've had several families who want to stop services, you know, they already know of our services and then they come back 2 years later.*
- Both Hispanics and Asians have stigmas associated with a child with a disability that inhibits them from seeking services.
- For Asians and Hispanics the level of education and income are related to receiving services (i.e., the more education and income you have the more services you receive).
- Language barriers limit their ability to use services. They are afraid to ask, or they are not taken seriously.
    - *And so they're…you know, there's a language barrier, the school intimidates them, they're not taken seriously when they bring up a concern, and so unless you get a good nurse there in IEP that will suggest a referral to us, I think most of the time my kids out there aren't getting spotted.*

- If families have a language barrier and are poor, then they tend to be satisfied with less, whereas higher educated and higher income families know what to ask for, and they get it. They are more informed and active because they can afford to take the time and do it. Immigrant families have to jump though hoops to get services so many of them just pay for the services out of their own pocket.
-

High Expenditure RC-Staff

- For Hispanic families cultural and linguistic differences are an obstacle in obtaining services.
    - *I think it is definitely an issue because I work with Early Start and babies and all of the counties are Spanish speaking. So those families come in with medical problems and we do have to push a little bit harder. Sometimes it is the transportation or the language variables that are obstacles.*
- Parents feel that receiving services will affect their goal of becoming a US citizen/legal resident.
    - *If they are in the process of becoming a naturalized citizen or a resident they think that it may affect them, so they may not want to get in the process. They do not want to accept the services.*
- Non-English speaking families will pay others to fill out their paper work, but staff found out and some now help the families.
    - *There are a lot of families who don't speak the language. There is the one page payee form that parents get, once a year. One of my families was spending $30 and another $40 for someone to fill out that form. Each year they had to do that until we caught on and of course I don't charge them because I consider it part of my job… Then when the SSI forms come out every three years they think, "Oh my god, I am going to have to pay $500 to have that formed filled out." It is a really big problem.*
- Hispanic families tend to be more passive and resistant to services, they prefer to take care of their own, so the staff will not offer the parents a particular service, for example, out of home placement, it is tradition that one takes care of their own family and you do not place your child out of your home.
    - *The Latino population is more passive and resistant to services, they would prefer to take care of their own.*
    - *Maybe at times the service coordinator doesn't discuss the option of supported services. I have found that with Hispanic families, we will offer this and they will benefit from this. And they are resistant.*
    - *Because it is tradition that you take care of your own family and that is your responsibility and you don't place them out of the home. They are really making culturally based decisions. Maybe it would have been better for the person to be living in independently with supported services than living in the home, but the 80 year old mom who is barely walking says…"oh no, no we plan to keep him with us."*
- There aren't enough staff members who speak the different languages to address some of the issues raised by the non-English speaking populations..
    - *For example, we have no social workers that speak Russian, we have Cantonese, we might have one Mandarin, we have one person that speaks a*

tiny amount of Korean, but no body is communicating with a lot of these populations.

- It is difficult to get a translator, but even if you do get one the translator only has the skills to translate words and not really address the family's issues.
- There is a need for Spanish-speaking services providers.
    - *We don't have enough service providers that can provide the service in the language that they need.*

How do clients first find out about services?

Parents/Consumers

- Parents indicated that they first learned about services from other parents, programs/community agencies, medical professionals, the school system, Regional Center, and family members.
    - *Besides the Regional Center, many parents found out about services through other parents.*
    - *He was just almost two and then we ended up by referral and again it takes time to get everything done, but from the referral from the physician here we got an MRI, then my pediatrician, anything I want I could have.*
- The most frequently cited sources of information in regards to first finding about services were other parents of children with disabilities and medical professionals.
    - *Oh yeah, and information. Information doesn't come down, we usually hear through the grapevine from families, from parents, or consumers, or other people, but it doesn't.*
    - *Well, I heard about the Regional Center from the neurologist who gave me a referral slip to call to get the services…*

Staff

- Staff had very similar view about where parents/consumers first find out about services. They mentioned such sources as other parents, programs/community agencies, medical staff, the school system, and Regional Center.
    - *Usually it is a referral from the school district.*
    - *Early Start program in Merced County, we have what's called the Roundtable, which is about 6 or 7 different agencies that get together once a week; the hospitals make the referrals. The parents can make referrals, the school system can make referrals, but a lot of the newborn babies are referred to Roundtable from the hospital right after birth. So that's how we get our kids.*
    - *I think we get a pretty decent amount of referrals from pediatricians, probably the Early Start program.*
    - *Most of the birth-to-age 3 referrals are coming from the hospitals or from the pediatrician and a lot of the referrals come from parents.*
- Staff stated more frequently that parents/consumers first learn about services through medical staff and the school system.
    - *A vast number of referrals came from a physician or a teacher or they would ask the parents to give us a call. For young and old adults, it was a mix from a physician or another community agency.*
    - *It is kind of a hard…I mean, like I was thinking of my case load of 65, I mean probably 30 of them were you know entered in the first grade through a teacher or somebody noticed it or maybe even kindergarten noticed that there was some sort of delay.*

Low Expenditure RC-Parents

- Parents at one of the low expenditure Regional Centers mentioned one other source, the military, but otherwise the referral sources mentioned were virtually the same as at the

higher expenditure centers. The only difference was that the sources were mentioned with more frequency; three out of the four focus groups had more comments about this issue as compared to the high expenditure focus groups.

- *I was really concerned about her speech being delayed and so when I had her speech and stuff tested through the military, the speech pathologist was the one that recommended the services at the Regional Center.*

High Expenditure RC-Parents

- Parents at the high expenditure Regional Centers, as stated above, mentioned nearly all of the same sources of information when first finding out about services, except that only three of the high expenditure Regional Center groups mentioned something about the issue. Two of the groups had brief comments on the issue and mentioned sources such as other parents, medical staff, and the school system, but the bulk of the comments came from another group, where they mentioned all of the above sources but with more frequency.

Low Expenditure RC-Staff

- Staff at low expenditure Regional Centers mentioned almost all of the same sources of information as the high expenditure Regional Centers, but they had two different sources, the military and radio broadcast.
    - *We have a lot of military families because California does have such good services. A lot of military families are encouraged to relocate to San Diego and I know the military connects families with the Regional Center.*
    - *If it is in the Asian community then we have Asian broadcast…when they hear about it on the radio they know about Regional Center.*
- Staff at the low expenditure groups mentioned almost equally that parents/consumers first find out about services through medical staff, the school system, and programs/community agencies.

High Expenditure RC-Staff

- Staff at high expenditure Regional Centers stated one different source as to how parents/clients first find out about services and that source of information was the court system.
- Staff at the high expenditure Regional Centers mentioned medical staff and the school system as sources of how parents/consumers first find out about services twice as much as compared to the low expenditure groups.

Are the same services available everywhere?

Parents

- Parents have learned that they have to be aggressive, threaten to sue, and fight to get the services that they believe their children need.
    - *I have learned from all my experience and my friends that the "Squeaky Wheel gets Oil." If you don't holler, jump up and down and threaten to sue, you get nothing."*
- Many parents felt that having a good caseworker is key to getting needed services.
    - *Now I have a good caseworker and she helps me a lot. And she helps me with everything, but it depends on the caseworker.*
- Parents report that one limitation in obtaining adequate services from the RC is the high turnover of RC employees.
    - *I have had a lot of service coordinators. Some of them said they would communicate what I needed. Then they would change service coordinators on me. They changed three or four times.*
- Parents, like staff, commented on many specific services that they needed. Many parents felt that they needed more respite services. Others commented on inadequate speech, OT, PT, social recreation, behavior modification, and numerous other services. In addition, many parents claim that they found out that other individuals were receiving more services or services that they were told were unavailable.
    - *Right now, I find I am getting angry, because I need my respite. They can't give me one and they don't know who to go to. Then somebody needs to do it temporarily because there are services that I need.*

Staff

- At each focus group there were complaints of badly needed services that are limited because of a lack of available vendors and excessive costs. These needed services included respite, nursing care, childcare, transportation, behavior modification, social recreation, speech, OT, PT, mental health services, and residential placements.
    - *We need more behavioral services. Our families have a lot of behaviors that they don't know what to do with it. We have one specialist available who has a lot of different kids. They really can't provide adequate services.*
- Some staff feel that in addition to the limited availability of services that poor quality from service providers also limits the available resources.
- Rural areas and large cities differ greatly in available services. There are fewer service providers in rural areas, which allow vendors to charge more for their services.
- Available resources very greatly by geographic region. Staff feel that this is true both with in and between Regional Centers.
    - *There are 21 regional centers in the State of California each one of them is run differently. It is very frustrating.*
- Some staff feel that the decision to provide a service is made arbitrarily by their supervisors. Sometimes this decision is strongly influenced by parents that go over their caseworker and call a supervisor to demand services.
    - *Sometimes you plead for an exception to the rule and I feel that they are done arbitrarily, like today it will be approved and tomorrow it won't be approved.*

That is frustrating because I don't ask for those unless I know my family needs them.
    - *They go over our head.*

Low Expenditure RC-Parents

- Services may be denied or discontinued because of a client's insurance coverage.
    - *Fighting insurance companies, like this big, huge monster out there, and they kept saying file the appeal, file the appeal. So, I filed the second one and I even talked to a manager at the insurance company.*
- Parents need help fighting with their local school districts to get services that their children need. Many feel that the RC needs to play a bigger role in advocating for them with the school districts.
    - *As we sit here and talk, I think every single one of us has said the fight is with school districts. I would love to see regional centers put in place somebody that would have helped us when we fought the schools, when there issues to fight.*

High Expenditure RC-Parents

- Some parents expressed a desire to have information on services more readably available. They are looking for a comprehensive website, book, or pamphlet that lists the types of services that the RC provides.
- Parents need more time and energy to find and obtain services for their child.
    - *I can be real honest and say, with the exception of three individuals, parents, conservatives, guardians whatever the case may be, only about three of them would have the energy or the stamina to do anything. And there have been times when we don't have the time or energy to do anything. When you run out of energy, it is energy, it is constant up against the wall.*

Low Expenditure RC-Staff

- Staff feel that they are limited in the types of placement options available to families because good group home are difficult to find.
- When a child reaches school age the RC staff has to work with the school system and some feel that this limits the services provided because many parents feel intimidated by the school system and both parents and RC staff have to "fight" with the school district to insure that the consumers receive an appropriate education.
    - *I think we also have additional problems with the transition group because our kids are in school and we have to do a lot of advocacy and sometimes downright fighting with the schools to make sure that they get a good, solid education. So, we have a shortage of providers in that age group just because they don't want to deal with all those schools and all the school issues.*
- Services that are considered to be "extra" or "out of the ordinary" are difficult for staff to provide.
    - *When research is still needed to prove that it works I might have a difficult time getting it.*
- There is "a single gatekeeper" that all requests and referral have to go through. This process can be very lengthy. Some staff have had parents apply for services and by the

time the funding for the service was approved the consumer was too old to receive the requested service.

- Some staff felt that their RC did provide ample services or better services than other centers.

High Expenditure RC-Staff

- Respite care is especially difficult to find in rural areas. If clients in rural areas do not have family members or friends that live close by that the RC can pay to provide respite then they do not receive respite services.
- The "budget crunch" has limited available services.
    - *What is happening too is the budget crunch. So, some of the services we had before we might not have now. I think we are all going through it now. Sometimes other service providers refer to us.*
- Caseworkers have to be "creative" to get clients the services they need. Sometimes being creative means that caseworkers have to bend the RC rules.
    - *Sometimes the services you can get like ILS you use for social recreation because there isn't any social rec. It may be used so that the person is taken to the movies. We are fudging that because we shouldn't be paying for that.*
- Some staff have observed that the availability of services depends on the SES of the family.

How does cost of services influence the choice of services?

Parents

- Cost can play a major influence in the services that are available to families. Some families feel that the RC avoids programs that are costly and send to the cheapest vendor even if it means the clients receive poorer services.
    - *Because it is a costly program from the Regional Center and so the fewer they have to serve the better.*
    - *I do believe the service you need depends on the money. Like right now with behavior so it is in demand. It depends how many ask for it. You need to prove that the child needs that service*

Staff

- Caseworkers are forced to have families use "generic resources" and follow preset cost guidelines before applying to have the RC pay for services. This helps the RC stay within the POS outline, but leaves consumers with few options.
    - *We have to go to all the generic resources, so if they want social rec, we have to go to the "Y." If they have a need for medical supplies then if the have Medi-Cal they have to go through Medi-Cal. We don't automatically fund, we are the payer of last resort.*
    - *No options. People don't have choices. Don't have options with mental health, living options they don't have work situations. Big trend to get people to live as independently as possible and we just don't have the people who are not to do that. There is limited supported living. People don't have that choice.*
- Cost can play a major influence in the services that are available for caseworkers to offer to clients. In fact, several caseworkers stated that some services are simply not provided because of cost.
    - *I'd say major.*
    - *Social Rec. Always denied. Because it's always expensive.*
- The RC has to go through Medi-Cal to get many services. This limits consumers' options because some agencies will not accept Medi-Cal and staff feel that Medi-Cal makes other agencies and consumers "jump through hoops."
    - *A lot of it has to do with the doctors. We are extremely limited by the fact that Medi-Cal, the doctors don't want to take Medi-Cal. A lot of us are, well our consumers use Medi-Cal is their primary insurance. And many doctors are not taking that any more, don't want to work with it anymore with the regional center.*

Low Expenditure RC-Parents

- Some parents felt that the RC used to pay for more, and that budget cuts play an important role in deciding what services are available to clients.
    - *I found out things that Regional Center offers years ago, even paid for commuters for some of the time. They don't no more, but they did for a while. And, it's my understanding that like with the thing that you did, they'll do it and then like when the word gets out and then the budget, it becomes to be such a deficit, they will cut way back on it.*

- Parents wondered if their children would receive more services and therefore show more progress in skill development if their family had a higher income and more money to spend on services.
    - *I think a lot more… you kind of wonder down in your heart, if I had enough more money and insurance only paid for this much, would your child be better. Would they be more functional in society or whatever? Would their skill be better, whatever?*
    - *… someone told me that autism is a rich man's disease. If you don't have money, your kid's not going to get well, bottom line. And a friend of mine who does have money, she was able to pay out of her own pocket to do the Cbat(?) program which costs her $500 a month, $540. And, she provides her own tutor. She did that for six months and her son showed good progress.*
- At one regional center some parents felt that availability of services had a bigger impact on what services they were offered than the cost of the services.

<u>High Expenditure RC-Parents</u>

- Parents complained that some homes do not take RC clients because the RC pays so poorly and others felt that certain services were difficult to obtain because the RC vendors at a lower rate than therapists expect to receive.
    - *Yes. The home program that my daughter has through BCRC(?) in Marin County, they will no longer take Regional Center kids unless they're begged to, because the Regional Center pays so poorly.*
    - *For physical therapy, since I tried to get an outside therapist and I finally got the RC to be willing to pay what their vendor rates were for physical therapy, which I think was $30 an hour, and the going rate is about $100 for a physical therapist in the City.*

<u>Low Expenditure RC-Staff</u>

- Consumers that do not have insurance have a much harder time getting needed services.
    - *And things become more difficult when they're undocumented and have no insurance.*
- The RC vendors at different rates.
    - *One of the things that I was going to mention is the day programs. Our Regional Center funds at a different rate. Like there's one agency in town that there are certain sites that we fund at $41 a day, but there are other sites that we fund at $55 a day.*

<u>High Expenditure RC-Staff</u>

- Vendors are often offered reduced rates or paid late by the RC. This makes vendors reluctant to provide services to RC clients.
    - *It wasn't the amount she was getting paid, it was that it took forever to get paid back. None of us could do business if we had to wait six months for our paycheck.*
- There is some difference in services offered based on the SES and educational level of parents. Some caseworkers feel that parents that come from a higher SES background are more demanding and therefore receive more services, while parents that come from a lower SES area are hesitant to ask for services and underutilize available services.

- *For me I work for adults, they have families that live in Palo Alto and have a lot of money and they get a lot of services. In Santa Cruz county it is very stratified. While there is cross over economically, there is stratification. You often see a dramatic difference between more educated, White who tend to have money and feel entitled to a lot of services.*

How does the frequency of a particular type of disorder influence the local availability of services for that type of disorder?

Parents

- There has been an increase in the number of individuals identified as having autism. Parents feel that because of this, information about autism receives more publicity and the increased attention means that there are more services available for individuals with autism.
    - *By the way, that is the same in the school districts, autism gets lots of services. I have a friend that has a child with fragile X that has very similar deficits and excesses as my son, and he gets nothing.*
    - *There is a lot of press out there that kids with autism who get early intervention get significant gain. And maybe that is why there is so much focus.*
- Many parents feel that even though there are more services available for individuals with autism that because of the high demand for those services they are still difficult for parents to obtain.
    - *I think part of it makes it more available because there's more people asking for something, so therefore there's more of something, but at the same time I think it makes it more difficult to get because there's so many people waiting to get that service.*

Staff

- An increase in the number of individuals diagnosed with autism have impacted the service delivery system and caused a demand for more services that directly meet the needs of these individuals.
    - *Preschool services, more so, not just preschool but services for children ages 3-5 especially for autism. There is a local program that the school provides but they don't meet everybody's needs. We have quite an influx of children with autism. Although not everybody gets their needs met, so we have interim programs that may not be adequate. We have quite an influx of children with autism.*
- When parents join together and create a strong voice to use when requesting services, there is a much stronger impact and services will be increased for those parents. Some staff feel that this is what has happened with parents of children with autism. They have joined together and demanded that more services be created. This makes many staff members feel like autism services take up a larger amount of their budget and that it makes a diagnosis of autism more desirable to parents than other diagnoses.
    - *I think the voice comes from the families. Like with autism, they kind of group together and speak out.*
    - *So they don't have that service. I think the demand of the parents and the need will create more services because the regional center is forced to find a resource for that family.*
- Frequency of disability definitely plays a role in influencing the availability of services. Although staff members now feel that autism is generating a great deal of attention, they feel that in the past there were more services available for consumers with Down syndrome.
    - *Certainly, I have seen in our area that the schools are trying to respond to that need. There is no way they are 100% there, but they are attempting to because*

they see kids that have the autistic spectrum disability are coming in greater numbers. I don't think there are proportionately more services for autistic kids but they are trying to catch up. Some kids are getting over identified. Autism is a little chic right now.

- *...And autism is the "label of choice" now.*

Low Expenditure RC-Parents

- Some parents feel that community awareness plays a more important role in creating services than the actual frequency of a particular disorder.
- One parent felt that individuals with Down syndrome receive more services.
  - *Oh, I think like Down syndrome, which is well known and people are real familiar with it, people are aware of the disorder and they get a lot of services, I think, on what to expect.*

High Expenditure RC-Parents

- Autism gets priority treatment over other disabilities.
  - *Yes, because there was a program for…home programs for autism way before they would even consider one for my daughter. And they had a whole load of things set up in the City and I knew that was going on, which was one of the reasons I thought, well, if they can have it, why can't we?*

Low Expenditure RC-Staff

- Staff at one RC felt that individuals with Mild MR get lost in the system or are limited by the lack of appropriate services.
  - *I think the mild MR clientele get lost in there because they are not low functioning enough to put them in with the developmentally delayed consumers but they are not high enough to fit in with their peers.*
- One staff member said that parents complain because they feel that children with certain syndromes receive more services.
  - *I have a parent who has a child with Down syndrome and she complains because she said, she said, if my child were autistic, my child would be getting more services. And so she sees that, you know, kids with autism have preferential treatment over, say, people with Down syndrome.*

High Expenditure RC-Staff

- Staff at one of the RC's felt that autism services were receiving a bigger portion of the RC budget than services for individuals with mental retardation.
  - *There is a rise in autism and I think you are aware that you can show with a pie what percentage have autism and what resources they take up. It is definitely three or four times their numbers compared to the clients who are just mentally retarded. It keeps on growing. For whatever the reason, the services for autism are taking up more of the budget.*

Are clients and their families directed to the services that they need or to the services that are available?

Parents

- Consumers are mostly directed to those services that are available because there is a lack of adequate providers and transportation. However, parents that advocate for their child or who have good caseworkers are more likely to get the services they need than other parents.
    - *I think they have our best interests but they are certainly not available where I am from. There are not the vendors. He is getting the services he needs, though.*
    - *You have to know what you want, because options are not always given to you. And this is real hard for people who don't know what is going on. You don't know what to ask for and you don't know exactly what you need. But if you know what you want, then you can push and go as far as you have to and sometimes have to go really far.*
- Some consumers are referred to inappropriate services. One consumer, who was not ambulatory, was annoyed that the RC referred her to a dance program.
    - *…why would I fight for this when this isn't really what she needs any more, she needs something different but it's not available for them.*

Staff

- Almost all of the RC staff felt that they try to offer clients the services that they need, but because of limitations beyond their control have to resort to providing services that are available.
    - *Available.*
    - *Personally I give them a list of what is available and I see it as consumer driven.*
    - *Yes. We shoot for need first, and then if we're turned down with that, we go with what's available.*
- Staff are limited by things like transportation and by the services that the school system are willing to provide. Many feel that unless a client has the money to provide transportation to a program, etc. that they have to go with what is available in the client's area.
- Some staff feel that some consumers take advantage of the system by requesting unnecessary services and that this limits their ability to provide services to families that need them.
    - *Certainly a great many of our families need respite but many don't need it at a rate of 24 hours per month. And people get hooked, especially when we make them the vendor, on the money that is coming in to their house. And they don't usually use it for respite they use it to supplement their income. There is real love hate relationship with that, some of the families are dirt poor and they need the money, the others do not.*

Low Expenditure RC-Parents

- Several parents at one RC were very positive about the services that the RC was providing for their children and felt that they were receiving the services that they needed.

- *I think both. You get the things you need and they give the opportunity to do more if you want them to.*
- *Oh, I think they give me what I really need.*

High Expenditure RC-Parents

- Parents report that to obtain services they have to educate themselves on what services their child would benefit from and fight for them because they are not automatically told by the RC about services that their child might benefit from.
    - *I think it's a matter of education. You don't…you have to understand what your needs are before you can do that, and that's why, you know, in our classes we always look at the big picture to find out what was needed and then we, you know, we fought for it, because you're not automatically told that…*
- Parents are limited by what providers will work with their insurance.

Low Expenditure RC-Staff

- Some RC staff try to assess the "big picture," what families need and what is available, before offering services to families.
    - *We take a full assessment of the whole situation, the family, the dynamic, what are the needs and what is available, and kind of put it all together, offer the family whatever they need.*

High Expenditure RC-Staff

- When there are a limited number of available resources staff are forced to come up with alternate situations to help support consumers.
    - *Square peg, round hole.*
    - *You go to plan b, c, and d.*

How does physical accessibility influence the choice of services?

Parents

- Transportation is a major problem for families. Some families have a hard time finding services and others who are receiving services reported that the services were unreliable and often left them waiting for hours.
    - *Transportation is a big issue.*
    - *I have not taken my… it's such a burden for me to be able to take him to that because I have other children, and I live so far out and trying to bring him in for that. And so there's no access for him for that because of where I live, so the transportation thing comes into effect.*
- Many families are limited in the services that are available to them because of the geographic area that they live in. For example, almost all of the parents at one northern RC felt that because they live in more rural areas that they had to travel several hours to receive services or did not receive the services.
    - *We are very limited in what we can have. They say this is the only person and if you don't like it that is your problem. Not everybody can go out of the area and I do take my daughter out of the area to various things. It is a battle.*

Staff

- Resources vary greatly by geographic region. In rural areas there are fewer service providers, which allows vendors to charge more and limits clients options.
    - *We do have some providers, which they might not have in a rural area that are close by.*
    - *In our service area, it is much easier to find a nurse in San Jose than it is Morgan Hill that is really only 5 miles more and nobody wants to drive it. And forget about Hollister, which is 17 miles SE of here and Gilroy.*
- Many clients, even those that attend programs near their home, rely on outside transportation to get them to and from their programs. Staff find it difficult to find safe reliable transportation to provide to their clients.
    - *We have one provider for our transportation, and we're not thrilled with them, but it's all we have, and it's an exorbitant amount that we're paying for them.*
    - *Transportation procedures, we're facing huge problems with transportation.*
- Sometimes clients are required to wait a ridiculous amount of time for transportation to arrive or to get to their destination.
    - *Sometimes too, they wait a long time. They may live like 10 minutes but because of the route, they can be on the van for two hours.*
    - *I see Elizabeth lot of time downstairs waiting for the van for hours for her to get to her next appointment, sometimes she can't meet us for another function outside of here because the transportation is so lousy, she is going to wait two hours and they don't show.*

Low Expenditure RC-Parents

- Some parents reported that they waited for months to get appointments, then waited for hours in a specialist's office only to see a doctor for a few minutes.

- *That's the other thing, especially like at Loma Linda that I was going to say in contrast to…what I've seen there is they have so many specialized services with so many people waiting to get in that there's just huge waiting lists. And then you get your 2 minutes of glory and if you don't talk fast enough you're out the door. And now that…I think it's the medical aspect that causes your biggest frustration.*

High Expenditure RC-Parents

- A couple of parents complained of the long wait times at appointments and to get services started.
  - *I think it has to do with the insurance you have. I would say the wait for appointments takes three or four months just to get services.*
- Two parents felt like the regional center is good about accommodating their transportation issues.
  - *He said that if transportation is a problem for any of the services that the regional center does offer it. (Son is severely disabled)*
- Parents at one high expenditure RC did not feel that transportation or long waits for services were a problem. They felt that there was adequate public transportation and that the RC got services started fairly quickly.

Low Expenditure RC-Staff

- Sometimes staff believes that parents "milk" the system to get transportation services.
  - *The one consumer that wants all the services. I don't really believe her because her school is not really far from her house, probably a 4-block radius. And she wants transportation.*

High Expenditure RC-Staff

- The RC often cannot provide some services because they are not available in some geographic regions.
  - *People need to understand that even if we are willing to pay for a service, you still need to find someone who will provide it. There are more things now where we vendor the family. Sometimes it is the geographic area or the reimbursement rate.*

Summary of Findings from Focus Groups

The majority of the focus group questions addressed, and thus included in this report, pertained specifically to aspects of service delivery, such as service availability and service accessibility. Of course, these distinctions are not always clear cut, but some general conclusions can be drawn.

Equity in service delivery. There was an impressive level of consistency, across staff and parents/consumers, in terms of how families found out about regional center services, regardless of ethnicity or location or regional center. Typical sources were physicians, teachers, Early Start programs at regional centers, and the "grapevine" of friends and neighbors. Less often cited, but of interest, were the military, radio shows (e.g., Asian broadcasts) and the court system as sources of information about regional center services.

However, the perceptions of both parents/consumers and staff is that services are not the same everywhere and for everyone. For parents, this may mean that the "squeaky wheel" gets the attention and the services. Parents also noted that having a "good caseworker" (i.e., service coordinator) made all the difference. Staff, on the other hand, expressed frustration that they did not always have the resources at hand to meet out as they saw fit. There was consistent mention of rural and urban areas having differential access to services. One staff participant mentioned that at times the service coordinator has to be "creative" (in terms of cost categories) in order to serve a given family.

Cultural differences. There is some evidence that cultural differences do affect access to services**.** While the question, "Are there cultural differences in obtaining services?" was not always asked directly of respondents, we culled a number of illustrative remarks from the focus group notes. However, cultural differences are likely correlated with education, income and general knowledge about the service system. In general, staff felt that families with more education and income were more likely to get services, or certainly more services. They felt this was true for both Hispanic and Asian families.

Another theme that emerged was that families involved in the process of immigration (getting visa, green card or actual citizenship) feared that their regional center involvement may interrupt or confound that process. This was related to a general feeling that Hispanic families, in particular, were reluctant to ask for services, in part because of a perception of timidity and in part because they perceived a stigmatizing aspect to making such requests. Of course, language issues are paramount and can have an alienating effect. Some staff expressed the need for true translators who could really talk to families and address these issues, rather than ones that can "only translate words." This lack of language knowledge may be related to the expressed frustration that service coordinators may not have had the cultural sensitivity to know what was really going on in the families.

Finally, there may be a service provider bias that Hispanic families wish to "take care of their own" and a consistent belief that they don't want services. Even though families, too, mentioned the desire to have family or extended family care for their son or daughter, they still expressed the need for more services. One mother pointedly wished that the service coordinator would recognize her [the mother's] fatigue and stress.

Concerns about service accessibility. For the most part, parents/consumers and staff felt that services were provided on the basis of need whenever possible. However, at times staff members felt hindered by lack of services, such as transportation, which forced them to provide services on the basis of availability rather than need.

Physical accessibility was a looming factor in accessing services. As expected, individuals in more rural areas might wait longer, have fewer provider choices and more difficulty finding specialized services. Some parents expressed frustration with long waits for medical appointments, or very short appointments once they did get in to see a physician; however, these issues seem outside the regional center purview. Overall, transportation needs, in particular, were recognized as key to service access by both parents/consumers and staff.

However, some staff highlighted the problem of having to fight with school districts to assure that their consumers have access to and receive appropriate services. Of course, costs are always insurmountable, and not surprisingly both parents and staff were cognizant of this. However, both groups mentioned that parents of higher income and educational background seemed to get more and better services (though there is no empirical evidence of that). Staff did mention that the low reimbursement rates for regional center limited access to certain vendors or services, and that Medi-Cal imposed tremendous constraints. Of concern, though, was the parental fear that their children would be better off if only they had more money, expressed by one by the statement: "…autism is a rich man's disease."

Overall, the participants in the focus groups expressed a number of concerns that reflected some of the issues addressed in POS Report #1 regarding ethnicity, consumer characteristics, and regional center. However, most sentiments were expressed by only a handful of participants and cannot be interpreted as widely representative. The affect expressed during the groups was generally upbeat -- neutral to very positive; negative comments were relatively rare. For the most part, both the staff and parents/consumers felt that services were provided on the basis of need whenever possible, and opinions expressed indicated that participants found the process of service delivery to be equitable. However, the constant reference to services unique to autism spectrum disorder (which was not a focus of this particular study) suggests that there is concern among consumer families and service coordinators about meeting this particular need.

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[a] This study will soon appear in the journal, *Mental Retardation* ("Alienated advocacy: The perspective of Latina mothers of young adults with developmental disabilities on service systems," Shapiro, Monzo, Rueda, Gomez, & Blacher, in press).

[b] The investigators developed procedures for conducting the focus groups in collaboration with Curt Acredolo, Associate Adjunct Professor, Division of Human Development and Family Studies, Department of Human and Community Development, at the University of California, Davis. Dr. Acredolo contracted with Susan Berman of ImpactResearch to conduct all focus group recruitment, moderation and analysis.

ImpactResearch is a full-service market research firm that specializes in conducting "sensitive" social science and health care research with difficult-to-reach populations. ImpactResearch (formerly ImageResearch) was founded by Susan Berman and Curt Acredolo in 1989. Acredolo held a *Ph.D.* in Child Psychology, 1975, Institute of Child Development, University of Minnesota, and Berman holds a Masters degree in Communications Research from Stanford University. Ms. Berman has conducted both qualitative and quantitative research on topics that include member/customer/patient satisfaction surveys with health plan members, focus groups on immunization tardiness and neglect, accessibility to medical care for the homeless and low income families, high risk pregnancies and deliveries and service accessibility for individuals with HIV/AIDS. Ms. Berman manages all of the firm's research projects, and does recruiting, moderating, analysis and report writing. Dr. Acredolo passed away in 2002, and we are grateful to Susan Berman for her continued collaboration and expertise.

[c] We thank Juan Gomez and Monica Schalow of the University of California Families Project (J. Blacher, PI) for their assistance in summarizing the vast amount of focus group data.

Appendix A

Family Needs and Supports:

Review of Literature

Jan Blacher, Ph.D. and Keith F. Widaman, Ph.D.

Co-Principal Investigators
POS II Study
Determination of Service Variation Across Regional Centers:
Implications for Clients and Policy

This review is from:

Blacher, J. & Feinfield, K.A. (in press). Supporting families with children who have disabilities. In: G. O'Reilly, P. N. Walsh, A. Carr, & J. McEvoy. *The handbook of intellectual disability and clinical psychology and practice*. London: Brunner- Routledge.

Relationship of Support Needs to the Caregiving Experience

There are a range of challenges, concerns, and needs expressed by parents of children with intellectual disabilities. ***First,*** parents of children with physical or intellectual disabilities have reported worse physical and mental health than parents of nondisabled children (Singhi, Goyal, Pershad, Singhi, & Walia, 1990). Caregivers of children with special needs reported experiencing fatigue (Heiman, 2002), feelings of being overwhelmed (Helitzer, Cunningham-Sabo, VanLeit, & Crowe, 2002), financial distress (Heiman, 2002; Singhi et al., 1990), and depression (Blacher, Lopez, Shapiro, & Fusco, 1997a; 1997b). ***Second***, parents have also reported experiencing interpersonal distress ranging from social isolation (Heiman, 2002; Helitzer et al., 2002) and poor social interactions (Singhi et al., 1990) to family stress (Baker et al., 2003). Relative to parents of typically developing children, research suggests that parents of children with developmental disabilities experienced frequent disruptions in family routines and more marital adjustment problems (Bristol, Schopler, & Gallagher, 1988; Singhi et al.1990). In fact, Singhi reported that 62% of the sample wished that they had never married. ***Third***, mothers of children with developmental disabilities may experience a variety of role adjustments including lower expectations from careers, a sense of losing their own identity (Helitzer et al.), and a feeling that they lack freedom (Heiman, 2002). Based on a study of children with intellectual disabilities living in a section of North Wales, Grant and McGrath (1990) found that nearly half of the caregivers reported that they could not leave their child alone either at all or for more than 10 minutes.

Parents of children with intellectual disabilities have also reported that the three most anxiety-provoking areas of caregiving involved surveillance, long-term support, and behavior (Grant & McGrath, 1990). They worry about their children's abilities to function independently in the future and express concerns about the need for ongoing care throughout adulthood (Floyd and Gallagher, 1997). In a Hispanic sample, Blue-Banning, Turnbull, & Pereira (2002) reported similar future-oriented concerns, including worries about residential options, employment, and skill proficiency. In addition to concerns about their children's futures, many parents struggle with their children's ongoing psychiatric and/or behavioral challenges. According to Hoare, Harris, Jackson, and Kerley (1998), 38% of children with severe disabilities have significant psychiatric morbidity. In a sample of children with intellectual disabilities, 75% of the caregivers reported problem behaviors, and more than one third reported at least three areas of difficulty (Grant and McGrath, 1990). Among families who have children with developmental disabilities, challenging behavior is a common predictor of parenting stress and/or burden (Heller, Markwardt, Rowitz, & Farber, 1994; McIntyre, Blacher, & Baker, 2002), and is a better predictor than the type of disorder (Floyd & Gallagher, 1997) or cognitive level (Baker et al., 2003). Likewise, challenging behaviors are generally more important than level of physical dependency in predicting parent needs. Behavior difficulties were predictive of a need for minding (e.g., respite) and a need for moral support (Grant and McGrath, 1990).

Coping Styles and Adjustment

Given the multitude of challenges these parents face, it is not surprising that researchers have explored which aspects of coping are most effective for improving personal and family

adjustment. Information seeking, problem solving or seeking social support are considered active coping strategies for parents, and found to relate to a more positive attitude toward their child's disability (Shapiro & Tittle, 1990) and to a decrease in psychological stress (Frey et al., 1989). Likewise, reframing has been associated with positive family adjustment (Lustig, 2002) and a more positive perception of child, family, and self (Hastings, Allen, McDermott, & Still, 2002). Other the other hand, passive coping styles (e.g., avoidance, self-blame, wishful thinking) show a variety of poor outcomes, ranging from increased psychological distress to low family adjustment and/or increased parenting stress (Frey, Greenberg, & Fewell, 1989).

Need for Support Systems

Informal: Social

Based on a sample of families with children who had developmental disabilities, Bristol et al. (1988) reported on the importance of spousal support (both instrumental and expressive) in mothers' level of personal, marital, and parental adaptation. In a sample of Latina mothers of children with mental retardation, spousal support was low; 40% were single and many of the married women felt that they were rejected because of their children's disability (Blacher, Lopez, et al., 1997). This group of women experienced higher levels of depression than both Latina women with typically developing children and Caucasian women with children who had developmental disabilities. In a Hispanic sample of families with children who had physical handicaps, Shapiro and Tittle (1990) found that emotional support from informal networks related to a decrease in maternal depression.

Salisbury (1990) reported a negative correlation between the size of mothers' social support networks and their stress levels. However, a number of researchers have found that the actual amount of support may be less important than one's perception of support. Shin (2002) found that mothers' perceived quality of support (i.e., helpfulness) mediated the relationship between the amount of informal support and maternal stress. In other words, mothers' perception of being cared for, rather than the degree of the service or the number of people providing it, was directly related to their level of stress. Likewise, in predicting to mothers' adaptation, Bristol et al. (1988) found that disharmony between mothers' current and expected level of spousal support was more important than the actual level of spousal support. These studies underscore the importance of including social support measures that go beyond evaluating availability and include quality of, or satisfaction with, support.

Formal: Respite

The need for respite care is common among caregivers of children with intellectual disabilities. Parents request respite care for a variety of reasons, including increasing community integration, developing their children's interests, and preparing their children for other living environments. However, the most common reason is providing the caregivers with a break (Grant & McGrath, 1990). Salisbury (1990) collected data on parents who had expressed interest in receiving respite services and found that only 30% ultimately used these services despite the expressed need. The top three reasons for non use were 1) they did not end up needing it, 2) they used family members instead, and 3) they were not able to obtain providers when needed. This discrepancy between expressed need and actual utilization may be explained by problems with the service

system (e.g., parents were required to contact the referral themselves without any personal contact between provider, agency staff, and parent; there was high turnover of providers without notification to the agency).

In order to better understand discrepancies between needs and utilization rates, Chadwick, Beecham, Piroth, Bernard, and Taylor (2002) addressed three questions: First, ***who wants respite services?*** Only 30% of families were receiving respite services, even though 68% wanted them: caregivers who wanted respite but did not receive it were told that no place was available (34%), were unwilling to take an overnight placement (9%), or were unaware of respite services (19%). Relative to those who did not want respite care, these caregivers were more likely to speak English, experienced more stress and distress, and they had children with more severe disabilities and behavior problems. However, these factors that distinguished who desired respite care were not relevant to who actually received it. Second, ***who receives respite services****?* Among families who wanted respite care, those that actually received it were more likely to consist of larger families, with an older target child, and with a target child with epilepsy. Third, ***who wants more respite services****?* The majority of caregivers (67%) who received respite care would like to receive even more. Grant and McGrath (1990) reported that the need for more respite care was related to challenging behaviors but not to level of physical dependency. Interestingly, families who received respite care were more likely to be larger, despite there being a lower proportion of large families in the group expressing a need for more respite (Chadwick et al., 2002). In fact, Salisbury (1990) found that one of three reasons cited for not needing respite services was that there were family members available to care for the child.

According to Chadwick et al. (2002), families who did not speak English at home were less likely to express a need for respite (Chadwick et al., 2002). This may be due, in part, to the fact that Latina mothers have been characterized by themes of self-sacrifice and duty (e.g., "He's my whole life now") (Mary, 1990; Shapiro, Monzó, Rueda, Gomez, & Blacher, in press). Too, they may have a low level of English proficiency, which has been shown to relate to higher need for, and use of, family and social support (Bailey, Skinner, Correa, et al., 1999; Bailey, Skinner, Rodriguez, et al., 1999). Although these factors may suggest that Spanish-speaking families are less likely to need respite, it is possible that they are less likely to express a need for formal services due to cultural issues (e.g., discrimination, personal duty toward child, issues of privacy) but could still benefit from formal services presented in a culturally appropriate fashion. Perhaps these families are more likely to turn inward for increased family support, rather than seeking formal support systems, which may seem cold and impersonal.

Needs and Service Utilization

One of the most commonly cited needs for families with children who have developmental disabilities is the need for information about services and/or developmental issues (Bailey, Skinner, Correa, et al., 1999; Bailey, Skinner, Rodriguez, et al., 1999; Haveman, Van Berkum, Reijnders, & Heller, 1997; Herman, 1994; Holland, 1980; Romer, Richardson, Nahom, Aigbe, & Porter, 2002). In particular, there is a need for information about respite services (Grant & McGrath, 1990; McCarthy & Boyd, 2002), life planning (Herman, 1994; Nicks, Villa, Reeves, & Nichols, 1999), and strategies for interacting with and/or teaching their children (Bailey, Skinner, Correa, et al., 1999; Bailey, Skinner, Rodriguez, et al., 1999; Herman, 1994). Given that 38% of

children with severe disabilities have significant psychiatric morbidity (Hoare et al., 1998), it is not surprising that parents express needs for respite and help dealing with their children. In fact, McCarthy and Boyd (2002) found that 64% of children with an intellectual disabilities and persistent challenging behaviors received no specialist mental health care. Ironically, Haveman et al. (1997) reported that more service use is associated with less caregiving burden.

In a study of needs and services, Floyd and Gallagher (1997) studied five groups: families of children with intellectual delays (ID) with and without behavior problems, families of children with chronic illnesses with and without behavior problems, and families of children with behavior problems. They reported high stress levels in families of children with intellectual disabilities and behavior problems, yet they found no relationship between stress/caregiving demands and mental health *use* (i.e., high need was not related to increased service use). Additionally, they reported that the group of children with ID and behavior problems was not more likely to use non mental health services (e.g., community support services such as respite and after school programs) than the other groups. They suggest that these services may not be supportive of those families who need them the most (i.e., stressed parents who need relief and/or behavior management strategies, and children who need opportunities to develop social competence).

A recent study (Ellis et al, 2002) involved the administration of a survey to parents that assessed needs, e.g., for information, support, community services, finances, family functioning. All 91 parents had children with autism, pervasive developmental disorder (PDD), or mental retardation. Families of younger children reported the most needs; families whose child had been placed in a residential setting reported the fewest number of needs. The authors recommended earlier and more intense distribution of information to these parents, in the form of written materials, information-sharing groups, parent training and home-based intervention. Unfortunately, there were no adolescents or adults included in the survey, so the finding about needs being highest among parents of the youngest children is limited to a school-age population. Furthermore, this survey had a focus on autism and PDD, where early intervention needs are critical. Finally, although there were excellent measures of socioeconomic status, ethnicity of parents was not reported.

Barriers to Utilization General

It is important to understand the specific obstacles that may be impeding the availability and accessibility of family services. Two of the greatest barriers include the lack of coordination between agencies (Castellani, Downey, Tausig, & Bird, 1986; Downey, Castellani, & Tausig, 1985; Freedman and Boyer, 2000) and parents' limited knowledge about how to navigate through the complex service systems (Downey et al., 1985; Freedman & Boyer, 2000). Based on a survey of 133 public and private service providers for people with developmental disabilities, Downey et al. reported that the majority of agencies (87%) provided information and referral services, but 84% were not coordinated with other agencies (e.g., lacked coordination in planning, referring, or joining). Agencies were quite limited in that they lacked knowledge about other agencies and referrals generally took place within one's own agency. Furthermore, the majority of agencies (72%) reported that consumers were unaware of the service. Other barriers include restrictive eligibility criteria and/or lengthy assessment periods (Castellani et al., 1986;

Freedman & Boyer, 2000; Herman & Hazel, 1991), crisis-driven systems (Ayer, 1984; Freedman & Boyer, 2000), shortage of qualified staff (Downey et al.; Freedman & Boyer, 2000; McCarthy & Boyd, 2002), and lack of funding (Castellani et al., 1986; Downey et al., 1985; Herman & Hazel, 1991).

Herman and Hazel (1991) conducted a survey of agencies in Michigan prior to and following new policy and funding for family support services; during 1984 and 1985, the state of Michigan provided 4.65 million dollars to the 55 county-based mental health boards that served Michigan's 83 counties. Ninety-eight percent of the boards responded to the survey. Despite this increased funding, there continued to be problems with availability and accessibility of services. Although there was a significant increase in five of nine policy recommended services, the availability differed between mental health boards, with decreases in number of services available occurring in boards with the least funding.

Hispanic Samples

Hispanics are the fastest growing minority group in the United States. They show high overall service need (Bailey, Skinner, Correa, et al., 1999; Bailey, Skinner, Rodriguez, et al., 1999), and low service use (McCallion, Janicki, & Grant-Griffin, 1997), yet only a handful of researchers have explored variables that may put Hispanic families at risk for limited access to services (Bailey, Skinner, Correa, et al., 1999; Bailey, Skinner, Rodriguez, et al., 1999). Hispanic families have been characterized as having more problems with the service delivery system, including poor access to and underutilization of services, reduced participation in planning and coordinating services (Bailey, Skinner, Correa, et al., 1999; Bailey, Skinner, Rodriguez, et al., 1999), difficulty participating in parent groups, and lack of information (Bailey, Skinner, Correa, et al., 1999; Bailey, Skinner, Rodriguez, et al., 1999; Heller et al., 1994).

There may be a clash between the Hispanic culture and the current service delivery system. An appreciation of certain Hispanic values may be important in understanding this clash, such as *personalismo* (interpersonal relationships based on trust) and *familism* (family unity). Bailey et al. (1999) suggest that there is a distrust of the professional service system, which has a history of an out-of home emphasis and an individual focus, as opposed to family-oriented emphasis (McCallion et al., 1997). Based on a variety of focus groups, Latina mothers have reported feeling patronized by workers who ignored parent expertise and were cold, untrustworthy, and too busy (McCallion et al., 1997; Shapiro et al., in press). Language issues and limited knowledge of systems have also been described as problematic: there is a lack of outreach to minority cultures, written materials are generally not in Spanish, and there is often an assumed level of education (Bailey, Skinner, Correa, et al., 1999; Bailey, Skinner, Rodriguez, et al., 1999; McCallion et al., 1997; Shapiro et al., in press). There may also be an experience of discrimination; parents have reported feeling stereotyped as being less involved/knowledgeable, and feel like there is a lack of effort by the service providers (e.g., no coordination or follow-through, limited consistency and continuity, withholding or denial of services) (Bailey, Skinner, Correa, et al., 1999; Bailey, Skinner, Rodriguez, et al., 1999; Shapiro et al., in press). Additionally, Latina mothers have been disgruntled by the system's history of emphasizing failure and deficits, rather than individual and family strengths (McCallion et al, 1997; Shapiro et al., in press).

In order to better understand and address the needs of minority families, we need to appreciate how culture impacts service needs and utilization. McCallion et al. (1997) recommends two major cultural themes for understanding the caregiving experience and service use. First, service providers need a clear picture of how the family perceives the disability (i.e., what is disability, who is the family, what cultural values are important?) Second, agencies need to understand how an individual family operates (i.e., who provides the care, how does the family make decisions, what are members' expectations for each other, what supports are received from friends and the community?) Providers should also consider intragroup variability including, but not limited to, level of acculturation, place of origin, social class, education level, and migration history. For example, McCallion et al. (1997) suggested that parents who were younger and more distant from their country of origin showed more diversity in their level of adherence to their own group norms. Based on parents' input during focus groups, McCallion and his colleagues made the following recommendation: "Workers should seek to understand key values around aging, disability, and caregiving common to the culture with which the family identifies. They should then explore the family's level of adherence to those cultural values, and the conflicts and disappointments caused by variation in adherence among family members and key community members."

Effectiveness/Satisfaction

In the early 1990s, family-centered services began to receive increasing support (Yuan, Baker-McCue, & Witkin, 1996). These programs aimed to identify individual family needs and current resources, as well as to assist families in locating and utilizing formal and informal support systems (Romer, Richardson, Nahom, Aigbe, & Porter (2002). Family support included services such as flexible funding, home care, respite services, support groups, family education, and family service coordinators. Yuan et al. (1996) evaluated the impact of two flexible funding programs in Vermont. Families were pleased with the concept of requesting money for services tailored to their individual needs, rather than being told how to spend the money. Although they found the money to be quite helpful, they continued to express the importance of having family support guides.

Romer et al. (2002) reported on the impact of a Community Guide Initiative in the state of Washington. This initiative was one of five components of the Families Support Opportunities program, and involved the use of community guides to assist families in linking up with community resources. Families tended to rate their experience with their guides as being either very dissatisfying (26%) or very satisfying (44%). Highly rated community guides tended to be persistent, clear about their roles, knowledgeable, and receptive to individual families' needs. Interestingly, satisfaction with the overall 5-component program was lower for families with poor guides than for those with no guides at all. This finding underscores the importance of comprehensive screening and training of community guides. Unfortunately, the results of this study were limited in that the response rate (less than 30%) was quite low. Shu, Lung, and Huang (2002) evaluated caregivers' mental health following a home care program which included guidance in accessing and utilizing community services and social support. Caregivers' mental health improved after nine months of receiving the home care services. However, these results

are limited by the lack of a control group and/or placebo group, and by lack of inclusion of non-English-speaking groups.

Conclusion

In order to meet the range of needs experienced by families with children who have disabilities, service delivery systems need to do more than simply provide money without guidance (e.g., flexible funding programs), and they need to go beyond just creating isolated, generic services. Based on a series of focus groups, Freedman and Boyer (2000) reported that families appreciated the empowerment of flexible funding, yet continued to experience a lack of education, advocacy, adequately trained staff, and service coordination. Public policy needs to place greater emphasis on interagency collaboration, thorough staff training, and family support. Researchers should continue to systematically identify which specific aspects of family support packages are particularly helpful and in what areas (e.g., caregiver mental health, stress levels, ability to keep child at home). Finally, continuing efforts to isolate areas of service need, to provide for those needs and to evaluate parent/consumer satisfaction with services received, are paramount.

Appendix B

a. FNSS* Parent (English)

b. FNSS Parent (Spanish)

c. FNSS Service Coordinator

* Family Needs, Services, and Satisfaction survey (FNSS)

A. FAMILY/CAREPROVIDER/CONSUMER NEEDS SURVEY

Study ID #:	PLACE PEEL-OFF STICKER HERE

About the Consumer
(If you are the Careprovider)

1. Child's/Consumer's age (Write in your answer)	_____ Years old	
2. Child's/Consumer's gender? ("√" to mark your answer)	___ Male	___ Female
3. Child's/Consumer's ethnicity? ("√" to mark your answer)	___ Caucasian(Not Hispanic)	___ Filipino/Pacific Islander
	___ Hispanic/Latino/a	___ Native-American
	___ African-American	___ Other/Mix
	___ Asian-American	
4. What is your relationship to the child/consumer? ("√" to mark your answer)	___ Mother	___ Other Family/Relative
	___ Father	___ Adult Consumer (self)
	___ Care/Service Provider	
	___ Other: Specify_____ & Skip "About You" section	
5. What government benefit programs are you or your consumer currently receiving? ("√" to mark your answer)	___ SSI	
	___ Social Security	
	___ Medi-Cal	
	___ Medicaid	
	___ In Home Support Services (IHSS)	
	___ Welfare/TANIF or Indigent Medical Supplement	
	___ Other: Specify:	
	___ None	

About You
(If you are the Consumer, the Parent, or the Careprovider)

1. **What is your age?** (Write in your answer)	_____ Years old	
2. **What is your marital status?**	___ Married/living with partner	___ Widowed

	("√" to mark your answer)	___	Divorced/Separated	___	Never Married
3.	**What is your gender?** ("√" to mark your answer)	___	Male	___	Female
4.	**What is your employment status?** ("√" to mark your answer)	___	Not Employed	___	Part-time (specify below)
		___	Full-time(specify to right>)	Job:	_____
5.	**What is your education level?** ("√" to mark your answer)	___	Grade 1 - 6	___	2-year college
		___	Grade 7 - 11	___	4-year college
		___	High School/ GED	___	Master's Degree
		___	Some college/trade school Number of years_____	___	Doctoral Degree (Ph.D., MD, JD)
6.	**What is your ethnicity?** ("√" to mark your answer)	___	Caucasian(Not Hispanic)	___	Filipino/Pacific Islander
		___	Hispanic/Latino/a	___	Native-American
		___	African-American	___	Other/Mix
		___	Asian-American		
7.	**What is your, or your family's annual income?** ("√" to mark your answer)	___	Less than $10,000	___	$50,000 to $69,999
		___	$10,000 to $19,999	___	$70,000 to $99,999
		___	$20,000 to $34,999	___	$100,000 to $149,999
		___	$35,000 to $49,999	___	$150,000 or more
8.	**Who pays for your or your consumer's care?** ("√" to mark your answer)	___	Parents pay all		
		___	Parents pay most		
		___	Parents/Agency/Others pay equally		
		___	Agencies/Others pay most		
		___	Agencies/Others pays all		
9.	**How long does it take you to get to your Regional Center from where you live?** ("√" to mark your answer)	___	Less than 20 minutes		
		___	21 to 40 minutes		
		___	41 to 60 minutes		
		___	60 minutes or more		
		___	I don't ever go to the Regional Center		

10.	**Please tell us, overall, how much you feel you have benefited from services received through your Regional Center** ("√" to mark your answer)	___ No apparent benefit to date ___ Slight benefit in some areas (some for us or our child) ___ Moderate benefit (changes that benefit my child) ___ High benefit (significant changes that benefit my child) ___ Very high benefit (significant changes in several areas)			
11.	**Did you have any help completing this survey?** ("√" to mark your answer)	___	Yes	___	No

PART I: INFORMATION

We are interested in finding out whether you have all the Information you need from your Regional Center. If you are a parent or careprovider, please answer with respect to your consumer. If you are the consumer, just let us know whether you are getting the information.

1. *I am getting information about:*
My Child's/Consumer's disability

____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

<u>If you are currently receiving this information</u>, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

2. *I am getting information about:*
Infant/Child/Adult development

____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

<u>If you are currently receiving this information</u>, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

3. *I am getting information about:*
How to teach my Child/Consumer

____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

<u>If you are currently receiving this information</u>, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

4. *I am getting information about:*
How to manage my Child's/Consumer's behavior

____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

<u>If you are currently receiving this information</u>, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

5.	*I am getting information about:* **Social development**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

<u>If you are currently receiving this information</u>, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

6.	*I am getting information about:* **Sexual development**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

<u>If you are currently receiving this information</u>, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

7.	*I am getting information about:* **Recreational services for my Child/Consumer**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

<u>If you are currently receiving this information</u>, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

8.	*I am getting information about:* **Vocational services for my Child/Consumer**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

<u>If you are currently receiving this information</u>, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

9.	*I am getting information about:* **Residential placements**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

<u>If you are currently receiving this information</u>, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

10.	*I am getting information about:* **Regional Center services**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.
	<u>If you are currently receiving this information</u>, please indicate your level of satisfaction			

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

11.	*I am getting information about:* **Other _____**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.
	<u>If you are currently receiving this information</u>, please indicate your level of satisfaction			

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

PART II : SUPPORT

We are interested in finding out whether you have all the SUPPORT you need from your Regional Center. If you are a parent or careprovider, please answer with respect to your consumer. If you are the consumer, just let us know what kinds of support you need.

1.	*I am getting:* **Help handling stress**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.
	<u>If you are currently receiving this support</u>, please indicate your level of satisfaction			

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

2.	*I am getting:* **Support from other parents/service providers who have children similar to mine**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.
	<u>If you are currently receiving this support</u>, please indicate your level of satisfaction			

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

3.	*I am getting:* **Regular meetings with my Regional Center Service Coordinator**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.
	<u>If you are currently receiving this support</u>, please indicate your level of satisfaction			

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

4.	*I am getting:* **Behavior management help**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.
	<u>If you are currently receiving this support</u>, please indicate your level of satisfaction			

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

5.	*I am getting:* **Financial help to purchase services or equipment**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.
	<u>If you are currently receiving this support</u>, please indicate your level of satisfaction			

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

6.	*I am getting:* **Other _____**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.
	<u>If you are currently receiving this support</u>, please indicate your level of satisfaction			

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

PART III: RESOURCES

We would like to know what other resources you might need from your Regional Center. If you are a parent or careprovider, please answer with respect to your consumer. If you are the consumer, just let us know whether you need help.

1. *I also need:*
An infant development program

____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

If you are currently receiving this resource, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied

2. *I also need:*
An infant development specialist

____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

If you are currently receiving this resource, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied

3. *I also need:*
A home health agency

____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

If you are currently receiving this resource, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied

4. *I also need:*
Respite care: In-home

____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

If you are currently receiving this resource, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied

5.	*I also need:* **Respite care: Out-of-home**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

If you are currently receiving this resource, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied

6.	*I also need:* **Day care or child development program**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

If you are currently receiving this resource, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied

7.	*I also need:* **Occupational therapy**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

If you are currently receiving this resource, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied

8.	*I also need:* **Speech therapy**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

If you are currently receiving this resource, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied

9.	*I also need:* **Physical therapy or physical development program**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

If you are currently receiving this resource, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied

10.	*I also need:* **Transportation**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

If you are currently receiving this resource, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

11.	*I also need:* **Vocational or habilitation program**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

If you are currently receiving this resource, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

12.	*I also need:* **Behavioral intervention or behavioral adjustment program**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

If you are currently receiving this resource, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

13.	*I also need:* **Specialized autism program**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

If you are currently receiving this resource, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

14.	*I also need:* **Social skills or social development program**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

If you are currently receiving this resource, please indicate your level of satisfaction

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

15.	*I also need:* **Medical services**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.
	If you are currently receiving this resource, please indicate your level of satisfaction			

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

16.	*I also need:* **Access to Medi-Cal**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.
	If you are currently receiving this resource, please indicate your level of satisfaction			

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

17.	*I also need:* **Access to SSI or other federal relief programs**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.
	If you are currently receiving this resource, please indicate your level of satisfaction			

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

18.	*I also need:* **Community living option**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.
	If you are currently receiving this resource, please indicate your level of satisfaction			

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

19.	*I also need:* **Day program option**			
	____ No. I'm not getting it. I don't need it	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.
	If you are currently receiving this resource, please indicate your level of satisfaction			

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied
_____	_____	_____	_____	_____	_____

20.	*I also need:* **Other** _____			
	____ No. I'm not getting it. I don't need it.	____No. I'm not getting it, but I need it.	____Yes. I'm getting it.	____Yes. I'm getting it, but I need more.

<u>If you are currently receiving this resource, please indicate your level of satisfaction</u>

Very Dissatisfied	Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Satisfied	Very Satisfied

B. CUESTIONARIO SOBRE LAS NECESIDADES DE LA FAMILIA / EL CONSUMIDOR

Study ID #:	PLACE PEEL-OFF STICKER HERE

SOBRE EL CONSUMIDOR

(Si usted es el proveedor de cuidado)

1.	¿Edad de su hijo(a)/del consumidor? (Escriba su respuesta)	_____ Años de edad			
2.	**¿Sexo de su hijo(a)/del consumidor?** ("√" para indicar su respuesta)	___	Masculino	___	Femenino
3.	¿Etnicidad de su hijo(a)/del consumidor? ("√" para indicar su respuesta)	___	Caucasiano(a) (no hispano)	___	Filipino(a), isleño(a) del Pacífico
		___	Hispano(a)/Latino(a)	___	Indio(a)-americano(a)
		___	Afro-americano(a)	___	Otro / mixto(a)
		___	Asiático-americano(a)		
4.	¿Cuál es su relación con el joven/consumidor? ("√" para indicar su respuesta)	___	Madre	___	Otro pariente (especifique):
		___	Padre	___	Consumidor Adulto / Uno mismo(a)
		___	Proveedor de cuidado o servicios	___	Otro (especifique): _____ Y no complete la sección "Sobre Usted"

5.	**¿Qué beneficios del gobierno está recibiendo su hijo(a)/el consumidor?** (“√” para indicar su respuesta)	___ SSI (Ingresos Suplementarios de Seguridad) ___ Seguro Social ___ Medi-Cal ___ Medicaid ___ Servicios de casa (IHSS, In home support services) ___ Welfare/TANIF or Indigent Medical Supplement ___ Otro (especifique): ___ Ninguno

SOBRE USTED

(Si usted es el consumidor, el padre, o el proveedor de cuidado)

1.	**¿Su edad?** (Escriba su respuesta)	_____ Años de edad			
2.	¿Su estado civil? (“√” para indicar su respuesta)	___	Casado(a)/viviendo con alguien	___	Viudo(a)
		___	Divorciado(a) o Separado(a)	___	Nunca fui casado(a)
3.	**¿Cuál es su sexo?** (“√”para indicar su respuesta)	___	Masculino	___	Femenino
4.	**¿Cuál es su estado de empleo?** (“√” para indicar su respuesta)	___	No estoy empleado(a)	___	Tiempo parcial (especifique abajo)
		___	Tiempo Completo (especifique a la derecha>)	Trabajo: _____	
5.	**¿Su nivel de educación?** (“√” para indicar su respuesta)	___	Grado 1 - 6	___	Completó 2 años de universidad
		___	Grado 7 - 11	___	Completó 4 años de universidad
		___	Diploma de liceo/GED	___	Título de Maestría
		___	Alguna universidad o escuela vocacional: _____número de años	___	Título Doctorado (Ph.D., MD, JD)
6.	¿Su etnicidad? (“√” para indicar su respuesta)	___	Caucasiano(a) (no hispano)	___	Filipino(a), isleño(a) del Pacífico
		___	Hispano(a)/Latino(a)	___	Indio(a)-americano(a)
		___	Afro-americano(a)	___	Otro / mixto(a)
		___	Asiático-americano(a)		
7.	**¿Ingreso de la familia?** (“√” para indicar su respuesta)	___	Menos de $10,000	___	$50,000 a $69,999
		___	$10,000 a $19,999	___	$70,000 a $99,999
		___	$20,000 a $34,999	___	$100,000 a $149,999
		___	$35,000 a $49,999	___	$150,000 o más

8.	¿Quién paga por su cuidado o el cuidado de su hijo(a)? ("√" para indicar su respuesta)	___	Padres pagan todo		
		___	Padres pagan la mayoría		
		___	Padres y agencias/otros pagan por igual		
		___	Agencias/otros pagan la mayoría		
		___	Agencias/otros pagan todo		
9.	**¿Cuánto tarda en llegar a su Centro Regional de donde vive?** ("√" para indicar su respuesta)	___	Menos de 20 minutos	___	60 minutos o más
		___	21 a 40 minutos	___	Nunca voy al Centro Regional
		___	41 a 60 minutos		
10.	Por lo general ¿cuánto siente que se ha beneficiado de servicios recibidos por parte del Centro Regional? ("√" para indicar su respuesta)	___	No hay beneficios aparentes hasta hoy		
		___	Pocos beneficios en ciertas áreas [algún progreso para nosotros o para nuestro(a) hijo(a)]		
		___	Beneficio moderado [cambios que beneficiarán a mi hijo(a)]		
		___	Alto beneficio [cambios significativos que beneficiarán a mi hijo(a)]		
		___	Muy alto beneficio [cambios significativos en varias áreas]		
11.	**¿Recibió ayuda en completar este cuestionario?** ("√" para indicar su respuesta)	___	Sí	___	No

SECCION I: INFORMACION

Estamos interesados en averiguar si usted tiene toda la Información que necesite del Centro Regional. Si usted es el padre o proveedor de cuidado, por favor conteste con respecto al consumidor. Si usted es el consumidor, déjenos saber si usted esta recibiendo la información.

1. *Estoy recibiendo información sobre:*
La incapacidad de mi hijo(a)/el consumidor

____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo esta información actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

2.	*Estoy recibiendo información sobre:* **El desarrollo de adulto/niñez/infancia**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	<u>Si usted está recibiendo esta información actualmente, por favor indique su nivel de satisfacción</u>					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____
3.	*Estoy recibiendo información sobre:* **Cómo educar a mi hijo(a)/el consumidor**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	<u>Si usted está recibiendo esta información actualmente, por favor indique su nivel de satisfacción</u>					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____
4.	*Estoy recibiendo información sobre:* **Cómo manejar el comportamiento de mi hijo(a)/el consumidor**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	<u>Si usted está recibiendo esta información actualmente, por favor indique su nivel de satisfacción</u>					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
5.	*Estoy recibiendo información sobre:* **Desarrollo social**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	<u>Si usted está recibiendo esta información actualmente, por favor indique su nivel de satisfacción</u>					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____

6.	*Estoy recibiendo información sobre:* **Desarrollo sexual**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	Si usted está recibiendo esta información actualmente, por favor indique su nivel de satisfacción					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____
7.	*Estoy recibiendo información sobre:* **Servicios de recreación para mi hijo(a)/el consumidor**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	Si usted está recibiendo esta información actualmente, por favor indique su nivel de satisfacción					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____
8.	*Estoy recibiendo información sobre:* **Servicios vocacionales para mi hijo(a)/el consumidor**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	Si usted está recibiendo esta información actualmente, por favor indique su nivel de satisfacción					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____
9.	*Estoy recibiendo información sobre:* **Colocación residencial**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	Si usted está recibiendo esta información actualmente, por favor indique su nivel de satisfacción					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____

10.	*Estoy recibiendo información sobre:* **Servicios de Centro Regional**			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.
	Si usted está recibiendo esta información actualmente, por favor indique su nivel de satisfacción			

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

11.	*Estoy recibiendo información sobre:* **Otro (Por favor especifique):** _____			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.
	Si usted está recibiendo esta información actualmente, por favor indique su nivel de satisfacción			

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

SECCION II: APOYO

Estamos interesados en averiguar si usted tiene todo el APOYO que necesite del Centro Regional. Si usted es el padre o proveedor de cuidado, por favor conteste con respecto al consumidor. Si usted es el consumidor, déjenos saber que tipos de apoyo necesita.

1.	*Estoy recibiendo:* **Ayuda con el manejo del estrés**			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.
	Si usted está recibiendo esta ayuda actualmente, por favor indique su nivel de satisfacción			

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

2.	*Estoy recibiendo:* **Apoyo de otros padres / proveedores de servicios que tienen hijos similares al mío**			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.
	Si usted está recibiendo esta ayuda actualmente, por favor indique su nivel de satisfacción			

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

3.	*Estoy recibiendo:* **Reuniones regularmente con mi coordinador de servicios del Centro Regional**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	Si usted está recibiendo esta ayuda actualmente, por favor indique su nivel de satisfacción					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____
4.	*Estoy recibiendo:* **Ayuda con el manejo del comportamiento de mí hijo(a)**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	Si usted está recibiendo esta ayuda actualmente, por favor indique su nivel de satisfacción					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____
5.	*Estoy recibiendo:* **Ayuda financiera para adquirir servicios o equipo**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	Si usted está recibiendo esta ayuda actualmente, por favor indique su nivel de satisfacción					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____
6.	*Estoy recibiendo:* **Otro (Por favor especifique):** _____					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	Si usted está recibiendo esta ayuda actualmente, por favor indique su nivel de satisfacción					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____

SECCION III: RECURSOS

Estamos interesados en averiguar cual otros recursos usted podría necesitar de su Centro Regional. Si usted es el padre o proveedor de cuidado, por favor conteste con respecto al consumidor. Si usted es el consumidor, déjenos saber si usted necesita ayuda.

1. *También necesito:*
Un programa del desarrollo infantil

____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

2. *También necesito:*
Especialista del desarrollo infantil

____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

3. *También necesito:*
Agencia de la salud para el hogar (Home Health Agency)

____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

4. *También necesito:*
Cuidanza de alivio (Respite care): En casa

____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

5.	*También necesito:* **Cuidanza de alivio (Respite care): Fuera de casa**			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho

6.	*También necesito:* **Programa de guardería o desarrollo infantil**			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho

7.	*También necesito:* **Terapia ocupacional**			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho

8.	*También necesito:* **Terapia lingüística (de habla)**			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho

9.	*También necesito:* **Fisioterapia / terapia física o programa del desarrollo físico**			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho

10.	*También necesito:* **Transportación**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____
11.	*También necesito:* **Programa vocacional o de habilitación**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____
12.	*También necesito:* **Intervención para el comportamiento o programa para el ajusto del comportamiento**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____
13.	*También necesito:* **Programa especializado para autismo**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____
14.	*También necesito:* **Un programa de habilidades sociales o el desarrollo social**					
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.		
	Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción					
	Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
	_____	_____	_____	_____	_____	_____

15.	*También necesito:* **Servicios médicos [para mi hijo(a)/el consumidor]**			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

16.	*También necesito:* **Acceso a Medi-Cal**			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

17.	*También necesito:* **Acceso a SSI (Ingresos Suplementarios de Seguridad) u otros programas federales de auxilio**			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

18.	*También necesito:* **Opciones para la colocación residencial en la comunidad**			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

19.	*También necesito:* **Opciones para programas diarios para adultos**			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

20.	*También necesito:* **Otro (Por favor especifique): _____**			
	____ No. No la estoy recibiendo. No la necesito.	____No. No la estoy recibiendo, pero la necesito.	____Sí. La estoy recibiendo.	____ Sí. La estoy recibiendo, pero necesito más.

Si usted está recibiendo este recurso actualmente, por favor indique su nivel de satisfacción

Muy Insatisfecho	Insatisfecho	Algo Insatisfecho	Algo Satisfecho	Satisfecho	Muy Satisfecho
_____	_____	_____	_____	_____	_____

C. FNSS SERVICE COORDINATOR QUESTIONS
(actual survey completed on-line)

Ques #	Question	
	Client ID Number:_____	
	Staff ID Number:_____	
	ABOUT YOU	
1	How long, in years, have you worked at this Regional Center?	
2	How long have you known this Regional Center client? (in years)	
3	In what languages are you fluent? English Spanish Tagalog Other	
	ABOUT the DDS Client	
1	Mental retardation	N/A No Yes
1a	**If yes**, please indicate the level of mental retardation	N/A Mild Moderate Severe Profound Not known
2	Epilepsy	N/A No Yes
3	Cerebral Palsy	N/A No Yes
4	Autism	N/A No Yes

About Services for this Client

PART I: INFORMATION

1 **My Childs'/Consumer's disability**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this information, please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

2 **Infant/child/adult development**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this information, please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

3 **How to teach the child/consumer**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this information, please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

4 **How to manage the child's/consumer's behavior**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this information, please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

5 **Social development**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this information, please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

6 **Sexual development**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this information, please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied
Very Satisfied

7 **Recreational services for my child/consumer**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

	If you are currently receiving this information, please indicate you level of satisfaction	N/A Very Dissatisfied Dissatisfied Slightly Dissatisfied Slightly Satisfied Satisfied Very Satisfied Very Satisfied
8	**Vocational services for my child/consumer**	No. I'm not getting it. I don't need it. No. I'm not getting it, but I need it. Yes. I'm getting it. Yes. I'm getting it, but I need more.
	If you are currently receiving this information, please indicate you level of satisfaction	N/A Very Dissatisfied Dissatisfied Slightly Dissatisfied Slightly Satisfied Satisfied Very Satisfied Very Satisfied
9	**Residential placements**	No. I'm not getting it. I don't need it. No. I'm not getting it, but I need it. Yes. I'm getting it. Yes. I'm getting it, but I need more.
	If you are currently receiving this information, please indicate you level of satisfaction	N/A Very Dissatisfied Dissatisfied Slightly Dissatisfied Slightly Satisfied Satisfied Very Satisfied
10	**Regional Center services**	No. I'm not getting it. I don't need it. No. I'm not getting it, but I need it. Yes. I'm getting it. Yes. I'm getting it, but I need more.

	If you are currently receiving this information, please indicate you level of satisfaction	N/A Very Dissatisfied Dissatisfied Slightly Dissatisfied Slightly Satisfied Satisfied Very Satisfied
11	**Other (please specify)**	No. I'm not getting it. I don't need it. No. I'm not getting it, but I need it. Yes. I'm getting it. Yes. I'm getting it, but I need more.
	If you are currently receiving this information, please indicate you level of satisfaction	N/A Very Dissatisfied Dissatisfied Slightly Dissatisfied Slightly Satisfied Satisfied Very Satisfied
	About Services for this Client	
	PART II: SUPPORT	
1	**Help handling stress**	No. I'm not getting it. I don't need it. No. I'm not getting it, but I need it. Yes. I'm getting it. Yes. I'm getting it, but I need more.
	If you are currently receiving this support, please indicate you level of satisfaction	N/A Very Dissatisfied Dissatisfied Slightly Dissatisfied Slightly Satisfied Satisfied Very Satisfied
2	**Support from other parents /service providers with children similar to yours**	No. I'm not getting it. I don't need it. No. I'm not getting it, but I need it. Yes. I'm getting it. Yes. I'm getting it, but I need more. N/A Very Dissatisfied

	If you are currently receiving this support, please indicate you level of satisfaction	Dissatisfied Slightly Dissatisfied Slightly Satisfied Satisfied Very Satisfied
3	**Meet more regular with Regional Center service coordinators**	
		No. I'm not getting it. I don't need it. No. I'm not getting it, but I need it. Yes. I'm getting it. Yes. I'm getting it, but I need more. N/A
	If you are currently receiving this support, please indicate you level of satisfaction	Very Dissatisfied Dissatisfied Slightly Dissatisfied Slightly Satisfied Satisfied Very Satisfied
4	**Behavior management help**	
		No. I'm not getting it. I don't need it. No. I'm not getting it, but I need it. Yes. I'm getting it. Yes. I'm getting it, but I need more. N/A
	If you are currently receiving this support, please indicate you level of satisfaction	Very Dissatisfied Dissatisfied Slightly Dissatisfied Slightly Satisfied Satisfied Very Satisfied
5	**Financial help to purchase services or equipment**	
		No. I'm not getting it. I don't need it. No. I'm not getting it, but I need it. Yes. I'm getting it. Yes. I'm getting it, but I need more. N/A
	If you are currently receiving this support, please indicate you level of satisfaction	Very Dissatisfied Dissatisfied Slightly Dissatisfied Slightly Satisfied Satisfied Very Satisfied

6 **Other (please specify)**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.
N/A

If you are currently receiving this support, please indicate you level of satisfaction

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

PART III: RESOURCES

1 **Infant development program**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.
N/A

If you are currently receiving this resource please indicate you level of satisfaction

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

2 **Infant development specialist**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.
N/A

If you are currently receiving this resource please indicate you level of satisfaction

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

3 **A home health agency**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this resource please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

4 **Respite care: In-home**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this resource please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

5 **Respite care: Out-of-home**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this resource please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

6 **Day care or child development program**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this resource please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

7 **Occupational therapy**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this resource please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

8 **Speech therapy**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this resource please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

9 **Physical therapy or physical development program**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this resource please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

10 **Transportation**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this resource please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

11 **Vocational or habilitation program**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this resource please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

12 **Behavioral intervention or behavioral adjustment program**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this resource please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

13 **Specialized autism program**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

If you are currently receiving this resource please indicate you level of satisfaction

N/A

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

14 **Social skills or social development program**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.
N/A

If you are currently receiving this resource please indicate you level of satisfaction

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

15 **Medical services**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.
N/A

If you are currently receiving this resource please indicate you level of satisfaction

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

16 **Access to Medi-Cal**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.
N/A

If you are currently receiving this resource please indicate you level of satisfaction

Very Dissatisfied
Dissatisfied
Slightly Dissatisfied
Slightly Satisfied
Satisfied
Very Satisfied

17 **Access to SSI or other federal relief programs**

No. I'm not getting it. I don't need it.
No. I'm not getting it, but I need it.
Yes. I'm getting it.
Yes. I'm getting it, but I need more.

	If you are currently receiving this resource please indicate you level of satisfaction	N/A Very Dissatisfied Dissatisfied Slightly Dissatisfied Slightly Satisfied Satisfied Very Satisfied
18	**Community living option**	No. I'm not getting it. I don't need it. No. I'm not getting it, but I need it. Yes. I'm getting it. Yes. I'm getting it, but I need more.
	If you are currently receiving this resource please indicate you level of satisfaction	N/A Very Dissatisfied Dissatisfied Slightly Dissatisfied Slightly Satisfied Satisfied Very Satisfied
19	**Day program option**	No. I'm not getting it. I don't need it. No. I'm not getting it, but I need it. Yes. I'm getting it. Yes. I'm getting it, but I need more.
	If you are currently receiving this resource please indicate you level of satisfaction	N/A Very Dissatisfied Dissatisfied Slightly Dissatisfied Slightly Satisfied Satisfied Very Satisfied
20	**Other**	No. I'm not getting it. I don't need it. No. I'm not getting it, but I need it. Yes. I'm getting it. Yes. I'm getting it, but I need more.
	If you are currently receiving this resource please indicate you level of satisfaction	N/A Very Dissatisfied Dissatisfied Slightly Dissatisfied

		Slightly Satisfied Satisfied Very Satisfied
1	**Parents'/Careproviders' openness to services received**	N/A Not at all open and accepting Not very open and accepting Somewhat open and accepting Generally open and accepting Very open and accepting
2	**Overall rating of Parents'/Careproviders' attendance and follow-through regarding services**	N/A Low Moderate High
3	**Overall estimate of benefits to this parent/child/family from RC services (select one):**	N/A No apparent benefit to date Slight benefit in some areas (Progress) Moderate benefit (Some changes that will benefit child outcomes) High benefit (Noteworthy changes that will benefit child outcome) Very high benefit (#4, but in multiple areas, or highly significant)
4	**Overall, how satisfied do you think the Parents/Careproviders of this client are with services offered by your Regional Center?**	N/A Very Dissatisfied Dissatisfied Slightly Dissatisfied Slightly Satisfied Satisfied Very Satisfied

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Department of Developmental Services

Purchase of Services Study II:

Supplementary Report:
Modeling Variation in Per Capita Purchase Of Services for Coffelt and Non-Coffelt Consumers

A Report to the Legislature
December 2003

Prepared for the Department of Developmental Services

Keith F. Widaman, Ph.D. and Jan Blacher, Ph.D.
UC Davis UC Riverside
"Determination of Service Variation Across Regional Centers: Implications for Clients and Policy"

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PREFACE

This report contains results derived from statistical modeling of the variation in per capita purchase of services for persons with mental retardation and developmental disabilities served by the 21 regional centers across California. The central focus of this report was cost variation for consumers moved to community placements under the Coffelt settlement. As in prior reports, we modeled variation in per capita purchase of services as a function of several system-related factors that should influence purchase of services (such as consumer age and place of residence) and several factors that, if the basis for substantial differential service expenditures, would represent biases in purchase of services (such as consumer ethnicity). We modeled purchase of services for consumers as a function of Coffelt status, both simply (i.e., without considering other variables) and then, in complex fashion, controlling for relevant variables. To determine the variation due to specific cost-related factors, one must carefully parcel out this variance based on knowledge of the process of service delivery, attempting to ascertain whether any biases in service delivery are present.

The Department of Developmental Services and the California Health and Human Services Agency recommended that a thorough examination of purchase of service data be undertaken, pursuant to the original Purchase of Services study report issued in April 1999. The present study was undertaken to fulfill this recommendation and was conducted in conjunction with the Association of Regional Center Agencies and stakeholder groups.

The present report is a supplement to the three reports to be completed under the project entitled Purchase of Services Study II (POS II). The first report presented an analysis of service costs for consumers throughout the State of California, identifying the factors that appear to influence individual and group differences in services. The second report discussed findings from a statewide survey of service coordinators and parents/guardians and a series of focus groups conducted at sites around the State of California with parents/guardians of persons receiving services through regional centers and with personnel from the regional centers. The third and final report will weave the findings from the first two reports into an overall summary. This report contains findings and recommendations based on statistical modeling of purchase of service data, with respect to the Coffelt and non-Coffelt consumers only.

PURCHASE OF SERVICES – STUDY II
SUPPLEMENTARY REPORT

EXECUTIVE SUMMARY

This report presents analyses of Purchase of Service (POS) data for persons with developmental disabilities who were served by the 21 California regional centers during the fiscal years from 1995-1996 through 1999-2000. Regional center personnel monitor and arrange for services provided to persons with developmental disabilities, in collaboration with the California State Department of Developmental Services (DDS), which has oversight responsibility. This system is a very large one, serving over 160,000 persons with developmental disabilities and providing services that totaled over $1 billion during each of the five years examined; current yearly expenditures are as high as $2.5 billion.

The present report is a supplemental report, containing analyses that complement those from our POS II Report #1. The analyses reported herein were undertaken to answer a rather restricted question: **Do consumers placed into community placements in connection with the Coffelt settlement have different levels of service expenditures than consumers who were not placed under this settlement?**

The present report contains results derived from statistical modeling of the variation in per capita purchase of services for persons with mental retardation and developmental disabilities served by the 21 regional centers across California across five fiscal years, from 1995-1996 through 1999-2000. Variation in per capita purchase of services was modeled as a function of (a) several system-related factors that should influence purchase of services (for example, consumer age and place of residence); (b) several factors that, if the basis for substantial differential service expenditures, could represent biases in purchase of services (for example, consumer gender or ethnicity); and (c) consumer status with regard to placement under the Coffelt settlement.

When analyzing expenditures, we estimated the effects of five legitimate cost-related factors, three potential bias factors, and Coffelt status. We have analyzed for differences on each of these factors in two ways: (1) without reference to the other factors, as in POS I, and (2) controlling for the effects of the other factors. The second approach to analysis allows us to see how much independent influence the factor has, above and beyond the influence of the other factors; it provides a clearer understanding of the importance of each factor. In the remainder of this Executive Summary, we highlight the effects we found of the Coffelt status variable.

EXPENDITURE PATTERNS RELATED TO COFFELT STATUS

Coffelt Consumers had Higher Service Costs than Non-Coffelt Consumers

- **The magnitude of the difference was moderated by treatment of cost values**
  - Based on raw cost values, Coffelt consumers received about 2.2 to 2.3 times the dollar amount of services received by non-Coffelt consumers ($ 35,679 vs. $ 15,826 in 1999-2000)
  - Based on trimmed cost values, Coffelt consumers received about 1.6 to 1.7 times the dollar amount of services received by non-Coffelt consumers ($ 19,988 vs. $ 14,586 in 1999-2000)
  - Based on Winsorized cost values, Coffelt consumers received about 1.8 to 2.0 times the dollar amount of services received by non-Coffelt consumers ($ 27,066 vs. $ 15,643 in 1999-2000)
- **The magnitude of the difference was moderated by whether other independent variables were controlled statistically**
  - Based on raw cost values, Coffelt consumers received about 2.25 times the dollar amount of services received by non-Coffelt consumers ($ 35,679 vs. $ 15,826 in 1999-2000) when other independent variables were not controlled, but only about 2.0 times the dollar amount of services ($ 28,104 vs. $ 14,027) when other independent variables were controlled statistically
  - Similar trends held for trimmed cost values and for Winsorized cost values

INFLUENCE OF OTHER INDEPENDENT VARIABLES

Most Results Confirmed Results from POS II, Report #1

- **Several independent variables were related to service costs, as in Report #1**
  - Residence type was consistently and moderately related to service costs
  - Client characteristic was also moderately related to service costs
  - Consumer level of mental retardation was significantly, but weakly related to service costs
  - Regional center differences in costs were relatively small, but consistent in magnitude

- Consumer levels of adaptive and maladaptive behavior had small-to-moderate relations with service costs

- **One independent variable was notably unrelated to service costs, as in Report #1**
  - Consistent with our Report #1, consumer gender was unrelated to service costs

Certain Results Disconfirmed Results from POS II, Report #1

- **Consumer age was unrelated to service costs**
  - Consumer age group (younger adult vs. older adult) had no effect on service costs, regardless of whether other independent variables were controlled statistically
  - In analyses in the present report, we excluded all infants, children, and adolescents from analyses, as the vast majority of Coffelt consumers were adults. In Report #1, the primary age-related difference in costs was for children and adolescents versus adults, thus the lack of age differences in this report is not surprising

- **Consumer ethnicity was unrelated to service costs**
  - Contrasting with Report #1, consumers from all ethnic groups received approximately equal dollar amounts of service, regardless of whether other independent variables were controlled statistically
  - In addition to excluding infants, children, and adolescents, we also excluded from all analyses adult consumers who did not live in the home of a parent or guardian, because almost no Coffelt consumers were placed in the home of a parent or guardian
  - These results imply that differences in dollar amounts of services for consumers of different ethnic groups occur for (a) consumers in the infant, childhood, or adolescent years, or (b) consumers who live in the home of a parent or guardian
  - The differences for non-adult consumers or those who live in the home of a parent or guardian may be due to subtle cultural differences, rather than any structural bias in the DDS system, and should be the object of study in further research

DIFFERENCES ACROSS COST CATEGORIES

- **Clear differences arose across categories of service with regard to ability to explain variations in costs**

- **The categories of (a) Out of Home expenses, (b) Day Program costs, (c) Transportation, and (d) Total POS were moderately well modeled by the set of predictors**

- Explained variance for each of the above categories of costs ranged between 20 and 64 percent of the variance.

- **The remaining categories of service expenditures of (e) Medical Care, (f) In Home Respite, (g) Out of Home Respite, (h) Other Non-Medical, and (i) Support Services were much less well modeled by the set of predictors**

  - Explained variance for each of the above categories of costs ranged between 1 and 14 percent of the variance.

CONCLUSIONS

This report demonstrated clear patterns of difference in service expenditures for DDS consumers based on their Coffelt status. Importantly, the patterns of service expenditures were quite similar across the five fiscal years examined, suggesting that the differences were not haphazard. With regard to the broad picture, the findings in this report replicated many results from POS II Report #1, supporting the contention that consumer-related factors drive much of the differences in service funding. The key consumer-related characteristics related to service costs were residence type, consumer characteristic, level of mental retardation, and levels of adaptive and maladaptive behavior. Consumer age, related to costs in Report #1, was unrelated to costs in the data on adult consumers that were analyzed in this report.

The potential biasing factors of gender and ethnicity were found to have negligible effects, and the third biasing factor – regional center serving the consumer – had statistically significant, but relatively small influences not accounted for by the consumer characteristics employed in the current statistical modeling. Contrasting with POS II, Report #1, the lack of service expenditure differences among ethnic groups – whether or not other independent variables were controlled statistically – suggests strongly that there is no ethnic bias in service delivery to adult consumers.

In comparison to these legitimate consumer-related characteristics and the potential biasing factors, consumer Coffelt status explained relatively small amounts of variance. However, Coffelt consumers used notably higher dollar levels of service in certain cost categories. In terms of overall raw cost values, Coffelt consumers received about 2.2 times the dollar amount of services (or about 120% more) when compared to non-Coffelt consumers. Using the more realistic overall trimmed cost values, Coffelt consumers received about 1.7 times the dollar amount of services (or about 70% more) when compared to non-Coffelt consumers. However, Coffelt consumers may have required even more service-related expenditures prior to their community placement (i.e., when they resided in state developmental centers). Thus, despite the discrepancy in service expenditures, community placements may be relatively inexpensive, in addition to being less restrictive, settings for Coffelt consumers. The ultimate basis for the Coffelt-related differences in service expenditures is beyond the scope of the present study to determine and deserves attention in future research.

I. INTRODUCTION

Background

On January 19, 1994, the Superior Court approved a settlement agreement in the class action case of COFFELT V. DEPARTMENT OF DEVELOPMENTAL SERVICES. Although four specific defendant regional centers were involved in the settlement (San Andreas Regional Center, Golden Gate Regional Center, Regional Center of East Bay, and North Bay Regional Center), DDS committed to make good faith efforts to obtain participation in the settlement by all 21 regional centers and was successful in that regard.

The Coffelt settlement covered five fiscal years, from July, 1993, to June, 1998, and had two main goals:

(1) To reduce the population of the state developmental centers (SDC's) statewide by the year 2000, by developing or obtaining community living arrangements for individuals who should (by virtue of their individual habilitation plans) appropriately be served in the community, and by preventing other individuals from being admitted to SDC's by providing appropriate placements in the community; and

(2) To develop or obtain appropriate alternative community placements for 300 consumers from defendant regional centers with difficult-to-meet needs who are currently in the community (referred to as "community target groups members").

The State Legislature allocated $ 20 million for the first year of implementation of this settlement, although adequate funding estimates to accomplish the above objectives were as high as $334,000,000 (according to a Summary of the Settlement Agreement: Coffelt, et al., v. DDS, et al., prepared by Protection and Advocacy, Inc., Counsel for Plaintiffs).

Now, almost a decade after the determination of the Coffelt Settlement Agreement, the investigators of the Purchase of Services II Study ["Determination of Service Variation Across Regional Centers: Implications for Clients and Policy"] are responding to a request by DDS and Legislative Consultants [a] to examine purchase of service expenditures related to the *Coffelt Implementation*. The rationale for this additional study was to examine a subset of individuals living in the community since the Coffelt settlement was enacted, and to determine if there were differential costs associated with that settlement. This report may be considered as a Supplement to the earlier POS II, Report #1.

In Report # 1 of the Purchase of Services Study II [*Determination of Service Variation Across Regional Centers: Implications for Clients and Policy*], we closely examined equity in service provision across a number of key variables. These included what we referred to as five "legitimate" cost-related factors: consumer chronological age, consumer place of residence,

[a] From a discussion at a presentation at the State Capitol by Drs. Blacher and Widaman, February 22, 2002; as requested by legislative analysts.

consumer level of MR, consumer levels of adaptive and maladaptive behavior, and client characteristics. We also examined three "potential bias" factors: consumer regional center, consumer gender, and consumer ethnicity. These factors are once again examined, along with the a factor that we referred to as "Coffelt status."

In the current report, we examine the patterns of purchase of services (POS) for persons who were deinstitutionalized under the stipulations of the Coffelt Settlement. For convenience, we will refer to these individuals as "Coffelt consumers" or the "Coffelt group" in the remainder of this report, and use the terms "non-Coffelt consumers" or the "non-Coffelt group" to refer to the remaining consumers served by the Regional Centers throughout California. For completeness, we analyzed data from five fiscal years, from 1995-1996 through 1999-2000.

Before launching into a description of the manner in which we analyzed the data and then the results we obtained, we discuss first two issues that we confronted. First, we analyzed the cost data in two ways: (a) considering only Coffelt group status, and (b) controlling for a variety of additional factors that might influence costs of services rendered. As discussed in a later section of this report, Coffelt group status was represented by year of placement under Coffelt regulations, with those never placed under such regulations being in the non-Coffelt group. Because it was likely that Coffelt consumers would differ systematically from non-Coffelt consumers, we considered it important to base our final conclusions on the analyses in which other factors were controlled. The two sets of analyses were compared, so that we could examine the magnitude of the effect of controlling for the additional factors.

Second, because cost variables are distributed in a quite non-normal fashion, we used several transformations of cost variables: (a) raw cost variables, (b) 1% trimmed cost values, and (c) 1% Winsorized values. Because the trimmed and Winsorized data were more normally distributed, they offered a more adequate basis for interpreting tests of significance and measures of effect size. In addition, we did not use log transformed in the current report, because the other transformations – trimming and Winsorizing – were more than adequate to the task and because log transformations were the least adequate in our previous Report #1.

We mentioned the preceding issues rather briefly here, to notify readers of these two issues that influenced our approach to analyses. We refer interested readers to the first chapter of POS II, Report #1, for a more detailed discussion of the two preceding issues and justification for our analytic choices.

II. FACTORS INFLUENCING PURCHASE OF SERVICES

In this section, we will discuss several factors that may influence the patterns of purchase of services through the 21 Regional Centers across California for persons with mental retardation and developmental disabilities. We will discuss these factors under four headings: Coffelt status, potential biasing factors, likely causal factors, and omitted variables.

A. COFFELT STATUS

The first variable that may be related to purchase of service costs – and the principal focus of the current report – is a variable we have called Coffelt status. The Coffelt consumers identified for current analyses were placed during the following fiscal years: 1995, 1996, 1997, 1998, 1999, 2000, or 2001. All remaining consumers comprised the non-Coffelt group and therefore had no identified year of placement under the Coffelt settlement.

We could have represented the Coffelt status variable as a simple dichotomous variable: presence in the Coffelt or non-Coffelt groups. This would, however, have led to certain problems in understanding and representing statistically the cost data. In particular, purchase of service costs through Regional Centers should vary systematically as a function of year of placement. That is, prior to a consumer's placement, services would be obtained either solely or primarily through the state residential institution where the consumer resided. Once the consumer was placed, services would be obtained through Regional Centers. Therefore, a simple contrast between Coffelt and non-Coffelt group would be a confounded comparison, lumping together all Coffelt consumers – some of whom had already been placed and some of whom had yet to be placed. The latter group should have much, much lower levels of purchase of services through Regional Centers.

Therefore, we used year of placement as the levels of the independent variable indexing Coffelt status. When analyzing cost data from a given fiscal year, one might expect that Coffelt consumers who had been placed that year or in prior years would have higher levels of service costs than Coffelt consumers who had not yet been placed but were to be placed in later fiscal years. Any "bump" in service delivery costs for a given cohort in the first year of placement should not be interpreted as a sudden increase in services provided. Instead, this sudden increase merely indicates that Coffelt consumers were now receiving services through Regional Centers and the service costs were now included in our data base, rather than having received services through state residential institutions (and having these service costs not represented in our data set). But, we analyzed data in this fashion to allow us to identify any potential placement cohort differences in purchase of service costs and to determine whether such differences continued to occur in later years.

Of course, the above discussion is a simplification of the course of placements over time for many consumers. That is, placement is usually treated as a "one time" occurrence, even though it is likely that multiple placements are necessary. Thus, it would be unsurprising if some Coffelt consumers were placed out of a state developmental center into a community placement, but to

have that placement fail to work out, necessitating placement for a time back in a state developmental center, followed by a subsequent placement into a community setting. In the data set available for our analyses, each Coffelt consumer was identified with a single year of placement (presumably their most recent placement). But, consumers who are identified in the data set as "placed in 1999" may have resided in a community setting in an earlier fiscal year (e.g., 1995-1996). They might have been returned to a state developmental center in 1997, and then placed for the last time into a community setting in 1999. Although some unknown amount of slippage is almost surely present in the data, our analyses will concentrate on comparing service expenses for non-Coffelt consumers with expenses for Coffelt consumers once they were placed for the final time (i.e., the final time through 2001) into a community placement.

B. POTENTIAL BIASING FACTORS

In POS II, Report #1, we identified three factors that, if significant statistically or practically, might indicate some form of bias in purchase of services for persons with mental retardation and developmental disabilities through the 21 regional centers around the State of California. These three factors are (a) the Regional Center providing services to the consumer, (b) the gender of the consumer, and (c) the ethnicity of the consumer. We discuss each of these factors in turn below.

Regional center. The first potential bias factor is the Regional Center providing services to a consumer. Suppose we observe wide variations across Regional Centers in the dollar amount of services provided to consumers. In the 1999 POS study (POS I), considerable variation was reported in the average dollar amount of services provided to consumers. In our POS II, Report #1, we found that notable differential patterns of expenditure clearly held in analyses in which other variables were not controlled. These analyses replicated the results from the original Purchase of Services Study and extended these analyses across additional years. However, we also found that differential costs as a function of regional center were considerably reduced, although not erased, when the remaining research factors were controlled statistically.

Still, we acknowledge the difficulties that arise when attempting to determine differential patterns of service delivery across regional centers. Each of the 21 regional centers across California has a unique consumer base, a unique blend of socio-economic surroundings, and a unique pattern of availability of service providers in close proximity to consumers. Moreover, regional centers tend to differ in philosophical approach to service delivery, so any differential effects associated with regional center are difficult to attribute to any particular variable that may differ across centers.

Gender. The second potential biasing factor is the gender of the consumer. Replicating previous work on adaptive and maladaptive behavior, we reported – in our Report #1 – that gender had almost no effect on service provision costs. We included gender in the current statistical models to ensure that any effects of gender would be accounted for when we estimated differences as a function of Coffelt status.

Ethnicity. The third factor representing potential bias in purchase of services is the ethnicity of the consumer. In the initial Purchase of Services study of April 1999, mean expenditures were

reported for different ethnic groups, and these means appeared to vary in practically important ways. Specifically, the average amount of services (in dollars) provided to Hispanic consumers was approximately one-half the dollar amount spent on White, or Euro-American, consumers. A finding of large mean expenditure differences for consumers in different ethnic groups in the current study would lead to strong recommendations to uncover the biases in service provision for consumers in these various ethnic groups.

However, the differential costs associated with ethnicity in the 1999 report were weighted marginal means, which implies that other factors that can and should influence service costs were not controlled when these means were calculated. In our Report #1, we found that effects of ethnicity were largely accounted for by other factors, such as age of the consumer. That is, a majority of minority consumers were children or adolescents, whereas a majority of White consumers were adults. Given expected patterns of service delivery as a function of age, we found much reduced differential expenditures as a function of ethnicity once other variables were controlled.

C. LEGITIMATE COST-RELATED FACTORS

In addition to potential bias factors, at least five classes of influences included in the DDS data set were likely to influence purchase of services in a legitimate fashion. These five classes of factors were: (a) age of the consumer, (b) type of residence in which the consumer lives, (c) general category into which the consumer is allocated, (d) consumer's level of mental retardation, and (e) levels of adaptive and maladaptive behavior exhibited by the consumer.

Consumer chronological age. The chronological age of the consumer (hereinafter referred to simply as "age") should have influences on the purchase of services, based on the manner in which the DDS system operates. Infants and children who are identified as needing services are likely to be more seriously affected (e.g., more likely to have profound mental retardation or an easily identified neuromotor disability, such as cerebral palsy) than is the case for individuals first identified at a later age. Thus, infants and children who are identified prior to elementary school may have serious physical problems or Neurodevelopmental disorders such as autism, may be medically fragile, and therefore may require high dollar amounts of service – and are likely to require a different pattern of services – than consumers identified during elementary school or later. Moreover, children and adolescents frequently receive their services through other agencies than DDS and therefore have relatively low levels of service costs during the schooling years. Once they "age out" of school and become adults, consumers receive a larger portion of their services through regional centers, so services provided to adults will tend to be higher than costs for children and adolescents.

These patterns of purchase of services costs were confirmed in our Report #1. Consumer age was a strong factor predicting service costs, whether other factors were controlled or not. Thus, it was imperative for us to include consumer age as a covariate in analyses for the current report. However, because the vast majority of Coffelt consumers were adults, we restricted our comparisons only to adult consumers, a difference in procedures from our Report #1 (categories used as listed in a later section of this report). This difference led to certain changes with regard

to effects of factors, and these effects will be noted later in this report.

Residence type. The home or facility in which a person resides may also have reasonable influences on purchase of services. In our Report #1, we found that residence type was also a clear and strong predictor of service costs regardless of whether other research factors were controlled statistically. Because only a small number of Coffelt consumers were identified as living in the home of a parent or guardian after placement out of a state developmental center, we deleted all consumers living in the home of a parent or guardian from our analyses. This is a second notable change in this analysis variable when compared with our Report #1 analyses, and we will discuss the impact of this change on results later in the present report.

Consumer category. Consumer category is a term that describes the primary categorical code under which a consumer is classified. Relevant codes are autism, behavior adjustment, and child development, among others. Although the categorical codes are not fully descriptive in themselves, the codes reflect aspects of the program of service a consumer is likely to need. Thus, children and adolescents with autism require intensive services of several types that are likely to be different than the pattern of services supplied for a person in the "habilitation" category. In Report #1, consumer category was moderately related to service costs in predicted ways, requiring the inclusion of this variable in any model representing service costs.

Consumer level of mental retardation. The DDS system provides services for persons with mental retardation and developmental disabilities, and level of mental retardation should have effects on the kinds and amounts of services utilized. We confirmed this prediction in our Report #1, with persons having severe and profound mental retardation having rather higher levels of service costs than persons having mild or moderate mental retardation or consumers who did not have mental retardation. Interestingly, the influence of level of mental retardation was attenuated when other factors were controlled statistically, although residual differences remained after such controls were instituted.

Consumer levels of adaptive and maladaptive behavior. Because the Client Development Evaluation Report (CDER) must be completed on persons receiving services through the DDS system, availability of scores on dimensions of adaptive and maladaptive behavior may be predictive of patterns of services beyond the factors identified above. These a priori predictions were confirmed in our Report #1. Although the levels of variance explained by levels of adaptive and maladaptive behavior were not large, these variables had expected effects on certain cost categories, particularly on higher respite services being used by parents/guardians of consumers with relative high levels of maladaptive behavior.

D. OMITTED VARIABLES

After discussing both potential bias factors and factors that might legitimately influence purchase of services, we must discuss the problem of omitted variables. Any statistical analysis is only as good as the variables included in the analysis. If important variables that influence an outcome variable are omitted from the analysis, the result will be a failure to model with great precision the process generating the data. This problem is not unique to the current analyses; indeed, every

analysis of data ever undertaken is potentially flawed by the failure to include relevant predictors. Here, we will discuss briefly three variables or sets of variables that were not included in the data set, yet were likely to influence the provision of services to consumers.

Consumer level of health problems or morbidity. Individual-level indicators of health problems or morbidity were not included in the data set, but such indicators of health status are likely to influence several categories of service. Principal among these is medical care costs; the greater the number and severity of health problems a consumer has, the greater the likely medical care costs incurred in treating these problems. Of course, health problems vary along several dimensions, such as acute versus chronic, mild to severe, etc. As a result, obtaining the types of health problem indicators that would be strongly related to services consumed would be a difficult undertaking, as many medical care costs are incurred in treating fairly episodic and unpredictable health problems, such as sickness.

The influence of health problems or morbidity may be especially important when modeling costs for Coffelt consumers. Consumers placed under stipulations of the Coffelt settlement are likely to be "difficult-to-place" consumers along one or more dimensions. Such consumers may have unusually high levels of maladaptive behavior; having indices of maladaptive behavior allowed us to control statistically for such effects. However, Coffelt consumers may also have relatively high levels of health problems or have morbidities of various types. Without measures of such problems, we could not control statistically for the effects of these variables. Thus, the resulting differences between Coffelt consumers and non-Coffelt consumers may be more a function of differences health or other morbidity than other, more surface aspects of the differences between groups.

Differences in knowledge regarding available services. Parents/guardians of persons with mental retardation are likely to have differing levels of knowledge about the kinds of services available for the consumer under their care. Some parents/guardians may be extremely knowledgeable about the entire range of services available for consumers, whereas other parents/guardians may have detailed knowledge of only limited forms of available service. No parents/guardians information was available on the DDS data set containing purchase of services, so effects of differential parents/guardians knowledge of DDS services could not be evaluated. Once again, effects of such variables may be responsible for some of any differences identified between Coffelt and non-Coffelt consumers.

Perceived need or desire for services. In addition to knowledge of available services, parents/guardians almost certainly vary widely in their perceived need or desire for certain kinds of service. In-home respite and out-of-home respite services may be readily available for parents/guardians who need such services. But, for any of a multitude of reasons, a parent/guardian may be uninterested in receiving any form of respite services. In the previous paragraph, we mentioned differences among parents/guardians in their knowledge of available services. When dealing with perceived needs or desires for service, one is confronting parent/guardian preferences for services or preferences to forego certain services. The DDS system cannot force services on consumers or parents/guardians who prefer not to use those services. Still, these preferences regarding services may be particularly powerful influences on

the pattern of services a consumer receives, and failing to have measures of such preferences almost surely ensures that we will be unable to capture fully the patterns of service delivery received by consumers. As with other categories of influence, differences in perceived need or desire for services could lead to differences between Coffelt and non-Coffelt consumers, and differences on these factors could not be modeled for this report.

Omitted variables and resulting bias in estimates. In summary, we simply note that many variables that ideally should be available to capture precisely the manner in which services are delivered to consumers were unavailable for analysis. Some of these variables could conceivably be assessed; others are virtually immune to careful measurement. With omission of these variables from our analyses, we acknowledge at the outset that biases will be present in the analyses. However, our task is to attempt to characterize the service delivery costs for Coffelt and non-Coffelt consumers within the DDS system using the data available to us. If the results will be necessarily biased, this should not stop us from pursuing a "broad strokes" analysis of purchase of services for these consumers associated with the DDS system. We will, given the variables available to us, provide estimates of service costs that control for various factors, enabling us to characterize the relative magnitude of cost differentials associated with various predictors. At least two states (or more) may be true: (a) there may indeed be bias in the system, leading to provision of greater dollar amounts of services to consumers in certain groups, or (b) certain variables that would explain differential service delivery costs were omitted from the analyses, leading to bias in the estimated cost expenditures, *not* bias in the service delivery system. Although we may never be able to identify which of these states is true, we can characterize the magnitude of the differential levels of service costs and attempt to determine whether the remaining differential costs are of practical importance. Moreover, we emphasize here that potential bias in estimates associated with various factors is not unique to the present analyses, but is present in virtually all analyses conducted in any area of scientific inquiry. Despite the ubiquitous presence of potential bias in estimates, we must move ahead and provide estimates that are as unbiased as we can achieve.

E. CORRELATIONS AMONG PREDICTORS

One important aspect of the purchase of service data that must be confronted is the inevitable correlations among predictors of service costs. Most of the predictors of purchase of services are categorical variables. For example, an individual consumer is either a male or female, belongs in only one of the ethnic status categories, etc. But, regardless of the categorical nature of these variables, we can still discuss the correlations, or lack of independence, among variables.

With continuous variables, correlations among variables can be captured easily by a scatterplot. One variable is assigned to the horizontal axis, the other to the vertical axis, and individual data points are plotted in the space. A scatterplot of this sort is often very useful information for deciding whether the relation between two variables is linear or some more complex nonlinear form.

With categorical variables, a scatterplot is less useful, because there is no natural ordering of values on the categorical variable. That is, we have no basis for saying that males or females are

"higher" on the gender variable, even if we assign values of 0 and 1 to identify males and females. Instead of a scatterplot, a cross-tabulation table is a useful way of investigating the correlation, or lack of independence, between variables. For example, consider Table III.1, which gives a cross-tabulation of ethnic status of consumers and the regional centers around the State of California. The values shown in Table III.1 are the number (or frequency) of consumers from each regional center who fell into each of the ethnicity categories and the resulting percentage of the consumers from the regional center who are of that ethnicity; the data in Table III.1 are from the 1995-96 fiscal year. For example, 346 consumers at the Alta Regional Center were Asian, and Asian consumers comprised 4.70% of the Alta Regional Center caseload served during 1995-96. In comparison, an almost identical number of Asian consumers were served by the Central Valley Regional Center (345); but, given the lower overall caseload of this center, the 345 Asian consumers constituted a larger percentage (5.34% vs. 4.70%) of the Central Valley overall caseload.

Study of Table III.1 will reveal that the 21 regional centers have rather different overall caseloads, from a high of 10,476 for the Inland Regional Center to a low of 1,486 for the Redwood Coast Regional Center. [Note: These numbers of consumers are the numbers of consumers with CDER data, not the total caseloads for the 21 regional centers. A total of 111,672 consumers had CDER data in the 1995-96 cost dataset, even though over 140,000 consumers were on the overall cost data set.].

Given the rather different caseloads for the regional centers, independence of the regional center and ethnicity variables would be shown by identical row percentages of each ethnicity in the table. For example, the last row of Table III.1 shows that 25.04% of consumers throughout the State of California were Hispanic. If persons of different ethnicity were equally distributed across the state and across the catchment areas for the regional centers, then an equal percentage of Hispanic consumers would be noted in each center. This clearly is not the case, as over 64% of consumers served by the East Los Angeles Regional Center were Hispanic, whereas only about 5% of the consumers at the Far Northern and Redwood Coast Regional Centers were Hispanic. Similar, wide fluctuations are observed for all ethnic groups. For example, over 80% of the consumers at the Redwood Coast Regional Center were White, whereas less than 13% of the consumers at the South Central Los Angeles Regional Center were White. Or, over 42% of the consumers at the South Central Los Angeles Regional Center were Black, whereas fewer than 2% of the caseloads of several regional centers around the state were Black.

A moment of consideration will lead to interesting questions: If we find regional center variation in services provided, is this variation due to differential availability of services in the local regional center area, to a different philosophy regarding service provision across centers, or because the centers have different percentages of persons of certain ethnicity? Or, if persons from a given ethnic group have different levels of service provision, is this due to discrimination against their ethnic group or because they are in the catchment area of a regional center that has a particular philosophy of service provision? Or, could differential costs for regional centers and differential costs for different ethnic groups be due to other factors? What other factors are possible? We have several other factors in the data set.

Table III.1

Distribution of Consumer Ethnicity by Regional Center

Regional Center		Ethnicity									
		Asian	Black	Fili-pino	His-panic	Native Am	Other	Poly-nesian	Un-known	White	Total
Alta	Number	346	776	61	665	44	383	16	229	4849	7369
	Pct	4.70	10.53	0.83	9.02	0.60	5.20	0.22	3.11	65.80	
Central Val.	Number	345	359	35	2379	28	276	1	135	3027	6585
	Pct	5.24	5.45	0.53	36.13	0.43	4.19	0.02	2.05	45.97	
East Bay	Number	534	1655	204	811	20	585	8	55	3538	7410
	Pct	7.21	22.33	2.75	10.94	0.27	7.89	0.11	0.74	47.75	
East Los Ang.	Number	303	47	45	2326	1	201	2	11	688	3624
	Pct	8.36	1.30	1.24	64.18	0.03	5.55	0.06	0.30	18.98	
Far Northern	Number	55	59	6	176	71	121	1	4	2770	3263
	Pct	1.69	1.81	0.18	5.39	2.18	3.71	0.03	0.12	84.89	
Golden Gate	Number	561	521	274	696	8	308	31	24	2197	4620
	Pct	12.14	11.28	5.93	15.06	0.17	6.67	0.67	0.52	47.55	
Harbor	Number	369	689	173	1423	11	309	24	184	2205	5387
	Pct	6.85	12.79	3.21	26.42	0.20	5.74	0.45	3.42	40.93	
Inland	Number	174	1154	76	2915	65	390	25	13	5664	10476
	Pct	1.66	11.02	0.73	27.83	0.62	3.72	0.24	0.12	54.07	
Kern	Number	17	304	30	865	16	98	2	18	1578	2928
	Pct	0.58	10.38	1.02	29.54	0.55	3.35	0.07	0.61	53.89	
Lanterman	Number	262	367	105	1368	8	272	5	109	1290	3786
	Pct	6.92	9.69	2.77	36.13	0.21	7.18	0.13	2.88	34.07	
North Bay	Number	53	243	70	271	7	216	3	48	2157	3068
	Pct	1.73	7.92	2.28	8.83	0.23	7.04	0.10	1.56	70.31	

Table III.1 (continued)

Distribution of Consumer Ethnicity by Regional Center

Regional Center		Ethnicity									
		Asian	Black	Fili-pino	His-panic	Native Am	Other	Poly-nesian	Un-known	White	Total
North LA	Number	155	427	103	1476	24	336	1	27	2941	5490
	Pct	2.82	7.78	1.88	26.89	0.44	6.12	0.02	0.49	53.57	
Orange	Number	672	159	69	1633	13	385	12	11	4603	7557
	Pct	8.89	2.10	0.91	21.61	0.17	5.09	0.16	0.15	60.91	
RedwdCoast	Number	24	21	1	67	57	58	2	22	1234	1486
	Pct	1.62	1.41	0.07	4.51	3.84	3.90	0.13	1.48	83.04	
San Andreas	Number	417	201	150	1321	19	319	13	77	2807	5324
	Pct	7.83	3.78	2.82	24.81	0.36	5.99	0.24	1.45	52.72	
San Diego	Number	263	781	225	2279	44	655	18	274	4829	9368
	Pct	2.81	8.34	2.40	24.33	0.47	6.99	0.19	2.92	51.55	
San Gab/Pom	Number	319	511	94	2292	11	268	12	75	2461	6043
	Pct	5.28	8.46	1.56	37.93	0.18	4.43	0.20	1.24	40.72	
South Ctl LA	Number	32	2072	15	2051	8	90	6	18	630	4922
	Pct	0.65	42.10	0.30	41.67	0.16	1.83	0.12	0.37	12.80	
Tri-Counties	Number	69	142	52	1210	15	313	1	141	2784	4727
	Pct	1.46	3.00	1.10	25.60	0.32	6.62	0.02	2.98	58.90	
Valley Mtn	Number	216	354	59	933	27	272	2	131	2928	4922
	Pct	4.39	7.19	1.20	18.96	0.55	5.53	0.04	2.66	59.49	
Westside	Number	111	942	36	808	3	190	9	71	1147	3317
	Pct	3.35	28.40	1.09	24.36	0.09	5.73	0.27	2.14	34.58	
Total	Number	5297	11784	1883	27965	500	6045	194	1677	56327	111672
	Pct	4.74	10.55	1.69	25.04	0.45	5.41	0.17	1.50	50.44	100.00

Consider next the factor of chronological age, specifically the cross-tabulation of consumer age and consumer ethnicity, shown in Table III.2, again for the 1995-96 fiscal year. The consumer age categories consist of age ranges, specifically 0-2 years (infancy), 3-11 years (childhood), 12-22 years (adolescence), 23-44 years (early adulthood), and 45+ years (later adulthood). Any detailed consideration will reveal that there are notable ethnic group variations in the age of consumers. For example, about 58% of the Asian consumers and over 62% of the Hispanic consumers were in the childhood and adolescence age categories (i.e., between 3 and 22 years of age), the highest percentages of children and adolescents for any of the identified ethnic groups. In contrast, fewer that 36% of the White consumers fell in these age categories. The remaining ethnic groups had percentages of children and adolescents that fell between these extremes. And, over 63% of the White consumers were in the early and later adulthood categories (aged 23 years or older), whereas between 36 and 41% of the Asian and Hispanic consumers were in these two older age categories. Again, consumers in other ethnic groups had concentrations between these extremes.

Given the lack of independence of ethnic status and age, the large variation in service costs across ethnic groups discussed in the April 1999 report is open to alternative explanation: Rather than the differential service costs for different ethnic groups being due to bias in the service delivery system, the differential costs may have arisen from the differential age distribution of consumers from the different ethnic groups. If the clear majority of Asian and Hispanic consumers are children and adolescents and the clear majority of White consumers are in adulthood, then higher services costs for White consumers in comparison to Asian and Hispanic consumers may result from the different pattern of services routinely provided for adults in comparison to children and adolescents, rather than bias against Asian and Hispanic consumers.

Additional tables such as Tables III.1 and III.2 could have been formulated, cross-tabulating levels of each pair of variables from the 1995-96 fiscal year. Further, similar tables could be presented for the remaining four fiscal years under investigation, fiscal years 1996-97 through 1999-2000. To save space, these tables will not be presented. But, we emphasize here that none of the eight variables along which consumer characteristics are arrayed is independent of the others. The lack of independence of predictors dictates a need to approach analyses with a carefully prepared analytic strategy that controls for legitimate cost-influencing factors before evaluating potential bias factors. This strategy is discussed in the next section.

Table III.2

Distribution of Consumer Ethnicity by Age Group

Ethnicity		Age Group 0-2 years	3-11 years	12-22 years	23-44 years	45+ years	Total
Asian	Number	72	1520	1539	1855	311	5297
	Pct	1.36	28.70	29.05	35.02	5.87	
Black	Number	53	3220	2746	4801	964	11784
	Pct	0.45	27.33	23.30	40.74	8.18	
Filipino	Number	17	453	536	769	108	1883
	Pct	0.90	24.06	28.47	40.84	5.74	
Hispanic	Number	496	9582	7858	8335	1694	27965
	Pct	1.77	34.26	28.10	29.81	6.06	
Native American	Number	3	126	104	197	70	500
	Pct	0.60	25.20	20.80	39.40	14.00	
Other	Number	100	2493	1698	1517	237	6045
	Pct	1.65	41.24	28.09	25.10	3.92	
Polynesian	Number	1	65	49	72	7	194
	Pct	0.52	33.51	25.26	37.11	3.61	
Unknown	Number	85	780	324	372	116	1677
	Pct	5.07	46.51	19.32	22.18	6.92	
White	Number	299	9975	10208	25225	10620	56327
	Pct	0.53	17.71	18.12	44.78	18.85	
Total	Number	1126	28214	25062	43143	14127	111672
	Pct	1.01	25.27	22.44	38.63	12.65	100.00

III. APPROACH TO ANALYSES

When exploring the factors that may influence purchase of services, one must design an approach to data analyses that is responsive to the nature and distribution of both independent and dependent variables. Moreover, this analytic approach must be consistent with what is known about the way the data were generated. In the current application, the analyses should take into account what is known about the ways in which Regional Centers provide services for consumers, particularly for Coffelt and non-Coffelt consumers.

Ideally, service coordinators work in collaboration with parents/guardians to evaluate the status of a person receiving services from the Regional Center. This collaboration will lead to the dollar amount and variety of services that are arranged for the individual consumer.

Purchase of Service Categories

The outcomes for the current study were the per capita costs for purchase of services in different categories. These categories of service were developed by DDS and the regional centers and serve as a useful taxonomy of types of service available to consumers. The cost categories were: (a) out of home, (b) day programs, (c) transportation, (d) medical care, (e) in-home respite, (f) out-of-home respite, (g) other non-medical services, (h) support services, and (i) POS total (standing for "purchase of services total"), which was the sum of cost for services in categories (a) through (h). Additional information on these cost categories, including account and service code information, is given in Appendix A.

We had available cost and consumer information for five fiscal years, the fiscal years of 1995-96 through 1999-2000. Therefore, we pursued five sets of analyses, one set of analyses for each of these fiscal years. Having information for five consecutive fiscal years was a great benefit, both to cross-validate trends across fiscal years as well as to uncover any trends across fiscal years.

Coding of Predictor Variables

Coffelt status. The Coffelt status of each consumer was represented as the fiscal year during which the consumer was placed. The Coffelt consumers identified for current analyses were placed during the following years: 1995, 1996, 1997, 1998, 1999, 2000, or 2001. All remaining consumers comprised the non-Coffelt group and therefore had no identified year of placement under the Coffelt settlement. Therefore, a total of 8 groups can be identified under the Coffelt status variable: 7 cohorts of Coffelt consumers (placed in 7 consecutive fiscal years) and an 8th group (the non-Coffelt group). As a result, seven pseudovariates were used to represent the eight groups distinguished under the Coffelt status variable. As will be shown when results are presented, the non-Coffelt group of consumers consisted of between 30,000 and 40,000 consumers, where the total number of consumers across the 7 cohorts of Coffelt consumers was about 1,650.

Regional center. The 21 regional centers in the State of California were coded using a set of 20

pseudovariates. Any variation in service costs associated with regional centers is associated with the 20 degrees of freedom representing differences among the 21 centers.

Gender. The gender of the consumer was also coded with a pseudovariate, with a code of 0 for male and 1 for female. Thus, any variation in service deliver costs is associated with a single degree of freedom associated with consumer gender.

Ethnic status. Consumers were identified as belonging to one of five ethnic categories, which are (alphabetically) Asian American, Black, Hispanic, Other, and White. Here, 4 pseudovariates were specified to capture differences among these five ethnic groups. We were unable to support a more differentiated treatment of ethnic groups differences (i.e., by using additional groups), due to the relatively small sample of Coffelt consumers.

Consumer chronological age. A choice is open when modeling the relation between consumer chronological age and expenditure patterns. This choice is between leaving chronological age in a continuous form, such as age in years, versus constructing age categories. When we received the data set from DDS, a categorical form of chronological age had been constructed. This categorical form had the following categories: 0-2 years (or infancy), 3-11 years (or childhood), 12-22 years (or adolescence), 23-44 years (or early adulthood), and 45+ years (or later adulthood). The advantage of this categorical system is that it is related to expected patterns of service usage. Consumers identified during infancy are more likely to retardation characterized as severe than those identified at later ages, so service costs should be rather high for this group.

Because only a very small minority of Coffelt consumers fell in the infancy, childhood, or adolescence categories (as expected), we could not estimate reliable effects for these consumers. Therefore, we deleted all infants, children, and adolescents from all of our analyses, leaving only younger adult and older adult groups, requiring one degree of freedom to represent the difference between these two groups.

Consumer residence type. The types of residences in which consumers resided were supplied by DDS in the following categories: (a) home of parent or guardian, (b) independent living, (c) community care facility (or CCF), (d) intermediate care facility (or ICF), (e) skilled nursing facility (SNF), or (f) other. Because so few Coffelt consumers were identified as living in the home of a parent or guardian, we deleted all persons residing in the home of a parent or guardian from all comparisons to avoid bias in results. But, we added one additional placement – residence in a state developmental center – for all Coffelt consumers who had not been placed by the current year under consideration. As a result, 5 pseudovariates were used to represent cost differences as a function of types of residence.

Consumer Characteristic. The consumer identifier called "consumer characteristic" is a variable that designates the primary types of programs that the consumer receives, based on his or her presenting symptoms. The levels of consumer characteristic were: (a) autism, (b) behavior adjustment, (c) child development, (d) habilitation, (e) medical, (f) physical development, (g) physical-social development, (h) sensory, and (i) social development. As should be clear, these labels are not transparent labels that allow a direct identification of all programs that a given

consumer was likely to receive. However, because consumer patterns of purchase of services may vary as a function of the "consumer characteristic" variable, we used 8 pseudovariates to represent the differences among the 9 categories on this variable.

Consumer level of mental retardation. The consumer level of mental retardation was categorized into six levels: (a) 000.0, or no retardation; (b) 317, or mild mental retardation; (c) 318.1, or moderate mental retardation; (d) 318.2, or severe mental retardation; (e) 318.3, or profound mental retardation; and (f) 319, or unspecified level of mental retardation. Our a priori hypothesis was that consumers with more severe levels of mental retardation were likely to require higher levels of service than were those with less severe mental retardation. We used 5 pseudovariates to represent differences among the six categories on the level of mental retardation variable.

Consumer level of adaptive and maladaptive behavior. With the availability of scores from the CDER, we formulated scores on four dimensions of adaptive behavior and two dimensions of maladaptive behavior, based on research on the CDER by Widaman, Gibbs, and Geary (1987). The four dimensions of adaptive behavior were (a) motor competence (sum of 12 CDER items), (b) independent living skills (sum of 9 CDER items), (c) cognitive competence (sum of 14 CDER items), and (d) social competence (sum of 6 CDER items); the two dimensions of maladaptive behavior were (a) social maladaption (or aggression against other persons or property; sum of 9 CDER items), and (b) personal maladaption (or self-injurious behaviors; sum of 7 CDER items). Additional information about which CDER items contribute to each of these dimensions is contained in the Widaman et al. (1987) paper.

We converted scores on these six CDER dimensions to a z-score metric based on data from the first fiscal year, 1995-96. That is, we used the mean and standard deviation (SD) of scores on each dimension in 1995-96 to covert all measures to z-scores. As a result, the scores on each of the dimensions had a mean of zero and SD of 1.0 for the 1995-96 fiscal year, and means and SDs that were slightly different from 0 and 1, respectively, in later years, but were calculated with reference to the 1995-96 year data. Thus, if the mean cognitive competence score were greater than 0 in a later fiscal year, this would indicate a somewhat higher score on the cognitive competence dimension in that fiscal year in comparison to the 1995-96 fiscal year.

Order of Estimating Effects of Cost-Related Factors

When modeling the relations of consumer characteristics on purchase of services, we performed the following sets of analyses. First, we separately estimated the effect of each predictor variable – particularly the Coffelt vs. non-Coffelt contrast – in an analysis in which it alone was the sole predictor of variation in purchase of services.

Then, we performed analyses in which we estimated relations of predictors when controlling for other factors. In doing so, we first estimated the effects of legitimate cost-related factors, estimating the effects of the following variables in the following order: (a) chronological age, (b) type of residence, (c) consumer characteristic, (d) consumer level of mental retardation, and (e) consumer levels of adaptive and maladaptive behavior. When estimating effects of the preceding

variables (a) through (e), we estimated the variance explained by a given predictor while partialing variables earlier in the list. Thus, we first estimated the effect of consumer age, then we estimated the influence of the type of residence (while partialing consumer age), next we estimated the effect of consumer characteristic (while partialing both consumer age and type of residence), and so forth, ending with our estimating of the influence of consumer levels of adaptive and maladaptive behaviors (while partialing consumer age, type of residence, consumer characteristic, and consumer level of mental retardation).

After estimating the effects of the preceding, legitimate cost-related variables, we then added the potential bias factors of (f) regional center, (g) consumer ethnic status, (h) consumer gender, and (i) Coffelt status, partialing all factors out of these bias factors. We could find no rationale for ordering the estimation of effects of these variables, so the effects of these bias factors were fully controlled, a conservative approach to estimating the magnitude of the effects of these factors that might represent bias in distribution of services.

As discussed below, we estimated variance explained by the preceding factors after partialing effects of other factors as we just described. But, after partialing to get estimates of variance explained, we obtained the estimated means on all factors – both the legitimate cost-related factors and the potential bias factors – while partialing all other factors. As a result, estimates of the costs for consumers in different age groups were estimated while partialing all other factors in the analysis, and this approach was taken for all predictor variables.

Alternative Treatments of the Dependent Variable, POS

Because the purchase of service outcome variables were positively skewed, we performed all analyses on three different ways of scoring the outcome variables. The first set of analyses was performed on raw purchase of service values, the typical way in which these data have been analyzed in the past. The positive skew of raw cost values means that a large number of persons have a relatively low level of purchase of services in a given category, and a relatively small number of persons have relatively high levels of purchase of services. This skew can lead to anomalous findings, as the mean (or average) of a set of numbers is heavily influenced by skewness of the set of scores.

To decrease the degree of positive skew, we also performed all analyses on two transformed versions of the purchase of service values. The first of these transformations was to trim, or delete, the largest 1% of values within each cost category. Trimming extreme values is a common method for dealing with skewed distributions, leading to much better defined estimates of the mean. Trimming 1% of the values is a conservative approach, as the trimming of 5% to 10% of extreme values is often performed. The second transformation is known as Winsorizing. Under Winsorizing, one truncates a given percentage of values so that they do not fall above a certain value. We Winsorized the top 1% of values by recoding these values equal to the value at the 99th percentile. Thus, instead of discarding outliers, the outliers are retained but forced to fall at a rather large, but not strictly unusual value. As with trimming, Winsorizing 1% of the values was a conservative approach, as researchers often Winsorize a larger percentage of cases.

Characterizing Differences: Statistical and Practical Significance

Statistical significance. The first and usual way to characterize differences as a function of a predictor variable is to evaluate the statistical significance of the difference. Statistical significance answers the question regarding whether the observed differences between groups (or the estimated regression coefficient) could have occurred by chance alone. When analyzing data, two means are never precisely equal, even if there is no true difference in the population means for the two groups. Given this, statistical significance allows one to conclude that a mean difference is larger than one would expect on the basis of chance alone. For the current study, because sample size was large and because of the large number of significance tests computed, we used the $\alpha = .001$ level to evaluate statistical significance. But, even using a conservative level of significance, virtually all significance tests computed fell in the significant range.

Practical significance: Variance explained. When sample size is large, statistical significance of comparisons is virtually assured. In such situations, even effects of trivial magnitude are often significant. Because of this, researchers often rely on measures of practical significance (or importance) when evaluating the magnitude of effects. The most common index of practical significance is variance in an outcome variable explained by a predictor. Cohen (1988) offered criteria for magnitude of effects based on variance explained, stating that explaining 25% or more of the variance constituted a large effect, explaining around 10% was a moderate effect, and explaining approximately 1% of the variance constituted a small effect. In the current report, we report variance explained to four decimal places and interpret these figures, but we present all variance explained values so that readers can determine for themselves how large various effects are.

Practical significance: The Cohen's *d* metric. A second way of indexing the magnitude of effects is to use the *d* statistic proposed by Cohen (1988). Cohen's *d* is calculated, simply, as the difference between two means divided by the residual SD of the variable. For example, if the means for two groups are 500 and 1,000 and the residual SD of the variable is 2,000, this would lead to a Cohen's *d* value of (1000 - 500)/2000 = 0.25, indicating that the mean difference between the groups is one-fourth the size of the residual SD. Cohen argued that a *d* value of 0.80 indicated a large effect, a value of 0.50 reflected a medium or moderate sized effect, and a value of 0.20 represented a small effect. We used these baseline values for indicating the magnitude of effects in our analyses to characterize how large the differences were between groups in their mean levels of expenditure.

IV. VARIANCE IN SERVICE EXPENDITURES

With a report such as the present one in which a large number of analyses are presented and summarized, one must beware of losing awareness of the core trends in the data as the various analyses are discussed. To guard against this possibility, we will discuss in greater detail the results of analyses only for the first year for which we have data (Fiscal Year 1995-1996). After portraying the somewhat different pictures of patterns of expenditure yielded by the various analyses for the first year, we will concentrate on differences between Coffelt and non-Coffelt consumers as shown by different forms of the cost variables for the remaining years.

A. FISCAL YEAR 1995-1996

Raw cost value analyses. The first set of analyses for data from Fiscal Year 1995-1996 used raw cost data as the dependent variable. In Table IV.A.1, we show the proportion of variance in each of the nine cost categories explained by each of the independent variables (a) when each independent variable is considered separately (i.e., not partialing any other variables; see top half of table), and (b) when other independent variables are controlled from each independent variable (see bottom half of table). For example, type of residence explained over 14% of the variance of Total Purchase of Services (POS Total) when considered alone (.1429), and an only slightly smaller and quite substantial 13.3% of the variance (.1334) over and above the effect of age group. Thus, partialing Age Group had little effect on variance in POS Total explained by type of residence. In contrast, Level of Mental Retardation explained over 6% of the variance (.0648) when considered alone, but a considerably reduced less than 1% of the variance (.0079) over and above Age Group, Residence Type, and Client Characteristic. The bottom line in the bottom half of the table, labeled "Multiple R^2," lists the overall proportion of variance explained by the best weighted combination of the predictor variables.

One trend to note in Table IV.A.1 is that a considerable percentage of the variance (i.e., between 24 and 44%) in four cost categories – out of home, day programs, transportation, and POS Total – was explained by the nine predictors. In the remaining five cost categories, more modest percentages of variance were explained (i.e., between 1 and 8%). This means that, in these latter categories, purchase of services – to the degree that service provision was related to systematic factors – was not well explained by the predictor variables to which we had access.

The primary goal of the present report is to investigate the effect of Coffelt status on expenditures. As shown in the top half of Table IV.A.1, when considered alone, Coffelt status tended to explain about two percent or less (i.e., .0177 or less) of the variance for costs within the first eight cost categories and over 2% of the variance (.0236) in POS Total. When other variables are controlled statistically, the variance explained by Coffelt status fell strongly. That is, as shown in the bottom half of Table IV.A.1, Coffelt status explained at most about one-third of one percent of the variance (.0039 or less) of each of the nine cost categories. Thus, in terms of explained variance, Coffelt status appears to explain little variance in service expenditure variance.

Table IV.A.1

Year 1995-1996, Raw Cost Values – Variance Explained by Each Independent Variable:
Other Independent Variables Not Controlled and Other Independent Variables Controlled

	Service Category								
Independent Variable	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
Other Independent Variables Not Controlled									
Regional Center	.0220	.0247	.3002	.0058	.0027	.0146	.0105	.0192	.0241
Gender	.0049	.0014	.0010	.0000	.0000	.0001	.0000	.0002	.0045
Ethnicity	.0008	.0003	.0087	.0001	.0002	.0002	.0001	.0010	.0002
Age Group	.0016	.0068	.0003	.0001	.0001	.0010	.0018	.0016	.0085
Residence	.3558	.1033	.0662	.0006	.0013	.0003	.0102	.0201	.1429
Client Characteristic	.0775	.1000	.0295	.0023	.0018	.0003	.0088	.0167	.1232
Mental Retardation	.0448	.0886	.0390	.0013	.0012	.0002	.0036	.0031	.0648
Adaptive Behaviors	.1340	.1230	.0590	.0050	.0049	.0020	.0147	.0111	.1613
Coffelt Status	.0103	.0177	.0051	.0024	.0001	.0004	.0077	.0020	.0236
Other Independent Variables Controlled									
Regional Center	.0095	.0302	.2572	.0056	.0024	.0145	.0074	.0150	.0178
Gender	.0005	.0002	.0000	.0000	.0000	.0001	.0000	.0000	.0004
Ethnicity	.0009	.0002	.0000	.0001	.0001	.0001	.0000	.0004	.0002
Age Group	.0016	.0068	.0003	.0001	.0001	.0010	.0018	.0016	.0085
Residence	.3583	.0910	.0636	.0006	.0012	.0002	.0093	.0187	.1334
Client Characteristic	.0402	.0701	.0116	.0024	.0030	.0004	.0108	.0277	.1079
Mental Retardation	.0006	.0204	.0056	.0016	.0013	.0004	.0012	.0023	.0079
Adaptive Behaviors	.0235	.0241	.0065	.0021	.0025	.0016	.0074	.0126	.0475
Coffelt Status	.0021	.0039	.0006	.0020	.0000	.0003	.0007	.0020	.0006
Multiple R^2	.4376	.2469	.3540	.0145	.0106	.0185	.0430	.0807	.3281

Note: Tabled values are either squared correlations or squared semipartial correlations, indicating the proportion of variance explained by the independent variable. Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services.

However, when sample sizes are very different, as in the present analyses, explained variance may not be the best way to characterize the effect of a predictor on an outcome variable. Rather than concentrating on variance explained, we can look at mean differences between groups both before other variables are controlled as well as after other independent variables are controlled statistically. For example, consider the values in the top half of Table IV.A.2, which contains mean expenditures for persons in each Coffelt status in each of the nine cost categories – but note that these means were computed without controlling for other predictor variables.

The Coffelt status variable has 8 levels, indicating year of placement. The largest group is the set of non-Coffelt consumers (almost 33,000 individuals), and the remaining seven groups consist of Coffelt consumers placed in 1995 through 2001. Only the Coffelt group placed in 1995 (N = 244) should have considerable levels of expenditures, because the remaining Coffelt samples (placed in 1996 through 2001, and numbering between 50 and 521 individuals across these samples) received most of their services through the state developmental centers in which they resided until their placement and few, if any, services through the Regional Centers. Accordingly, the average Total Purchase of Services for the 1995 Coffelt group was more than $ 21,350 per year, as opposed to the approximately $ 10,300 per year for non-Coffelt consumers. Recall that Coffelt status explained only about 2% of the variance in Total Purchase of Services. However, the means in the top half of Table IV.A.2 indicate that there was an approximately 2.1:1 ratio of service costs for 1995 Coffelt consumers when compared to non-Coffelt consumers, a substantial difference in service costs.

We could examine costs within each of the nine service categories, but here we will stress the POS Total variable, which reflects total purchase of services for individuals in the different ethnic categories. The difference between non-Coffelt and 1995 Coffelt consumers translates into a Cohen's *d* of 1.23, which is a quite large effect. This effect was estimated as the difference between the two means divided by the SD, or [(21,369 – 10,289) / 8,998].

The mean differences reported in the top half of Table IV.A.2 did not have other predictors – such as consumer age – controlled statistically. When other predictors are controlled statistically, we get the values shown in the bottom half of Table IV.A.2. As shown there, the mean estimates of expenditures are greatly altered when other predictors are controlled. Not surprisingly, the 1995 Coffelt consumers still have much higher levels of Total purchase of service expenditures than other consumers (over $ 14,000 per year), especially when compared to non-Coffelt consumers (about $ 7,200 per year). Thus, the ratio of expenditures for Coffelt vs. non-Coffelt consumers was reduced slightly from about 2.1:1 to 2.03:1 in Total Purchase of Services. The Cohen's *d* for this comparison was reduced importantly to 0.82, although a Cohen's *d* of 0.82 is still a large effect. In addition, note that, particularly after partialing other independent variables (see bottom of Table IV.A.2), the 1995 Coffelt consumers have higher levels of expenditures relative to non-Coffelt consumers primarily in only three of the first eight cost categories – out of home, other, and support services – where Cohen's *d* values were between .61 and .62.

Table IV.A.2

Year 1995-1996, Raw Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
		Other Independent Variables Not Controlled								
Non-Coffelt	32954	3926	4831	436	79	33	29	471	484	10289
1995	244	7694	7028	527	659	79	101	2804	2476	21369
1996	521	1652	1164	114	131	7	85	1019	541	4713
1997	296	198	216	45	63	0	4	276	130	933
1998	153	425	276	13	25	0	6	173	16	935
1999	126	1582	1157	76	8	0	8	269	92	3193
2000	75	1307	817	37	71	0	0	302	168	2703
2001	50	1441	976	89	3	0	0	265	571	3345
Mean		2278	2058	167	130	15	29	697	560	5935
Residual SD		4652	5095	1006	2091	463	2340	3031	3799	8998
		Other Independent Variables Controlled								
Non-Coffelt	32954	2369	3575	329	114	23	5	487	296	7198
1995	244	5232	3273	345	683	2	80	2374	2631	14621
1996	521	517	-746	81	235	-8	70	1479	526	2153
1997	296	652	2342	507	277	-31	-12	976	374	5085
1998	153	1630	2788	278	136	-17	17	696	-84	5446
1999	126	4052	4022	482	17	7	24	405	38	9046
2000	75	2133	3245	140	197	-19	-34	851	631	7145
2001	50	2123	2174	309	-15	-19	-2	282	747	5598
Mean		2339	2584	309	205	-8	19	944	645	7037
Residual SD		4652	5095	1006	2091	463	2340	3031	3799	8998

Note: Tabled values are mean per client service costs. Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services.

Trimmed cost values. One problem with the preceding analyses, based on raw cost values, is that a few extreme values can have large effects on means and thereby distort comparisons among groups. One way around this problem is to use transformations of the raw cost values, transformations that retain the easily interpretable metric of the outcome variables (in dollars), yet decrease the impact of outliers on the estimates of explained variance and mean values. The first of these two transformations used in the current report is the use of trimmed cost values.

The differences arising from the use of trimmed cost values are illustrated in Table IV.A.3, which gives the variance explained by predictors. Values in this table can be compared with those in Table IV.A.1, which were based on analyses of raw cost values. Comparisons across tables show that the values in Table IV.A.3 tend to be consistently larger than those in Table IV.A.1, suggesting that trimming the outlier cost values enabled the predictors to explain more variance in service costs. In turn, this implies that the large positive outlier cost values represent unpredictable variation that is the result of non-systematic factors of the individual consumer, rather than systematic effects of legitimate or biasing factors.

Once again, we concentrate here on the Coffelt Status variable. In the top half of Table IV.A.3, the reported values show that Coffelt Status tended to explain about 3 percent or less (.0273 or less) of the variance of the nine cost variables. In addition, after controlling other independent variables statistically, Coffelt Status explained even less variance, typically explaining only at most one percent of the variance. Thus, based on variance explained, Coffelt Status appears to have little influence on service expenditures.

However, as with raw cost values, mean differences across groups can often tell a more important story. Differences among Coffelt groups in mean levels on the trimmed data are shown in Table IV.A.4, with means prior to controlling other independent variables shown in the top half of the table and means controlling for other independent variable shown in the bottom half of the table. In the top half of the table, Total POS expenditures varied widely between the non-Coffelt and 1995 Coffelt samples, with an a 1.8:1 ratio in average expenditures (16,643:9,237), corresponding to a Cohen's *d* value of 1.09, a substantial difference.

However, as shown in the bottom half of Table IV.A.4, when other independent variables were controlled statistically, the differences between the non-Coffelt and 1995 Coffelt groups were reduced. The ratio of expenditures for 1995 Coffelt group relative to the non-Coffelt group was reduced only slightly to 1.67, but the Cohen's *d* for this comparison was reduced substantially, $d = 0.63$. Thus, although the Coffelt consumers received substantially greater amounts of services than did the non-Coffelt consumers, the differences were not as great as the raw cost values or the uncontrolled trimmed values implied.

Table IV.A.3

Year 1995-1996, 1% Trimmed Cost Values – Variance Explained by Each Independent Variable: Other Independent Variables Not Controlled and Other Independent Variables Controlled

	Service Category								
Independent Variable	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
Other Independent Variables Not Controlled									
Regional Center	.0209	.0215	.2769	.0173	.0040	.0058	.0391	.0264	.0246
Gender	.0037	.0010	.0008	.0000	.0002	.0001	.0005	.0002	.0036
Ethnicity	.0006	.0003	.0039	.0013	.0000	.0007	.0005	.0005	.0006
Age Group	.0000	.0046	.0000	.0001	.0001	.0005	.0041	.0014	.0049
Residence	.4571	.1748	.0752	.0004	.0028	.0012	.0774	.0238	.2299
Client Characteristic	.0576	.1267	.0302	.0033	.0026	.0012	.0066	.0031	.1112
Mental Retardation	.0573	.1397	.0444	.0016	.0019	.0000	.0202	.0109	.0908
Adaptive Behaviors	.1296	.1737	.0623	.0067	.0043	.0015	.0292	.0113	.1777
Coffelt Status	.0124	.0215	.0055	.0007	.0002	.0058	.0088	.0002	.0273
Other Independent Variables Controlled									
Regional Center	.0109	.0292	.2452	.0175	.0036	.0054	.0253	.0250	.0210
Gender	.0003	.0000	.0000	.0000	.0003	.0002	.0001	.0001	.0003
Ethnicity	.0008	.0000	.0000	.0010	.0001	.0002	.0007	.0003	.0004
Age Group	.0000	.0046	.0000	.0001	.0001	.0005	.0041	.0014	.0049
Residence	.4599	.1627	.0722	.0003	.0026	.0011	.0739	.0225	.2194
Client Characteristic	.0201	.0662	.0106	.0043	.0043	.0010	.0052	.0004	.0748
Mental Retardation	.0007	.0275	.0069	.0015	.0022	.0002	.0006	.0010	.0101
Adaptive Behaviors	.0147	.0196	.0051	.0034	.0015	.0008	.0051	.0008	.0347
Coffelt Status	.0023	.0055	.0007	.0014	.0001	.0049	.0104	.0008	.0027
Multiple R^2	.5101	.3147	.3446	.0298	.0147	.0149	.1259	.0522	.3686

Note: Tabled values are either squared correlations or squared semipartial correlations, indicating the proportion of variance explained by the independent variable. Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services.

Table IV.A.4

Year 1995-1996, 1% Trimmed Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
Other Independent Variables Not Controlled										
Non-Coffelt	32954	3275	4373	366	25	14	8	242	75	9237
1995	244	6395	6020	495	50	32	53	862	99	16643
1996	521	1596	1036	107	47	7	65	529	64	4460
1997	296	198	216	45	7	0	4	90	35	631
1998	153	425	164	13	25	0	6	87	16	935
1999	126	892	896	76	8	0	8	101	92	2477
2000	75	1307	817	37	37	0	0	213	92	2703
2001	50	781	976	89	3	0	0	265	28	1545
Mean		3213	4251	356	26	14	9	248	74	9048
Residual SD		3254	4003	624	149	189	101	631	457	6768
Other Independent Variables Controlled										
Non-Coffelt	32954	1777	3375	280	22	24	7	259	55	6277
1995	244	4549	2376	349	34	44	45	930	100	10513
1996	521	1059	-772	92	61	24	85	856	132	2912
1997	296	1004	2461	472	39	11	3	317	194	4626
1998	153	1998	2358	240	153	10	27	428	108	6165
1999	126	2544	3955	476	27	14	16	255	265	7825
2000	75	2752	3456	134	139	9	-10	746	329	7820
2001	50	1158	2469	266	9	8	-7	457	50	3120
Mean		2105	2460	289	61	18	21	531	154	6157
Residual SD		3254	4003	624	149	189	101	631	457	6768

Note: Tabled values are adjusted mean per client service costs (i.e., least squares means). Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services

Winsorized cost values. Analyses were also conducted on Winsorized cost values, the second of the transformations of the cost values. These analyses were somewhat less preferred than the analyses of trimmed data, primarily because of the larger residual SD values obtained in the Winsorized data analyses. However, the variance explained by independent variables for Winsorized data and trimmed data were fairly comparable; given their similarity, we will not present these variance explained values, so that we can concentrate on the estimated cost values.

Differences among Coffelt groups in mean levels on the Winsorized data are shown in Table IV.A.5, with means prior to controlling other independent variables shown in the top half of the table and means controlling for other independent variable shown in the bottom half of the table. In the top half of the table, Total POS expenditures varied fairly widely between the non-Coffelt and 1995 Coffelt samples, with an almost 2:1 (i.e., 1.91:1) ratio in average expenditures (19,199:10,046), corresponding to a Cohen's *d* value of 1.17, a substantial difference.

However, as shown in the bottom half of Table IV.A.5, when other independent variables were controlled statistically, the differences between the non-Coffelt and 1995 Coffelt groups were clearly reduced. With regard to Total Purchase of Services, the ratio of expenditures for 1995 Coffelt group relative to the non-Coffelt group was over 1.75 (1.78), but the Cohen's *d* for this comparison was cut almost in half, $d = 0.69$, confirming the results with the trimmed data. Although the Coffelt consumers received substantially greater amounts of services than did the non-Coffelt consumers, the differences were not as great as the raw cost values or the uncontrolled trimmed values implied.

For brevity, we have concentrated here on the Total Purchase of Services variable, which is the sum of the preceding eight categories of services. We note here that the 1995 Coffelt group appeared to differ substantially from the non-Coffelt group primarily in three categories – out of home, day programs, and other – when considering the uncontrolled values in the top half of Table IV.A.5. But, after other independent variables were controlled statistically, the values in the bottom half of the table show that the 1995 Coffelt and non-Coffelt group tended to differ substantially on only two categories of expenditures – out of home and other – for which the Cohen's *d* values fell between 0.64 and 1.15. Cohen's *d* values for the remaining categories of expenditures tended to be much smaller (i.e., less than 0.40).

Table IV.A.5

Year 1995-1996, 1% Winsorized Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
		Other Independent Variables Not Controlled								
Non-Coffelt	32954	3860	4647	417	42	21	15	347	192	10046
1995	244	7509	6328	520	136	56	75	1649	467	19199
1996	521	1646	1119	113	60	7	75	777	238	4674
1997	296	198	216	45	39	0	4	134	73	908
1998	153	425	264	13	25	0	6	130	16	935
1999	126	1521	1127	76	8	0	8	206	92	3098
2000	75	1307	817	37	68	0	0	299	167	2703
2001	50	1311	976	89	3	0	0	265	256	3147
Mean		2222	1937	164	48	11	23	476	188	5589
Residual SD		4336	4236	679	245	277	171	1022	897	7835
		Other Independent Variables Controlled								
Non-Coffelt	32954	2292	3568	315	47	30	8	347	120	6976
1995	244	5088	2634	351	108	39	65	1523	482	12409
1996	521	599	-651	92	87	21	80	1195	320	2505
1997	296	747	2477	499	203	2	-1	481	327	5422
1998	153	1721	2780	267	159	5	25	618	69	5781
1999	126	3896	4144	484	35	17	19	406	203	8932
2000	75	2232	3357	141	246	4	-16	996	587	7386
2001	50	1897	2418	300	14	2	-4	401	435	5527
Mean		2309	2591	306	112	15	22	746	318	6867
Residual SD		4336	4236	679	245	277	171	1022	897	7835

Note: Tabled values are adjusted mean per client service costs (i.e., least squares means). Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services

B. FISCAL YEAR 1996-1997

The results of analyses for Fiscal Year 1996-97 were, in broad strokes, quite similar to those for 1995-96, with one major, predicted exception to be discussed below. Because the explained variance figures were quite similar to those reported for 1995-1996, we will not present these values here. Instead, we will concentrate on the estimates of service expenditure costs for the different groups of consumers.

Raw cost values. The mean expenditures based on raw cost values are shown in Table IV.B.1. In the top half of the table, values reported represent simple effects of Coffelt status, with other independent variables not controlled; values in the bottom half of the table show the effects of Coffelt status with other variables controlled. For analyses of 1996-1997 cost data, the non-Coffelt group numbered over 34,000 individuals, the 1995 and 1996 Coffelt samples had 245 and 501 persons, respectively, and the remaining Coffelt groups had between 50 and 291 individuals. The 1995 and 1996 Coffelt groups are the key groups in this analysis: because both of these groups were placed in community settings for the 1996-1997 fiscal year, they should show elevated levels of expenditures, whereas the remaining Coffelt groups should have relatively low levels of expenditures. This increased level of expenditure for two Coffelt groups – the 1995 and 1996 Coffelt groups – was the single, predicted change expected in the present analyses.

As shown in the top half of Table IV.B.1, the 1995 and 1996 Coffelt groups had much higher levels of expenditure (approximately $ 25,700) than did the non-Coffelt group (approximately $ 11,000), a ratio of about 2.34:1 in spending. Interestingly, the two Coffelt samples of interest – the 1995 and 1996 Coffelt groups – had approximately equal levels of service expenditures, suggesting an absence of cohort effects. That is, the Coffelt consumers placed in 1995 had approximately equal levels of expenditures to the Coffelt consumers placed in 1996, implying that the two groups were similar in makeup and in the need for services. In addition to a 2.34:1 ratio of service expenditures for the Coffelt vs. non-Coffelt groups, the mean difference is associated with a Cohen's *d* of 1.55, a large effect.

The mean expenditures for different groups when other independent variables are controlled statistically are shown in the bottom half of Table IV.B.1. The difference between the 1995 and 1996 Coffelt groups and the non-Coffelt sample were clearly reduced, but a ratio of 2.27:1 in spending was still evident. This difference corresponded to a Cohen's *d* of 1.11, much smaller than the *d* based on raw cost values, but still a large effect.

Table IV.B.1

Year 1996-1997, Raw Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
		Other Independent Variables Not Controlled								
Non-Coffelt	34418	4304	4919	457	82	36	40	362	761	10961
1995	245	9374	8291	674	625	19	209	978	5552	25720
1996	501	11690	7105	604	325	24	205	2150	3542	25645
1997	291	1936	1280	153	22	0	105	1003	1323	5823
1998	159	464	262	17	13	0	16	61	445	1277
1999	133	1819	1249	44	19	0	80	127	265	3603
2000	78	1728	776	58	47	0	46	367	248	3271
2001	50	1980	1381	107	5	2	24	371	1670	5540
Mean		4162	3158	264	142	10	91	677	1726	10230
Residual SD		5065	4885	795	1192	758	577	1857	5193	9523
		Other Independent Variables Controlled								
Non-Coffelt	34418	2930	3706	369	77	37	16	474	661	8271
1995	245	6967	4668	549	652	1	194	1109	6095	20231
1996	501	8226	2869	386	215	8	165	2205	3294	17369
1997	291	623	-1561	81	7	-17	62	1509	1838	2541
1998	159	2046	3226	485	-10	9	54	3	2328	8140
1999	133	5409	4517	336	-32	-2	267	411	162	11068
2000	78	2612	3103	336	4	-11	107	1052	870	8074
2001	50	4064	3555	384	9	12	-5	723	3094	11837
Mean		4110	3010	366	115	5	108	936	2293	10942
Residual SD		5065	4885	795	1192	758	577	1857	5193	9523

Note: Tabled values are mean per client service costs. Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services.

Trimmed cost values. The mean expenditures for the various Coffelt groups based on trimmed cost values are shown in Table IV.B.2. As shown in the top half of the table, the 1995 and 1996 Coffelt groups have substantially higher levels of expenditures. The two Coffelt groups have average mean expenditures over $ 17,400 per year versus an average of less than $ 10,000 per year for the non-Coffelt group, a ratio of over 1.7:1 in spending (i.e., 1.76:1). The difference in spending corresponds to a Cohen's *d* of 1.04, a large effect.

The bottom half of Table IV.B.2 shows mean expenditures controlling statistically for other independent variables. Here, the 1995 and 1996 Coffelt groups have much lower overall mean expenditures, around $ 12,300 per year as compared with the approximately $ 7,600 per year for non-Coffelt consumers, a 1.62:1 ratio in expenditures. The Cohen's *d* for this comparison is 0.66, considerably reduced from both the raw expenditures and from the trimmed expenditures without other independent variables controlled.

Winsorized cost values. Mean expenditures based on Winsorized cost values are shown in Table IV.B.3. Because Winsorizing reduces but does not eliminate extreme values, the results shown here fall somewhere between the results for raw and trimmed cost values. Specifically, the 1995 and 1996 Coffelt consumers had mean uncontrolled expenditures of about $ 22,400 per year as compared with just over $ 10,700 for non-Coffelt consumers, a 2.08:1 ratio across the groups. This mean difference has a Cohen's *d* of 1.41, a rather large effect.

When other independent variables are controlled statistically, the values shown in the bottom half of the table reveal that the two Coffelt groups have mean expenditures of about $ 15,600 per year versus about $ 8,100 per year for the non-Coffelt group. This cost difference is still over a 1.9:1 ratio in spending (specifically 1.92:1), but this is less than prior to the controlling of other independent variables. The Cohen's *d* of 0.90 still represents a rather large effect, but is considerably smaller than the 1.41 observed prior to the controlling of other independent variables.

Table IV.B.2

Year 1996-1997, 1% Trimmed Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
Other Independent Variables Not Controlled										
Non-Coffelt	34418	3518	4509	385	23	14	9	216	164	9927
1995	245	4650	7659	608	43	19	23	158	55	16501
1996	501	5685	6659	490	47	12	49	506	149	18344
1997	291	1936	1280	153	22	0	59	323	260	5530
1998	159	464	154	17	13	0	16	61	224	1277
1999	133	1136	660	44	19	0	11	83	105	2866
2000	78	1016	776	58	15	0	0	133	2	3271
2001	50	1308	1381	107	5	2	24	236	69	2853
Mean		3504	4486	382	24	13	10	219	163	9936
Residual SD		3285	4090	641	140	185	121	469	836	7189
Other Independent Variables Controlled										
Non-Coffelt	34418	2365	3384	335	25	16	11	282	66	7581
1995	245	3885	4166	531	46	26	25	296	65	12175
1996	501	4362	2573	342	46	22	48	633	168	12425
1997	291	1512	-1398	110	33	5	47	533	568	3569
1998	159	2694	2790	428	16	5	86	208	1134	9046
1999	133	4268	2919	336	41	5	0	303	102	10364
2000	78	1700	3253	303	0	1	-4	313	-81	8837
2001	50	3136	3713	363	10	8	-5	539	184	7129
Mean		2990	2675	343	27	11	26	388	276	8891
Residual SD		3285	4090	641	140	185	121	469	836	7189

Note: Tabled values are adjusted mean per client service costs (i.e., least squares means). Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services

Table IV.B.3

Year 1996-1997, 1% Winsorized Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
Other Independent Variables Not Controlled										
Non-Coffelt	34418	4209	4787	437	38	22	21	283	368	10743
1995	245	8695	8048	657	114	19	73	406	1013	21483
1996	501	10459	7034	553	121	23	116	1086	1021	23307
1997	291	1936	1280	153	22	0	90	673	638	5796
1998	159	464	251	17	13	0	16	61	282	1277
1999	133	1748	1110	44	19	0	58	125	175	3488
2000	78	1714	776	58	43	0	40	204	123	3271
2001	50	1847	1381	107	5	2	24	346	631	5337
Mean		3884	3083	253	47	8	55	398	531	9338
Residual SD		4561	4322	691	231	279	232	770	1563	8283
Other Independent Variables Controlled										
Non-Coffelt	34418	2836	3602	360	40	26	15	326	459	8099
1995	245	6396	4465	552	110	24	67	475	1260	15763
1996	501	7144	2864	361	108	33	100	1119	1170	15391
1997	291	782	-1492	97	29	2	73	976	1261	2936
1998	159	2217	3119	470	14	5	75	142	1653	8436
1999	133	5302	3991	342	32	7	190	432	424	11045
2000	78	2745	3121	328	77	-2	115	514	534	8295
2001	50	3808	3688	383	14	2	-4	759	1346	11537
Mean		3904	2920	362	53	12	79	593	1013	10188
Residual SD		4561	4322	691	231	279	232	770	1563	8283

Note: Tabled values are adjusted mean per client service costs (i.e., least squares means). Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services

C. FISCAL YEAR 1997-1998

The results of analyses for Fiscal Year 1997-98 were generally quite similar to those for the prior two years, again with one major, predicted exception to be discussed below. Because the explained variance figures were quite similar to those reported for 1995-1996 and 1996-97, we will not present these values here. Instead, we will concentrate on the estimates of service expenditure costs for the different groups of consumers.

Raw cost values. The mean expenditures based on raw cost values are shown in Table IV.C.1. Values reported in the top half of the table represent simple effects of Coffelt status, with other independent variables not controlled; values in the bottom half of the table show the effects of Coffelt status with other variables controlled. For analyses of 1997-1998 cost data, the non-Coffelt group numbered over 35,000 individuals, the 1995, 1996, and 1997 Coffelt samples had 253, 507, and 288 persons, respectively, and the remaining Coffelt groups had between 53 and 161 individuals. The 1995, 1996, and 1997 Coffelt groups are the key groups in this analysis: because these three groups were placed in community settings for the 1997-1998 fiscal year, they should show elevated levels of expenditures, whereas the remaining Coffelt groups should have relatively low levels of expenditures. This increased level of expenditure for these three Coffelt groups – the 1995, 1996, and 1997 Coffelt groups – was the predicted change expected in the present analyses.

As shown in the top half of Table IV.C.1, the 1995, 1996, and 1997 Coffelt groups had much higher levels of expenditure (approximately $ 28,000) than did the non-Coffelt group (approximately $ 12,100), a ratio of about 2.31:1 in spending. Interestingly, the three Coffelt samples of interest – the 1995, 1996, and 1997 Coffelt groups – had reasonably equal levels of service expenditures, suggesting an absence of cohort effects. In addition to a 2.3:1 ratio of service expenditures for the Coffelt vs. non-Coffelt groups, the mean difference is associated with a Cohen's *d* of 1.54, a rather large effect.

The mean expenditures for different groups when other independent variables are controlled statistically are shown in the bottom half of Table IV.C.1. The ratio difference between the 1995, 1996, and 1997 Coffelt groups and the non-Coffelt sample somewhat higher, 2.66:1 But, this difference corresponded to a Cohen's *d* of 1.26, smaller than the *d* based on controlled raw cost values, but still a large effect.

Table IV.C.1

Year 1997-1998, Raw Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
		Other Independent Variables Not Controlled								
Non-Coffelt	35402	4845	5039	438	84	42	51	446	1170	12116
1995	253	9636	7799	702	574	0	209	1078	5221	25219
1996	507	12425	7851	633	158	12	67	1337	5182	27666
1997	288	12070	7939	728	169	19	88	2187	8053	31253
1998	161	2652	975	89	54	14	79	990	1777	6630
1999	138	1256	440	40	49	1	40	273	422	2520
2000	79	2067	606	53	49	17	80	444	790	4108
2001	53	1813	1756	22	17	4	4	563	1486	5666
Mean		5846	4051	338	144	14	77	915	3013	14397
Residual SD		5320	4968	792	1285	959	700	2272	6263	10340
		Other Independent Variables Controlled								
Non-Coffelt	35402	2461	4255	396	44	19	65	441	161	7841
1995	253	6813	5176	556	598	-55	243	1116	4597	19045
1996	507	9370	4658	456	115	-41	87	1315	4214	20175
1997	288	8864	4597	560	114	-32	105	2083	7042	23333
1998	161	686	-736	194	11	-49	87	1131	1846	3170
1999	138	2631	3401	414	-70	44	170	541	345	7476
2000	79	3596	3052	264	42	14	274	1326	1507	10075
2001	53	1574	5202	342	-25	37	54	735	2194	10112
Mean		4500	3701	397	104	-8	136	1086	2738	12653
Residual SD		5320	4968	792	1285	959	700	2272	6263	10340

Note: Tabled values are mean per client service costs. Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services.

Trimmed cost values. The mean expenditures for the various Coffelt groups based on trimmed cost values are shown in Table IV.C.2. As shown in the top half of the table, the 1995, 1996, and 1997 Coffelt groups have substantially higher levels of expenditures. The three Coffelt groups of interest have average mean expenditures of just over $ 18,600 per year versus an average of just over $ 11,000 per year for the non-Coffelt group, a ratio of almost 1.7:1 in spending (i.e., 1.69:1). The difference in spending corresponds to a Cohen's *d* of 0.96, a large effect.

The bottom half of Table IV.C.2 shows mean expenditures controlling statistically for other independent variables. Here, the 1995, 1996, and 1997 Coffelt groups have much lower overall mean expenditures, around $ 13,650 per year as compared with about $ 7,300 per year for non-Coffelt consumers, a 1.88:1 ratio in expenditures. The Cohen's *d* for this comparison is 0.81, reduced from both the raw expenditures and from the trimmed expenditures without other independent variables controlled, but still a large effect.

Winsorized cost values. Mean expenditures based on Winsorized cost values are shown in Table IV.C.3. Because Winsorizing reduces but does not eliminate extreme values, the results shown here fall somewhere between the results for raw and trimmed cost values. Specifically, the 1995, 1996, and 1997 Coffelt consumers had mean uncontrolled expenditures of about $ 24,700 per year as compared with almost $ 11,900 for non-Coffelt consumers, a 2.08:1 ratio across the groups. This mean difference has a Cohen's *d* of 1.43, a rather large effect.

When other independent variables are controlled statistically, the values shown in the bottom half of the table reveal that the two Coffelt groups have mean expenditures of about $ 17,800 per year versus about $ 7,800 per year for the non-Coffelt group. This cost difference is a slightly higher 2.28:1 ratio in spending. But, the Cohen's *d* of 1.11, a large effect, is considerably smaller than the 1.43 observed prior to the controlling of other independent variables.

Table IV.C.2

Year 1997-1998, 1% Trimmed Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
Other Independent Variables Not Controlled										
Non-Coffelt	35402	4309	4623	370	24	12	11	243	403	11038
1995	253	5846	7393	599	34	0	4	141	491	17962
1996	507	6017	7242	533	51	0	7	197	790	18373
1997	288	5810	7605	540	48	19	22	362	1071	19503
1998	162	2652	975	89	40	14	79	507	472	5794
1999	138	759	313	40	9	1	40	133	275	1788
2000	79	1230	606	53	18	17	4	54	418	2611
2001	53	494	1756	22	17	4	4	259	394	2647
Mean		4353	4699	375	25	11	11	245	416	11222
Residual SD		4082	4134	642	136	164	138	549	1745	7870
Other Independent Variables Controlled										
Non-Coffelt	35402	2056	3634	344	18	11	42	207	212	7270
1995	253	4184	4551	483	27	0	35	216	388	13460
1996	507	4898	3936	389	43	1	35	263	763	13333
1997	288	4270	4254	405	44	23	59	445	1072	14182
1998	161	1447	-852	178	54	-1	89	871	796	3608
1999	138	1872	2718	361	24	10	151	299	713	6782
2000	79	2360	2844	257	52	9	34	91	1274	7989
2001	53	836	5000	282	34	8	30	357	612	7624
Mean		2740	3261	337	37	8	59	344	729	9281
Residual SD		4082	4134	642	136	164	138	549	1745	7870

Note: Tabled values are adjusted mean per client service costs (i.e., least squares means). Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services

Table IV.C.3

Year 1997-1998, 1% Winsorized Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
		Other Independent Variables Not Controlled								
Non-Coffelt	35402	4784	4904	418	39	22	27	329	771	11871
1995	253	9254	7742	676	94	0	64	487	2418	22922
1996	507	11341	7775	601	93	11	29	709	2363	24592
1997	288	10988	7904	619	78	19	49	1010	3083	26686
1998	161	2652	975	89	53	14	79	726	978	6316
1999	138	1212	423	40	25	1	40	224	394	2455
2000	79	2008	606	53	45	17	52	134	625	3756
2001	53	1682	1756	22	17	4	4	490	703	5206
Mean		5490	4011	315	56	11	43	514	1417	12975
Residual SD		4946	4365	695	225	289	286	915	2934	8999
		Other Independent Variables Controlled								
Non-Coffelt	35402	2391	4103	377	32	14	53	274	236	7778
1995	253	6444	5104	542	90	-13	95	510	2080	16885
1996	507	8240	4577	435	85	1	56	705	1918	17284
1997	288	7748	4598	462	64	9	79	984	2651	19113
1998	161	784	-749	185	53	-11	90	1078	1189	3220
1999	138	2592	3193	390	24	19	155	532	796	7703
2000	79	3488	2987	261	137	8	193	324	1556	9323
2001	53	1524	5233	312	38	14	38	750	1076	9682
Mean		4151	3631	370	65	5	95	645	1438	11374
Residual SD		4946	4365	695	225	289	286	915	2934	8999

Note: Tabled values are adjusted mean per client service costs (i.e., least squares means). Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services.

D. FISCAL YEAR 1998-1999

The results of analyses for Fiscal Year 1998-1999 were, once again, quite similar to those for the previous three years. Because the explained variance figures were quite similar to those reported for 1995-1996, we will not present these values here. Instead, we will concentrate on the estimates of service expenditure costs for the different groups of consumers.

Raw cost values. The mean expenditures based on raw cost values are shown in Table IV.D.1. Values reported in the top half of the table represent simple effects of Coffelt status, with other independent variables not controlled; values in the bottom half of the table show the effects of Coffelt status with other variables controlled. For analyses of 1998-1999 cost data, the non-Coffelt group numbered over 36,000 individuals, the 1995, 1996, 1997, and 1998 Coffelt samples had 257, 512, 295, and 149 persons, respectively, and the remaining Coffelt groups had between 55 and 143 individuals. The 1995, 1996, 1997, and 1998 Coffelt groups are the key groups in this analysis: because all four of these groups were placed in community settings for the 1998-1999 fiscal year, they should show elevated levels of expenditures, whereas the remaining Coffelt groups should have relatively low levels of expenditures. This increased level of expenditure for the four Coffelt groups – the 1995, 1996, 1997, and 1998 Coffelt groups – was the single, predicted change expected in the present analyses.

As shown in the top half of Table IV.D.1, the 1995, 1996, 1997, and 1998 Coffelt groups had much higher levels of expenditure (approximately $ 28,500) than did the non-Coffelt group (approximately $ 13,850), a ratio of about 2.06:1 in spending. Interestingly, the Coffelt samples of interest – the 1995, 1996, 1997, and 1998 Coffelt groups – had fairly equal levels of service expenditures, suggesting an absence of cohort effects. In addition to a 2.06:1 ratio of service expenditures for the Coffelt vs. non-Coffelt groups, the mean difference is associated with a Cohen's *d* of 1.30, a large effect.

The mean expenditures for different groups when other independent variables are controlled statistically are shown in the bottom half of Table IV.D.1. The difference between the 1995-1998 Coffelt groups (mean expenditures of about $ 20,600 per year) and the non-Coffelt sample (about $ 8,100 per year) was slightly higher, a ratio of 2.55:1 in spending. This difference corresponded to a Cohen's *d* of 1.12, rather smaller than the *d* based on uncontrolled raw cost values, but still a large effect.

Table IV.D.1

Year 1998-1999, Raw Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
		Other Independent Variables Not Controlled								
Non-Coffelt	36613	5891	5349	507	87	43	58	453	1466	13854
1995	257	10178	7350	873	502	0	334	988	4449	24674
1996	512	13189	8116	614	175	24	48	1445	5329	28942
1997	295	12960	8913	752	198	8	224	1140	7051	31245
1998	149	14588	5568	531	54	53	242	2922	5088	29045
1999	143	2520	1222	160	189	0	218	956	1220	6484
2000	82	1578	556	44	330	0	73	297	534	3411
2001	55	2742	1690	23	48	0	83	622	1336	6544
Mean		7956	4845	438	198	16	160	1103	3309	18025
Residual SD		5803	5172	912	1252	1021	759	2300	7109	11244
		Other Independent Variables Controlled								
Non-Coffelt	36613	3001	3381	498	9	14	46	512	632	8093
1995	257	8074	4011	749	481	-52	396	1188	4165	19013
1996	512	10129	4105	441	77	-18	53	1613	4732	21133
1997	295	9805	4836	635	127	-44	168	1241	6194	22960
1998	149	9994	1140	376	-11	16	289	3391	4285	19479
1999	143	2439	661	355	320	-12	375	1113	1241	6491
2000	82	3863	3965	469	942	14	26	586	1755	11621
2001	55	4059	4722	402	74	-5	205	764	2161	12382
Mean		6421	3353	491	252	-11	195	1301	3146	15147
Residual SD		5803	5172	912	1252	1021	759	2300	7109	11244

Note: Tabled values are mean per client service costs. Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services.

Trimmed cost values. The mean expenditures for the various Coffelt groups based on trimmed cost values are shown in Table IV.D.2. As shown in the top half of the table, the 1995, 1996, 1997, and 1998 Coffelt groups have substantially higher levels of expenditures than the non-Coffelt group. The four Coffelt groups have average mean expenditures over $ 18,900 per year versus an average of about $ 12,700 per year for the non-Coffelt group, a ratio of 1.50:1 in spending. The difference in spending corresponds to a Cohen's *d* of 0.73, a moderate-to-large effect.

The bottom half of Table IV.D.2 shows mean expenditures controlling statistically for other independent variables. Here, the 1995, 1996, 1997, and 1998 Coffelt groups have lower overall mean expenditures, around $ 13,800 per year as compared with the about $ 7,400 per year for non-Coffelt consumers, a 1.85:1 ratio in expenditures. The Cohen's *d* for this comparison is 0.73, identical to that for expenditures without other independent variables controlled.

Winsorized cost values. Mean expenditures based on Winsorized cost values are shown in Table IV.D.3. Because Winsorizing reduces but does not eliminate extreme values, the results shown here fall somewhere between the results for raw and trimmed cost values. Specifically, the 1995, 1996, 1997, and 1998 Coffelt consumers had mean uncontrolled expenditures of about $ 25,600 per year as compared with almost $ 13,600 for non-Coffelt consumers, a 1.89:1 ratio across the groups. This mean difference has a Cohen's *d* of 1.22, a large effect.

When other independent variables are controlled statistically, the values shown in the bottom half of the table reveal that the four Coffelt groups have mean expenditures of about $ 17,800 per year versus about $ 8,000 per year for the non-Coffelt group. This cost difference is a slightly higher 2.24:1 ratio in spending, as compared to the ratio prior to the controlling of other independent variables. The Cohen's *d* of 1.00 still represents a rather large effect, but is notably smaller than the 1.22 observed prior to the controlling of other independent variables.

Table IV.D.2

Year 1998-1999, 1% Trimmed Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
Other Independent Variables Not Controlled										
Non-Coffelt	36613	5255	4939	437	26	15	13	254	525	12682
1995	257	6405	6893	723	36	0	12	133	749	18183
1996	512	6628	7514	533	22	10	12	238	749	19930
1997	295	4966	8231	614	36	8	10	250	908	17856
1998	149	6365	5488	443	54	53	42	272	1414	19917
1999	143	2026	1222	160	14	0	179	420	399	5809
2000	82	616	355	44	39	0	13	151	534	1893
2001	55	2061	1137	23	48	0	83	316	243	4300
Mean		5252	4982	439	26	14	14	254	535	12789
Residual SD		4474	4396	742	144	206	166	585	2099	8663
Other Independent Variables Controlled										
Non-Coffelt	36613	2584	3115	438	20	14	27	244	401	7434
1995	257	5473	3672	622	33	-1	32	227	763	13911
1996	512	5610	3759	409	15	12	29	360	792	14113
1997	295	4282	4531	535	30	5	23	338	834	13154
1998	149	4824	1303	339	58	65	64	390	1374	13885
1999	143	1853	683	391	12	3	269	611	349	6526
2000	82	2172	3310	416	106	5	44	256	1411	8533
2001	55	3492	4431	354	95	-5	172	488	457	10022
Mean		3786	3100	438	46	12	82	364	798	10947
Residual SD		4474	4396	742	144	206	166	585	2099	8663

Note: Tabled values are adjusted mean per client service costs (i.e., least squares means). Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services.

Table IV.D.3

Year 1998-1999, 1% Winsorized Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
Other Independent Variables Not Controlled										
Non-Coffelt	36613	5820	5230	490	41	23	34	346	956	13596
1995	257	9764	7293	833	87	0	101	459	2129	22730
1996	512	12150	8059	598	82	22	21	817	2342	25855
1997	295	11829	8828	702	73	8	71	553	2754	27500
1998	149	13522	5560	512	54	53	133	1284	2788	26487
1999	143	2489	1222	160	61	0	209	748	905	6463
2000	82	1459	548	44	93	0	68	236	534	3129
2001	55	2663	1686	23	48	0	83	563	574	6055
Mean		7462	4803	420	67	13	90	626	1623	16477
Residual SD		5409	4637	796	233	309	350	992	3350	9897
Other Independent Variables Controlled										
Non-Coffelt	36613	2927	3286	480	28	17	39	322	511	7950
1995	257	7622	3972	718	75	-9	129	532	1958	17001
1996	512	9015	4062	441	71	19	35	903	2064	18007
1997	295	8629	4796	593	65	-2	65	584	2289	19305
1998	149	8946	1159	365	50	57	170	1469	2435	17061
1999	143	2421	603	371	81	3	350	984	1081	6691
2000	82	3579	3836	455	258	9	39	513	1590	10763
2001	55	3998	4729	388	96	-3	187	899	998	11748
Mean		5892	3305	476	91	11	127	776	1616	13566
Residual SD		5409	4637	796	233	309	350	992	3350	9897

Note: Tabled values are adjusted mean per client service costs (i.e., least squares means). Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services.

E. FISCAL YEAR 1999-2000

The results of analyses for Fiscal Year 1999-2000 were, not surprisingly, fairly similar to those for the preceding four fiscal years. However, the 1999-2000 fiscal year is the most recent snapshot available for analyses of purchase of services across the State of California, so a more complete reporting of results will be given in this section.

Raw cost values. The variance explained by each independent variable in the raw cost values is shown in Table IV.E.1, first without other independent variables controlled (see top half of table) and then with other independent variables controlled (see bottom half of table). The primary aim of this report was to characterize the differences among consumers based on their status with regard to the Coffelt settlement. As shown in the top half of Table IV.E.1, Coffelt status explained around 4 percent or less of the variance of each dependent variable when other independent variables were not controlled. But, when other independent variables were controlled statistically, values in the bottom half of the table reveal that Coffelt status never explained over 2 percent of the variance of any dependent variable and usually explained only a very small portion of variance.

The mean expenditures based on raw cost values are shown in Table IV.E.2. In the top half of the table, values reported represent simple effects of Coffelt status, with other independent variables not controlled; values in the bottom half of the table show the effects of Coffelt status with other variables controlled. For analyses of 1999-2000 cost data, the non-Coffelt group numbered over 37,500 individuals, the 1995, 1996, 1997, 1998, and 1999 Coffelt samples had 204, 422, 238, 123, and 100 persons, respectively, and the remaining Coffelt groups had 25 and 45 individuals. The 1995 through 1999 Coffelt groups are the key groups in this analysis: because all of these groups were placed in community settings for the 1999-2000 fiscal year, they should show elevated levels of expenditures, whereas the remaining Coffelt groups should have relatively low levels of expenditures.

As shown in the top half of Table IV.E.2, the 1995-1999 Coffelt groups had much higher mean levels of expenditure (approximately $ 35,700) than did the non-Coffelt group (about $ 15,800), a ratio of 2.25:1 in spending. Interestingly, the Coffelt samples of interest – the 1995-1999 Coffelt groups – had approximately equal levels of service expenditures, suggesting an absence of cohort effects. In addition to a 2.25:1 ratio of service expenditures for the Coffelt vs. non-Coffelt groups, the mean difference is associated with a Cohen's *d* of 1.55, a large effect.

The mean expenditures for different groups when other independent variables are controlled statistically are shown in the bottom half of Table IV.E.2. The difference between the 1995-1999 Coffelt groups and the non-Coffelt sample were reduced slightly, but a ratio of 2.0:1 in spending was still evident. This difference corresponded to a Cohen's *d* of 1.10, considerably reduced from that based on uncontrolled raw cost values, but still a large effect.

Table IV.E.1

Year 1999-2000, Raw Cost Values – Variance Explained by Each Independent Variable:
Other Independent Variables Not Controlled and Other Independent Variables Controlled

	Service Category								
Independent Variable	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
Other Independent Variables Not Controlled									
Regional Center	.0290	.0245	.2115	.0068	.0025	.0156	.0246	.0179	.0311
Gender	.0074	.0018	.0001	.0000	.0001	.0000	.0000	.0002	.0065
Ethnicity	.0009	.0004	.0050	.0005	.0000	.0003	.0002	.0011	.0003
Age Group	.0008	.0027	.0004	.0000	.0000	.0009	.0011	.0026	.0049
Residence	.5127	.1239	.0562	.0018	.0015	.0008	.0182	.0457	.2086
Client Characteristic	.0871	.1009	.0200	.0017	.0013	.0002	.0032	.0111	.1116
Mental Retardation	.0638	.1115	.0314	.0003	.0020	.0001	.0023	.0052	.0655
Adaptive Behaviors	.1810	.1556	.0423	.0020	.0047	.0007	.0073	.0224	.1932
Coffelt Status	.0241	.0113	.0019	.0013	.0000	.0011	.0082	.0088	.0426
Other Independent Variables Controlled									
Regional Center	.0054	.0225	.1836	.0062	.0024	.0052	.0198	.0123	.0160
Gender	.0007	.0001	.0002	.0000	.0001	.0000	.0000	.0000	.0005
Ethnicity	.0009	.0001	.0002	.0005	.0001	.0003	.0003	.0007	.0004
Age Group	.0008	.0027	.0004	.0000	.0000	.0009	.0011	.0026	.0049
Residence	.5196	.1226	.0563	.0018	.0015	.0005	.0178	.0440	.2088
Client Characteristic	.0317	.0431	.0064	.0021	.0022	.0002	.0035	.0278	.0801
Mental Retardation	.0011	.0143	.0033	.0002	.0020	.0003	.0006	.0044	.0043
Adaptive Behaviors	.0231	.0194	.0031	.0006	.0018	.0005	.0030	.0215	.0502
Coffelt Status	.0129	.0020	.0005	.0011	.0000	.0009	.0057	.0077	.0202
Multiple R^2	.5974	.2271	.2597	.0125	.0101	.0188	.0527	.1220	.3875

Note: Tabled values are either squared correlations or squared semipartial correlations, indicating the proportion of variance explained by the independent variable. Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services.

Table IV.E.2

Year 1999-2000, Raw Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
		Other Independent Variables Not Controlled								
Non-Coffelt	37535	7818	5147	483	105	60	75	501	1638	15826
1995	204	14240	9585	952	763	0	432	1203	5204	32379
1996	422	17487	9225	717	232	21	74	1584	6618	35958
1997	238	18260	10179	850	339	0	203	1303	7397	38525
1998	124	21548	7401	662	145	1	108	2503	4851	37220
1999	100	15920	7597	533	161	0	199	2547	7354	34311
2000	45	4077	1498	112	123	29	105	3051	1081	10076
2001	25	6265	2888	267	119	0	48	1056	483	11126
Mean		13202	6690	572	248	14	156	1718	4328	26927
Residual SD		6896	5585	1008	1507	1238	893	2525	7952	12849
		Other Independent Variables Controlled								
Non-Coffelt	37535	4617	5520	536	140	59	45	801	2309	14027
1995	204	10232	6807	746	778	4	391	1421	5997	26376
1996	422	12565	6274	547	254	32	46	1828	6924	28471
1997	238	13186	7281	700	341	4	160	1530	7651	30846
1998	124	14327	4588	535	151	-1	83	2618	5444	27746
1999	100	10929	5187	524	150	-4	146	2718	7430	27079
2000	45	1484	-89	76	-41	-21	97	2988	-1091	3403
2001	25	2933	2080	454	1	-24	69	408	-3927	1993
Mean		8784	4706	515	222	6	130	1789	3842	19993
Residual SD		6896	5585	1008	1507	1238	893	2525	7952	12849

Note: Tabled values are mean per client service costs. Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services.

Trimmed cost values. The variance explained by each independent variable in trimmed cost values is shown in Table IV.E.3, first without other independent variables controlled (see top half of table) and then with other independent variables controlled (see bottom half of table). The primary aim of this report was to characterize the differences among consumers based on their status with regard to the Coffelt settlement. As shown in the top half of Table IV.E.3, Coffelt status explained less than one percent or less of the variance in each dependent variable when other independent variables were not controlled. When other independent variables were controlled statistically, the values in the bottom half of the table reveal that Coffelt status never explained over three-fourths of one percent of the variance of any dependent variable and usually explained an extremely small portion of variance.

The mean expenditures for the various Coffelt groups based on trimmed cost values are shown in Table IV.E.4. As shown in the top half of the table, the 1995-1999 Coffelt groups have substantially higher levels of expenditures than did the non-Coffelt group. The five Coffelt groups have average mean expenditures over $ 19,950 per year versus an average of only about $ 14,600 per year for the non-Coffelt group, a ratio of 1.37:1 in spending. The difference in spending corresponds to a Cohen's *d* of 0.54, a moderate-sized effect.

The bottom half of Table IV.E.4 shows mean expenditures controlling statistically for other independent variables. Here, the 1995-1999 Coffelt groups have much lower overall mean expenditures, around $ 19,200 per year as compared with the approximately $ 11,900 per year for non-Coffelt consumers, a 1.62:1 ratio in expenditures. The Cohen's *d* for this comparison is 0.74, somewhat larger than prior to the statistical controlling of other effects.

Table IV.E.3

Year 1999-2000, 1% Trimmed Cost Values – Variance Explained by Each Independent Variable: Other Independent Variables Not Controlled and Other Independent Variables Controlled

	Service Category								
Independent Variable	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
Other Independent Variables Not Controlled									
Regional Center	.0207	.0215	.2158	.0359	.0050	.0069	.0433	.0277	.0276
Gender	.0062	.0014	.0003	.0000	.0003	.0003	.0000	.0000	.0055
Ethnicity	.0008	.0008	.0024	.0026	.0001	.0002	.0017	.0003	.0007
Age Group	.0000	.0019	.0000	.0002	.0000	.0000	.0041	.0022	.0020
Residence	.5862	.1805	.0726	.0005	.0023	.0006	.1014	.0303	.3156
Client Characteristic	.0718	.1214	.0236	.0029	.0013	.0005	.0120	.0044	.0989
Mental Retardation	.0760	.1547	.0387	.0019	.0022	.0006	.0336	.0106	.0851
Adaptive Behaviors	.1655	.1977	.0510	.0056	.0024	.0011	.0380	.0145	.1956
Coffelt Status	.0024	.0065	.0015	.0006	.0001	.0022	.0016	.0004	.0077
Other Independent Variables Controlled									
Regional Center	.0032	.0211	.1930	.0358	.0044	.0067	.0264	.0246	.0133
Gender	.0006	.0000	.0002	.0000	.0002	.0000	.0000	.0000	.0003
Ethnicity	.0006	.0002	.0002	.0021	.0001	.0011	.0015	.0003	.0004
Age Group	.0000	.0019	.0000	.0002	.0000	.0000	.0041	.0022	.0020
Residence	.5897	.1792	.0719	.0004	.0023	.0004	.0997	.0283	.3162
Client Characteristic	.0188	.0437	.0068	.0036	.0021	.0003	.0015	.0022	.0516
Mental Retardation	.0008	.0211	.0046	.0022	.0019	.0004	.0016	.0016	.0037
Adaptive Behaviors	.0150	.0180	.0029	.0018	.0002	.0005	.0024	.0037	.0346
Coffelt Status	.0040	.0018	.0006	.0013	.0001	.0007	.0035	.0015	.0077
Multiple R^2	.6333	.2871	.2831	.0478	.0113	.0092	.1389	.0641	.4309

Note: Tabled values are either squared correlations or squared semipartial correlations, indicating the proportion of variance explained by the independent variable. Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services.

Table IV.E.4

Year 1999-2000, 1% Trimmed Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
		Other Independent Variables Not Controlled								
Non-Coffelt	37535	6612	5257	460	30	16	17	268	632	14586
1995	204	8533	7309	667	38	0	9	234	676	19397
1996	422	8695	7190	526	49	18	9	354	888	20908
1997	238	6970	7881	627	33	0	14	207	923	20077
1998	124	5590	5729	469	29	0	18	237	280	18764
1999	100	9467	6116	370	87	0	127	657	729	20792
2000	45	2558	1228	55	44	0	164	497	342	5966
2001	25	498	413	28	52	0	20	307	198	2247
Mean		6691	5344	466	30	16	17	272	640	14826
Residual SD		5599	4669	771	164	218	200	625	2370	9960
		Other Independent Variables Controlled								
Non-Coffelt	37535	3950	4887	469	40	28	25	335	777	11880
1995	204	8223	6168	637	53	17	17	408	1213	19339
1996	422	8357	5305	495	68	41	20	599	1485	19759
1997	238	7427	6178	609	49	18	25	401	1393	19979
1998	124	5937	3897	478	45	19	31	438	698	18530
1999	100	7829	4835	472	127	17	104	826	1081	18691
2000	45	1345	346	97	75	7	121	863	136	2796
2001	25	1280	1044	152	149	-13	53	584	-221	2101
Mean		5544	4083	426	76	17	49	557	820	14134
Residual SD		5599	4669	771	164	218	200	625	2370	9960

Note: Tabled values are adjusted mean per client service costs (i.e., least squares means). Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services

Winsorized cost values. The variance explained values for the different independent variables for Winsorized cost values were quite similar to values presented above for raw and trimmed cost values. In the interest of economy, the variance explained values are not presented here, so we can concentrate on the differences in mean levels of expenditures.

Mean expenditures based on Winsorized cost values are shown in Table IV.E.5. Because Winsorizing reduces but does not eliminate extreme values, the results shown here fall somewhere between the results for raw and trimmed cost values. Specifically, the 1995-1999 Coffelt consumers had mean uncontrolled expenditures of about $ 27,000 per year as compared with over $ 15,600 for non-Coffelt consumers, a 1.73:1 ratio across the groups. This mean difference has a Cohen's *d* of 1.00, a large effect.

When other independent variables are controlled statistically, the values shown in the bottom half of Table IV.E.5 reveal that the five Coffelt groups of interest have mean expenditures of approximately $ 24,900 per year versus about $ 13,400 per year for the non-Coffelt group. This cost difference reflects a 1.85:1 ratio in spending, slightly higher than prior to the controlling of other independent variables. The Cohen's *d* of 1.01 still represents a rather large effect and is virtually identical to the effect size prior to the controlling of other independent variables.

Table IV.E.5

Year 1999-2000, 1% Winsorized Cost Values – Average Per Client Service Expenditures by Coffelt Status: Other Independent Variables Not Controlled and Other Independent Variables Controlled

		Service Category								
Year of Placement	N	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
		Other Independent Variables Not Controlled								
Non-Coffelt	37535	7205	5559	514	47	28	44	363	1139	15643
1995	204	11196	7680	754	74	0	133	482	1993	24417
1996	422	13714	7900	584	94	18	40	798	2489	27380
1997	238	13737	8862	715	57	0	50	498	2335	29268
1998	124	15259	6305	556	59	0	52	1017	1992	27521
1999	100	13102	6347	420	103	0	165	1422	2011	26745
2000	45	3033	1228	55	44	0	227	833	592	7258
2001	25	1740	1165	86	52	0	20	522	198	3965
Mean		9873	5631	461	66	6	91	742	1594	20275
Residual SD		6484	4923	825	260	355	429	1034	3807	11373
		Other Independent Variables Controlled								
Non-Coffelt	37535	4515	5272	518	64	39	37	504	1396	13408
1995	204	9916	6609	722	99	21	151	723	2840	24057
1996	422	11711	6032	536	124	46	31	1102	3363	25141
1997	238	12124	6956	687	80	22	41	735	2944	27221
1998	124	12611	4418	516	84	27	57	1298	2841	24608
1999	100	10229	4928	514	150	22	155	1580	2410	23541
2000	45	1481	98	95	71	6	117	1352	-73	3794
2001	25	2709	2176	348	150	-17	69	662	-1555	2805
Mean		8162	4561	492	103	21	82	994	1771	18072
Residual SD		6484	4923	825	260	355	429	1034	3807	11373

Note: Tabled values are adjusted mean per client service costs (i.e., least squares means). Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services

F. SUPPLEMENTARY RESULTS

In this section, we review very briefly the nature of certain results with regard to major research factors that provide confirmation or lack of confirmation of trends noted in our POS II Report #1.

Confirming results. The results presented in earlier sections of this report largely support or confirm trends that we detailed in our POS II Report #1. This is not surprising, as the current results relied on subsets of the data that served as the basis for Report #1, which were then supplemented with one additional research factor – Coffelt status. However, in the present report, we (a) based all analyses only on adult consumers (deleting all infants, children, and adolescents), and (b) deleted all consumers from both the Coffelt and non-Coffelt groups who were identified as living in the home of a parent or guardian. We deleted the abovenoted consumers because so few Coffelt consumers were below the age of 22 years or were reported as having been placed into the home of a parent or guardian. After deleting the consumers noted above, the comparison between Coffelt and non-Coffelt consumers was clearly less confounded, but offered a rather different basis on which to estimate the effects of cost-related factors. As a result, certain findings might vary in important ways.

The first set of confirming results pertained to Residence Type. In POS II Report #1, Residence Type was perhaps the largest and most consistent cost-related factor, and this pattern was confirmed in the current report. Even discarding all consumers living in the home of a parent or guardian, Residence Type had the largest effect on Total POS, regardless of whether other independent variables were controlled statistically.

The second pattern of results confirming those from Report #1 was related to Client Characteristic. The effects of Client Characteristic fell within the small-to-moderate range, particularly with other independent variables controlled statistically. This pattern held in all results presented in our Report #1 and was mirrored in similar fashion in the current report.

The effect of the consumer's Level of Mental Retardation was a fairly small one in both Report #1 and the present report. When estimated without other independent variables controlled, Level of Mental Retardation had somewhat larger effects in the current report than in Report #1. However, after controlling other independent variables, the effect of Level of Mental Retardation was small in all analyses.

The fourth pattern of results that confirmed our Report #1 conclusions concerned the effect of Regional Center. In 8 of the 9 cost categories, the effects of Regional Center were in the small range, from 1 to 3 percent of the variance explained, regardless of whether other independent variables were controlled statistically. In a single expenditure category – Transportation, Regional Center was a large effect, explaining between 12 and 28 percent of the variance. These findings held in POS II Report #1 and were replicated in the present report. The basis for the continuing effects of Regional Center – which probably concern differences across Regional Centers in philosophy regarding and availability of services in the catchment area – is an intriguing issue that deserves further study.

The fifth and final pattern of results in the present report that confirmed our earlier Report #1 findings dealt with effects of Gender. In general, males and females received such similar dollar amounts of services that any differences in service expenditures were so small as to be practically insignificant. That is, service expenditures very so little across males and females that the gender distinction has no utility at all in predicting patterns of expense, and both Report #1 and the current report are consistent with this conclusion.

Disconfirming results. Of greater interest here are the results that disconfirmed trends reported in our POS II Report #1. Effects of three sets of variables differed noticeably across the two reports, and these trends are discussed below.

The first pattern of results that was notably different from Report #1 concerned the effects of consumers' levels of adaptive and maladaptive behavior. In POS II Report #1, levels of adaptive and maladaptive behavior were rather small, explaining 5 percent or less of the variance in any individual cost category when other independent variables were uncontrolled and only about 2 percent or less when other independent variables were controlled. In contrast, in the current report, levels of adaptive and maladaptive behavior explained between 15 and 20 percent of the variance in certain cost categories, particularly in Total Purchase of Services. Importantly, this trend held only when other independent variables were not controlled statistically. When other independent variables were controlled, levels of adaptive and maladaptive behavior still explained 4 to 5 percent of the variance in some cost categories. So, among adult consumers who are not living in the home of a parent or guardian, the relation of adaptive and maladaptive behaviors is noticeably stronger than apparent in our Report #1.

The second independent variable exhibiting a rather different trend in the current study was Age Group. In POS II Report #1, Age Group had a strong and consistent effect on cost of services, frequently explaining from 5 to 15 percent of the variance in several cost categories, even after other independent variables were controlled statistically. In Report #1, the primary explanatory power of the Age Group variable resided in the contrast between (a) children and adolescents, who had relatively low levels of expenditures, and (b) younger and older adults, who had much higher levels of expenditures. In the current report, we excluded children and adolescents from all analyses because very few Coffelt consumers were below the age of 22 years. As a result, all analyses in the current report were performed on younger and older adults. Given this, it is perhaps not surprising that Age Group had miniscule levels of explained variance in the current report. The results presented in the current report verify that younger and older adults receive essentially the same levels of service, as represented by service expenditures, a gratifying outcome supporting balanced service delivery by the DDS system with regard to consumer age.

The third and final set of results in the current study that conflict with those reported in POS II Report #1 concerns the effect of Ethnicity on service expenditures. In our Report #1, Ethnicity explained a moderate amount of variance prior to the controlling of other independent variables and smaller, but still significant amounts of variance after the controlling of other variables. More importantly, prior to controlling other independent variables, it appeared that White consumers received almost twice the dollar amount of services as did Hispanic consumers. Once other independent variables were controlled statistically, the differences between ethnic groups

were greatly reduced. However, our results still suggested that White consumers continued to have a favored status with regard to most minority groups, continuing to receive more services (perhaps 6 to 10 percent higher expenditures).

This patterns of differential service expenditures as a function of Ethnicity was completely negated in our current analyses. These results are sufficiently important that we have reported results in two tables: In Table IV.F.1, we present means based on raw cost values; in Table IV.F.2, we present means based on trimmed cost values. In both of these tables, estimated means prior to the controlling of other independent variables are shown in the top half of the table and means after controlling of other independent variables are shown in the bottom half of the table. In addition, we report values from fiscal year 1999-2000; results from other fiscal years were so similar as to be redundant.

In general, inspection of Tables IV.F.1 and IV.F.2 will reveal extremely small differences among ethnic groups in mean expenditures within each of the cost categories, including Total POS, whether or not other independent variables were controlled statistically. Instead of receiving clearly the highest level of service expenditures, White consumers received levels of service expenditures that were remarkably similar to those for other groups. If anything, White consumers tended to receive slightly lower levels of service than did Asian or Hispanic consumers. The overall impression is one in which there was no notable pattern of greater levels of service expenditures for any ethnic group.

The difference between Report #1 and the analyses reported in the current report is striking. It is clear, from the current report, that adult consumers receive levels of service expenditures that are essentially unrelated to Ethnicity, regardless of whether other independent variables are controlled statistically. The different outcomes noted in the two reports arise from the different samples used in analyses. Evidently, inclusion of children and adolescents leads to notable differences among ethnic groups in the pattern of service expenditures. The impact of consumers who live in the home of a parent or guardian is difficult to isolate, as these were excluded from all analyses in the present report. Still, it is clear that ethnic differences in service expenditures arise only when children and adolescents and consumers living in the home of a parent or guardian are included in analyses. Whether these differences arise from any bias in the service delivery system or from another basis (e.g., differential desire for services) cannot be determined from the current data and should be the object of future study.

Table IV.F.1

Year 1999-2000, Raw Cost Values – Average Per Client Service Expenditures by Ethnicity

	Service Category								
Ethnicity	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
Other Independent Variables Not Controlled									
Asian American	8652	6284	659	32	36	16	374	1929	17982
African American	7866	5714	780	53	38	66	473	1414	16404
Hispanic	8168	5995	581	182	50	53	600	1218	16847
Other	7073	5494	460	110	37	44	520	2054	15791
White	7424	5774	506	105	59	83	514	1985	16451
Mean	7837	5852	597	96	44	53	496	1720	16695
Residual SD	6896	5585	1008	1507	1238	893	2525	7952	12849
Other Independent Variables Controlled									
Asian American	8633	4732	590	170	-3	90	1710	4079	20001
African American	8866	4732	494	195	16	161	1801	3515	19780
Hispanic	9356	4722	491	301	12	141	1912	3687	20620
Other	8683	4654	499	217	-15	120	1717	3779	19653
White	8382	4692	499	226	21	136	1804	4150	19909
Mean	8784	4706	515	222	6	130	1789	3842	19993
Residual SD	6896	5585	1008	1507	1238	893	2525	7952	12849

Note: Tabled values are adjusted mean per client service costs (i.e., least squares means). Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services

Table IV.F.2

Year 1999-2000, 1% Trimmed Cost Values – Average Per Client Service Expenditures by Ethnicity

	Service Category								
Ethnicity	Out of home	Day pgm	Trans-port	Med care	In hm resp	Out hm resp	Other	Supp svcs	POS Total
Other Independent Variables Not Controlled									
Asian American	7504	5589	573	19	16	9	212	684	15663
African American	6994	5038	583	23	14	20	290	650	14941
Hispanic	7068	5658	492	51	15	13	336	567	15379
Other	6030	5128	418	41	26	25	298	778	13745
White	6610	5334	447	27	15	17	258	641	14768
Mean	7837	5852	597	96	44	53	496	1720	14695
Residual SD	6896	5585	1008	1507	1238	893	2525	7952	12849
Other Independent Variables Controlled									
Asian American	5418	3935	487	66	17	45	532	898	13845
Black	5658	4001	398	69	15	50	559	765	14110
Hispanic	5962	4265	404	93	17	48	620	739	14806
Other	5413	4150	428	80	22	56	533	851	13843
White	5268	4061	414	70	13	48	540	848	14069
Mean	5544	4083	426	76	17	49	557	820	14134
Residual SD	6896	5585	1008	1507	1238	893	2525	7952	12849

Note: Tabled values are adjusted mean per client service costs (i.e., least squares means). Service categories are: Out of home = all out of home expenses, Day pgm = day programs, Transport = transportation, Med care = medical care, In hm resp = in-home respite, Out hm resp = out-of-home respite, Other = other non-medical, Supp svcs = support services, POS Total = total Purchase of Services

V. FINDINGS AND RECOMMENDATIONS

This report demonstrated clear and interpretable patterns of differential service expenditures for consumers based on their Coffelt status. Importantly, the patterns of service expenditures were quite similar across the five fiscal years examined, lending support to the stability of the patterns of expenditures uncovered. The results demonstrated that consumers placed in the community in response to the Coffelt settlement exhibit considerably higher levels of service needs, reflected in service expenditures, when compared to service expenditures for non-Coffelt consumers.

With regard to the broad picture, the findings in this report replicated many results from POS II Report #1, supporting the contention that consumer-related factors drive much of the differences in service funding. The key consumer-related characteristics were residence type, consumer characteristic, level of mental retardation, and levels of adaptive and maladaptive behavior. The potential biasing factors of gender and ethnicity were found to have negligible effects, and the third biasing factor – regional center serving the consumer – had statistically significant, but relatively small influences not accounted for by the consumer characteristics employed in the current statistical modeling. In comparison to these legitimate consumer-related characteristics and the potential biasing factors, consumer Coffelt status explained relatively small amounts of variance.

But, when samples are relatively small in number – as several of the Coffelt samples were – explained variance is not the best way to capture the importance of the research factors. Instead, indicators of the magnitude of the mean differences are better able to represent the differences in service expenditures associated with Coffelt and non-Coffelt consumers. Coffelt consumers tended to receive more services than did non-Coffelt consumers, but the differences between groups were moderated by the form of the dependent variable:

> When analyzing raw cost values, Coffelt consumers received over twice the dollar amount of services as did non-Coffelt consumers, averaging a 2.2:1 ratio in uncontrolled values and a 2.3:1 ratio when other independent variables were controlled statistically. The Cohen's *d* values for these differences were 1.43 and 1.08, respectively, indicating that the differences were relatively large.
>
> When trimmed cost values were the basis of analyses, Coffelt consumers received about 60 to 70 percent more in services than did non-Coffelt consumers, averaging a 1.6:1 ratio in uncontrolled values and a 1.7:1 ratio when other independent variables were controlled statistically. The Cohen's *d* values for these differences were 0.87 and 0.71, respectively.
>
> As for Winsorized cost values, Coffelt consumers received about twice the dollar amount of services as did non-Coffelt consumers, averaging a 1.94:1 ratio in uncontrolled values and a 2.0:1 ratio when other independent variables were controlled statistically. The Cohen's *d* values for these differences were 1.25 and 0.94, respectively.

Thus, our general conclusion is that consumers placed into community settings in connection with the Coffelt settlement receive higher levels of service expenditures than do consumers who

were not placed in connection with the Coffelt settlement. How these differences in levels of service expenditures are interpreted is a different matter, one that falls beyond the information available for the present report. Coffelt consumers tended to be persons who were, for various reasons, more difficult to place in community settings. When eventually placed into the community, these hard-to-place consumers may need higher levels of services to remain in community settings. Moreover, we have no way to estimate how much the services received by these consumers cost when the consumers resided in state developmental centers (i.e., prior to their placement into the community). It is entirely possible that Coffelt consumers "cost more" than non-Coffelt consumers when residing in the community, but that Coffelt consumers "cost less" when residing in community settings than in state developmental centers.

Our principal conclusions concern the differential service expenditures associated with Coffelt and non-Coffelt consumers. Because raw cost values are likely to bias results due to inclusion of a small number of outliers, we feel more confident when examining either trimmed or Winsorized data. These results indicate that Coffelt consumers have service costs that fall about 60 to 100 percent higher than those for non-Coffelt consumers. Further research should be undertaken to explain these differences.

Appendix A:

Service Codes Subsumed Under the Nine Cost Categories Analyzed

Accounts and Service Codes used in Budget Categories

Out Of Home
- **Community Care Facility Account**
- **ICF/SNF Facility Account**

Day Programs
- **Day Training Account**
- **Prevention Services Account (Infant Development Program service only)**

Transportation
- **Transportation Account**
- **Transportation / Contracts Account**

Medical Care
- **Hospital Care Account**
- **Medical Equipment Account**
- **Medical Care - Professional Services Account**
- **Medical Care - Program Services Account**

In-Home Respite
- **Respite - In-Home Account**

Out-Of-Home Respite
- **Day Care**
- **Respite - Out-Of-Home Account**

Miscellaneous
- **Anything not in Budget Categories 1, 2, 3, 4, 5, 6, & 8**

Support Services
- **Services:**
- **Crisis Evaluation And Behavior Intervention**
- **Personal Emergency Response System**
- **Community Integration Training Program**
- **Personal Assistance**
- **Community Activities Support Services**
- **Parent Coordinated Supported Living Program**
- **Supplemental Residential Program Support**
- **Supplemental Day Services Program Support**
- **Supplemental Program Support (Other)**
- **Adaptive Skills Trainer**
- **Behavior Management Consultant**
- **Independent Living Specialist**
- **Home Health Agency**

Supported Living Services
Supported Living Services
Supported Living Services
Supported Living Services Vendor Administration
Supported Living Services

Accounts and Service Codes used in Budget Categories
With Account and Service Codes

Budget Category = '1' - 'Out Of Home'

Accounts **'32010' - Community Care Facility**
'32020' - ICF/SNF Facility

Budget Category = '2' - 'Day Programs'

Account **'43020' - Day Training**
'65060' And Service '805' - Prevention Services, Infant Development Program

Budget Category = '3' - 'Transportation'

Accounts **'65050' - Transportation**
'65051' - Transportation / Contracts

Budget Category = '4' - 'Medical Care'

Accounts **'65090' - Hospital Care**
'65100' - Medical Equipment
'65110' - Medical Care - Professional Services
'65120' - Medical Care - Program Services

Budget Category = '5' - 'In-Home Respite'

Account **'65130' - Respite - In-Home**

Budget Category = '6' - 'Out-Of-Home Respite'

Account **'43010' - Day Care**
'65140' - Respite - Out-Of-Home

Budget Category = '7' - 'Miscellaneous'

Anything Not In 1, 2, 3, 4, 5, 6, & 8

Budget Category = '8' - 'Support Services'

Services
'017' - Crisis Evaluation And Behavior Intervention
'051' - Personal Emergency Response System
'055' - Community Integration Training Program
'062' - Personal Assistance
'063' - Community Activities Support Services
'073' - Parent Coordinated Supported Living Program
'109' - Supplemental Residential Program Support
'110' - Supplemental Day Services Program Support
'111' - Supplemental Program Support (Other)
'605' - Adaptive Skills Trainer
'620' - Behavior Management Consultant
'635' - Independent Living Specialist
'854' - Home Health Agency
'891' - Supported Living Services
'892' - Supported Living Services
'893' - Supported Living Services
'894' - Supported Living Services Vendor Administration
'896' - Supported Living Services

Department of Developmental Services

Purchase of Services Study II:

Final Report Summary

Determination of Service Variation Across Regional Centers:

Implications for Clients and Policy

A Report to the Legislature

March, 2004

The Co-Principal Investigators for this study were Jan Blacher, Ph.D., University of California, Riverside (jan.blacher@ucr.edu) and Keith Widaman, Ph.D., University of California, Davis (kfwidaman@ucd.edu). The investigators are grateful to DDS, to ARCA, and to their representatives for providing the opportunity and resources to conduct this study. The investigators also appreciate the effort of the consumers and their families involved in this project.

We dedicate this report to the memory of Al Brown, with whom we worked for only a very short but significant time.

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I. PROJECT OVERVIEW

This is the Final Report from the study, *"Determination of Service Variation Across Regional Centers: Implications for Clients and Policy,"* also known as POS II. The key question addressed by this project was, "Is there equity in service delivery across regional centers in California?" In order to answer this fundamental question, we developed one main study goal and three objectives. The overall goal was **to understand further the variability in purchase of services per capita expenditures across regional centers**.

The first objective, *to examine existing analyses of statewide data, and to conduct further analyses, in order to identify linkages between that work and our proposed workscope,* was addressed in Report #1. In that report we provided results of statistical modeling of the variation in per capita purchase of services for persons with mental retardation and developmental disabilities served by the 21 regional centers across California. We replicated, in part, earlier analyses by other investigators, and we examined statewide data across five years. The earlier reports found enormous variability by regional center and by ethnicity. We, too, found per capita expenditures varied by regional center (2:1 ratio between highest and lowest center's expenditures) and by ethnicity (2:1 ratio of European American: Hispanic). However, by controlling for variables related to service utilization we found that these differences were lessened considerably. A brief summary of that report, and its implications, is provided herein.

We note that shortly after this project began, we added another dimension to the statewide data analyses. The purpose of this supplementary report was to model variation in per capita purchase of services for Coffelt and non-Coffelt consumers, to see if there were differential costs associated with that settlement. The dataset available to us allowed us to ask some questions about overall cost expenditures over a period of time.

The second objective of the POS II study was *to address the issue of variability in purchase of services by obtaining new data, using a combination of survey and focus group methodologies.* Toward this end, we developed a survey measure that focused on Family Needs, Services, and Satisfaction (FNSS), which was administered to regional center parents/consumers and staff, as well as to a smaller sub sample of Latina and European American mothers. The purpose of the survey was to supplement what was found in the statewide data about purchase of services, by allowing consumer families to respond directly about their own needs and receipt of services.

We also developed a focus group protocol and conducted 16 focus groups at eight regional centers. This enabled us to obtain qualitative information, in a discussion group format, about service needs and supports provided directly to regional center families and consumers.

The third objective was *to identify key variables that may affect variation in service utilization*. This involved secondary analyses of existing longitudinal data gathered from

regional center families in order to provide information about the relationship between service use and client variables (e.g., age, ethnicity, household income, adaptive behavior). We related family service needs and satisfaction (assessed using the FNSS survey) to family demographics and maternal well-being. The second and third objectives of the POS II study were addressed, in detail, in Report #2.

Before presenting a summary of the findings of this project, we as investigators would like to comment on the process of conducting this research. The Department of Developmental Services (DDS) made a large dataset available to us, and upon our request, allowed us to examine five years of data. Both DDS and Regional Center personnel cooperated with the development, pilot testing, and final dissemination of the survey instrument. A large number of consumer families completed the survey, some took part in focus groups, and a target group of Hispanic mothers in the subsample completed the survey as part of a larger interview. Thus, the conceptualization and gathering of these data was multi-faceted, and provided ample opportunity for us to discern any systematic bias, as well as satisfaction and dissatisfaction by consumers around the issue of purchase of services.

II. REVIEW OF FINDINGS

What did we learn from the analyses presented in Report #1?

A. The Statewide Data Analyses

In the first part of the POS II study, we presented analyses of purchase of services data across five years. The findings, presented in Report #1, demonstrated clear and interpretable patterns of service expenditures for clients served through the 21 regional centers in the State of California. ***Importantly, the patterns of service expenditures were very similar across the five fiscal years examined (1995-96 through 1999-00), suggesting that regional centers maintain consistent standards for service delivery.***

Furthermore, this first report documented the influences of several legitimate cost-related factors: client chronological age, residence type, consumer characteristic, level of mental retardation, and levels of adaptive and maladaptive behavior. These consumer-related characteristics should drive services - and they do. In particular, consumer age and residence type have large, consistent, and expected effects on the major cost categories. The variables of consumer characteristic, level of mental retardation, and levels of adaptive and maladaptive behavior had smaller, but still quite consistent and expected effects on service costs. Not surprisingly, older residents who live outside of the family home, and those with more severe maladaptive behavior and more severe levels of mental retardation, require more purchase of services, i.e., they cost more when housed in community placements.

In addition to the legitimate cost factors that we hypothesized might influence service delivery, we examined three potential biasing factors – factors highlighted in the POS I study of service provision. These potential biasing factors were: consumer gender, consumer ethnicity, and the consumer's particular regional center. We examined the

impact of each of these three potential biasing factors on cost, with all of the other (legitimate and potential biasing) factors controlled statistically. Consumer *gender*, in all analyses across five years of data, had no relationship to service costs, and will not be discussed further.

Cost differences by consumer *ethnicity* were reduced considerably when the legitimate cost factors were controlled for. This finding was also reflected in a supplementary report we produced, described below.

However, ethnicity did continue to have a small but statistically significant relationship to service costs in Report #1, even with the legitimate cost factors controlled for. We offer two explanations for this, based on the variables available to us. One is that is that when compared with European American (White) consumers, the proportion of adult to child consumers was lower for ethnic groups, mainly, Hispanic consumers. We know that services for adult consumers tend to cost more than services for children, which are largely provided by the public school system during childhood. The other is that the proportion of out-of-home placements for Hispanic consumers was lower, and such placements tend to be very expensive when compared to living in the family home. Given the information available on the statewide database, we were unable to further discern the causes of this small residual difference in ethnicity.

Regional centers continued to differ slightly in per capita expenditures, even when the five legitimate cost factors were controlled for (e.g., consumer age, place of residence, level of mental retardation, consumer characteristic, level of adaptive and maladaptive behavior). However, although these differences appear as "statistically significant," they may have little clinical significance, as the effects were rather small. It is possible that certain of these differences across regional centers in their average consumer service costs may be due to legitimate cost-related variables that were unavailable or not assessed in the current study. For example: Were there client medical conditions that either affected access to services, or that were served by other agencies? Were there differences in the availability and or cost of services in a given catchment area? Are there differences in parent or family ability or willingness to access services? Does service coordinator caseload affect purchase of services for consumer families? Are some family purchase of service needs offset by the services they receive from other agencies, such as the public school system?

We produced a Supplementary Report to POS II, Report #1, entitled, "Modeling Variation in Per Capita Purchase of Services for Coffelt and Non-Coffelt Consumers." In that report we responded to a request by DDS and Legislative Consultants to examine purchase of service expenditures related to the *Coffelt Implementation*. The rationale for this additional study was to examine a subset of individuals placed into the community since the Coffelt settlement was enacted, and to determine if there were differential costs associated with that settlement. In addition, we determined whether or not the Coffelt consumers were different, as a group, from other similar consumers living in their family homes. Thus, we examined a number of cost-related variables (e.g., ethnic breakdown, services received).

As in Report #1 (described above), consumer-related factors also appeared to drive many of the differences in service funding of the Coffelt consumers. The Coffelt supplementary report excluded children and adolescents, and excluded consumers living in the home of a parent or guardian, because there were so few Coffelt consumers in these groups. *Of note is that there were no ethnic differences among Coffelt consumers and non-Coffelt consumers in any of these analyses*. It is likely that the small differences in expenditures for some ethnic groups identified in Report #1 were due to the current, younger generation of Hispanic consumers, and as they enter adulthood, ethnic differences in expenditures will likely be eliminated completely.

In the Supplementary Report, the key consumer-related characteristics were residence type, consumer characteristic, level of mental retardation, and levels of adaptive and maladaptive behavior. The potential biasing factors of gender and ethnicity were found to have negligible effects, and the third biasing factor – regional center serving the consumer – had statistically significant, but relatively small influences not accounted for by the consumer characteristics employed in the current statistical modeling. In comparison to these legitimate consumer-related characteristics and the potential biasing factors, consumer Coffelt status explained relatively small amounts of variance.

Thus, the first report of the POS II study involved re-analyses using a large database available from DDS, and was restricted to what variables were available. The findings were similar to a supplementary study of purchase of services that involved Coffelt and non-Coffelt consumers living in the community. The second report, summarized below, was based solely on information obtained directly from consumer families (in some cases, from consumers themselves). While the same kind of statistical controls could not be placed on these new data, we incorporated multiple perspectives from which to view actual purchase of services, e.g., survey data gathered from consumer families who were randomly selected, their matched service coordinators, and focus group participants from regional centers designated as high or low expenditure centers in POS I and in our Report #1 of POS II.

What did we learn from the studies conducted and described in Report #2?

B. Findings from Survey Analysis

The second report from the POS II study included two sets of survey data: (1) Survey data gathered from a representative sample of regional center consumer families statewide, including corresponding data from their service coordinators, and (2) Survey data and more in-depth assessment of consumer and caregiver characteristics from a sub-sample of Hispanic and European American families interviewed individually.

To provide a context for understanding the data gathered as part of the POS II project, we conducted a review of extant literature. We paid particular attention to studies containing non-English speaking families who had sons or daughters with mental retardation or intellectual disabilities. Clearly, researchers have been interested in the

relationship between service delivery and caregiver well-being for some time. Most of the studies reviewed, and provided as an Appendix to Report #2, were conducted with small samples and less diverse populations. In the present study, we received survey data from over 1,000 caregivers or consumers as well as from their service coordinators.

The Statewide Survey

In view of per capita cost differences, we sought to obtain further information about the extent to which individual families perceived a need for services, received services, and were satisfied with the services they received. To study the relations among client characteristics, family perceived needs, services received, and satisfaction, we gathered data from a random sample of clients served by regional centers. We sought a sample large enough to adequately represent each regional center and to be diverse on important dimensions (e.g. client age and functioning; family race/ethnicity and socioeconomic status). One caveat was that we had the capability to provide measures only in English or Spanish, so we were limited to respondents who were fluent in one of these languages.

A survey instrument for families, developed for the purpose of this study, was previewed by a group of Stakeholders invited by DDS for this purpose as well as by colleagues in the field. The survey included three types of services received by parents/consumers: Information (11 items), Support (6 items), and Resources (20 items). For each service that was actually received, the respondent indicated a level of satisfaction with that service. The survey was available in both English and Spanish. [Copies of the survey are included in an appendix to Report #2.]

We refer to this survey instrument as the FNSS (Family Needs, Services, and Satisfaction). Families had the option of either mailing the survey and materials back to UC Davis (in the stamped envelope provided) or completing the survey on-line; 117 families completed the survey on-line. We received a total of 1,118 surveys from parents/guardians.

In addition to the mailed survey from each family, we also designed a short survey to be filled out by the service coordinator for each consumer. All service coordinators completed surveys on-line, and the data were compiled immediately on a computer at UC Davis. The structure of the service coordinator questionnaire closely followed certain parts of the FNSS completed by families. The parallel structure enabled us to determine the extent to which family respondents and service coordinators agreed on the family's and client's needs and the services received to meet those needs. In addition, we were able to determine whether family satisfaction with services, and with interactions with regional center personnel, were consistent with perceived family satisfaction on the part of service coordinators.

Did service coordinators and parents/consumers "agree?"

The simple answer to this question is, "Yes." Overall, there was high level of agreement between consumer families and service coordinators on the numbers and types of services received. We provide a brief summary here.

The FNSS survey used in this part of the study allowed us to assess three broad categories of service: (a) Information, (b) Support, and (c) Resources; within each broad category, there were a number of items representing specific examples of the services offered by at least some regional centers. With regard to type of service, we asked each respondent (either parent or consumer) to indicate: (1) Need for Services; (2) Services Received; and (3) Satisfaction with Services Received. There were rather high levels of agreement between service coordinators and parents/consumers on the overall mean levels of services received across categories of service, that is, on the total number of services received as well as within the sub-categories of information, supports and resources received. More specifically, service coordinators and parents/ consumers agreed rather well with regard to which services were received by many consumers and which were received by few consumers.

Despite these high levels of agreement on the general receipt of services by category of services, service coordinators and parents/guardians did not exhibit notable agreement on which individual consumers were receiving which services. At the individual level, service coordinators and parents/consumers tended to show modest levels of agreement. High levels of agreement were achieved only for categories of service for which extremely low levels of receipt of services were reported. For all categories of service for which a moderate proportion of the population received services, agreement between service coordinators and parents/consumers was modest at best. These modest levels of agreement on case-by-case receipt of services were a bit surprising, given the high agreement across categories. In other words, service coordinators and parents agreed rather well on which services were received by many consumers and which were received by few; however, they agreed less well on which individual consumers were receiving which services.

How satisfied were respondents with the services received?

Overall, respondents indicated a high level of satisfaction with most services.

In addition to inquiring about receipt of information, support, and resources, we asked both service coordinators and parents/guardians to report on satisfaction **if** they actually received a specific service. This question asked (a) parents/consumers to rate how satisfied they, themselves, were with information, support, and resources received, and (b) service coordinators to rate how satisfied the parent or consumer was with information, support, and resources received.

With regard to satisfaction with **information received**, both parents/consumers and service coordinators reported fairly high levels of satisfaction. On a scale of 1 (very dissatisfied) to 6 (very satisfied), parents/consumers reported scores on individual items ranging from 4.56 and 4.96, solidly in the "satisfied" range; service coordinators ranged from 4.79 and 5.04. However, on some of the 11 items, there were differences between how satisfied parents reported they were and how satisfied service coordinators reported the parents were. In all cases, parent ratings of satisfaction were lower than those of the service coordinators. These differences in satisfaction ratings regarding **information received** pertained to the following five items: (1) social development, (2) recreational services, (3) vocational services, (4) residential placement, and (5) regional center services. Although the differences between parent/consumer and service coordinator ratings were considered rather "small" statistically, they nonetheless suggest important areas (e.g., residential placement and regional center services) that service coordinators may want to pay attention to.

The findings with regard to **satisfaction with support received** were similar, again with small but statistically significant differences between the two groups of respondents in their ratings of satisfaction. Differences between parents/consumers' and service coordinators' satisfaction ratings occurred on the following items: (1) handling stress, (2) support from other parents, and (3) financial assistance for obtaining services or equipment. Again, with all of these differences, parents/consumers gave lower satisfaction ratings than service coordinators.

With regard to **satisfaction with resources received**, the same pattern held, whereby both parents/consumers and service coordinators perceived fairly high levels of family satisfaction. On over half of the types of resources received, the two groups of respondents did not differ significantly in their mean ratings of satisfaction, a positive finding. However, few of the respondents received the following types of resources: infant development program, home health agency, out-of-home respite, and day care or child development program. Lack of variance in responses to these items could account for the failure to find significant differences. Too, we are mindful that some of the system's youngest consumers were purposefully excluded from this dataset because they didn't have a CDER assessment (necessary for the predictor analyses described below.)

All of the satisfaction ratings reported above pertain to mean levels of satisfaction between groups. We also examined agreement on ratings of satisfaction between individual parents/consumers and their corresponding service coordinator. Here, agreement on individual cases appeared to be quite low. One reason for this was a lack of variance; since most respondents gave ratings at the high end of the scale (i.e., means around 4.8 to 5.0), it was difficult to distinguish among high levels of satisfaction. To counter this, we calculated the percentage of ratings by service coordinators and parents/guardians/consumers that were within one scale point. In doing so, we found that the two groups of respondents tended to agree highly (80 % or above). In sum, parents/consumers appeared to be satisfied, overall, with the information, support and resources that they received from regional centers.

What predicted aspects of services received?

Did respondent ratings vary significantly by regional center, ethnicity and so on? In order to answer this question, we ran a number of regression models, or "predictor analyses," to see if any specific variables could help us identify bias in service delivery. The variables we considered were: age of consumer, level of mental retardation, gender, ethnicity, regional center, and respondent (i.e., whether parent or service coordinator). We report findings of import, in summary form, here.

Age of consumer had a significant effect; the receipt of information and resources varied positively with age. That is, parents of older consumers received more information and resources. Respondents who had older consumers also had greater expressed need for information, support, and resources. As expected, respondents who had consumers with more severe **levels of retardation** received higher levels of resources. **Gender** had little effect on the receipt of services, the need for more services, or satisfaction with services.

With regard to **ethnicity,** there were significant main effects, indicating that ethnicity affected (a) receipt of resources, (b) need for additional resources, and (c) satisfaction with support. The results of our analyses revealed the following: (a) African American consumers received somewhat fewer resources than did European American consumers, but consumers from the remaining identified minority ethnic groups (Asian American and Hispanic) received about the same number of services as European American consumers; (b) consumers from all identified minority groups (African American, Asian American, and Hispanic) had higher reported levels of need for additional resources than did European American consumers; and (c) relative to the remaining groups, Asian American consumers had lower levels of satisfaction with support services, and Hispanic consumers somewhat higher levels of satisfaction with support services. [We note here that findings reported from our subsample of Hispanic families (below) generally reflect those from the Hispanic respondents in this larger survey.]

These discrepancies among groups may arise from several sources, such as socioeconomic status. For example, despite receiving about the same number of resources as European American consumers, consumers from the identified minority groups (African American, Asian American, and Hispanic) may have a higher reported need for additional resources because they might have lower incomes and rely on DDS for a larger proportion of their service needs. Regardless of the basis, these differences should be the topic of further research.

The main effect of **regional center** was significant in several analyses. Interestingly, but not surprisingly, high per-capita-expenditure regional centers had higher mean levels of number of resources provided and slightly higher levels of satisfaction with those resources received. Both of these effects were of rather small magnitude, suggesting that the differences revealed should be noted but are not of major concern.

The final effect was that of **respondent**. Uniformly, service coordinators reported higher levels received of two types of service – support and resources – than did parents/consumers, and service coordinators reported substantially lower consumer needs for additional services in all three categories – information, support, and resources. The consistency of the effects and their direction should be a reason to consider the extent to which service coordinators are aware of family needs and services received. We cannot determine from the available data whether service coordinators or parents/consumers are more accurate in their reports of number of services received. Clearly, additional work must be done to understand the differences associated with the differing viewpoints of service coordinators and parents/consumers in order to bring perceptions and expectations into closer agreement.

Are these findings consistent with those from Report #1?

It is important to remember that analyses of the statewide data and of these newly gathered surveys vary widely in scope and purpose. The former (Report #1) was an attempt to see if there was any systematic bias in service delivery variables or purchase of services; overall, we were unable to detect such systematic effects, of sufficient magnitude, either at one time, or across the five years. The survey analyses represent "real" data (meaning they reflect responses given from actual individuals rather than numbers entered onto a computer database) from a much smaller, though more random, sampling pool (roughly 1000 vs. over 100,000). Furthermore, survey data are not causative, that is, they cannot tell us *why*, just *what is*. We feel confident in stating that, overall, consumer families are satisfied with services received, but they indicated more areas of service need than service coordinators.

The Subsample

We also obtained the Family Needs, Services, and Satisfaction measure from a small sub-sample of families who had been participating in the University of California, Riverside, Families Project. There are over 300 families involved in this larger project; 95 Spanish-speaking Hispanic families and 40 Anglo families participated in the portion of the study using the instrument development for the POS II study. All of these families had young adults between the ages of 18 and 28, and all had been involved for several years in a broader investigation of the transition to adulthood in young adults with severe disabilities (Blacher, 2001; Kramer & Blacher, 2001; Kraemer, Blacher, & Marshal, 1997).

The purpose of obtaining the FNSS from this sub-sample was three-fold: (1) It allowed us to gather survey data from a larger sample of Hispanic families than we might be able to obtain from the statewide survey, which was distributed randomly; (2) It allowed us to gather more in-depth accounts of service needs and supports because we administered the FNSS in person, through personal interview, which enabled clarifications not possible in our surveys mailed to parents/consumers from each regional center; and (3) It allowed us to relate the FNSS to additional parent measures gathered from this sample (e.g. well-being; acculturation; attitudes toward placement) that were not available in the larger survey. Although the Families Project has over 300 ongoing parent participants, many of

them had already been interviewed prior to introducing the FNSS measure and it was too soon to interview them again; hence the smaller sample. Nonetheless, as the analyses described in depth in Report #2 indicated, the sample was large enough to find meaningful and significant relationships.

We obtained FNSS data on 95 Hispanic families (most monolingual Spanish speaking), and 40 European American families (all English speaking). These families live in Southern California and, together with the larger sample, are served by nine regional centers. Over the years we have focused on the impact of a child with severe disabilities on the family, with particular emphasis on supports that mitigate stresses and decrease the likelihood of out-of-home placement. We have monitored the use of informal and formal supports (that include state-provided respite care, support from regional center service coordinators, government subsidies and so on). It is important to note that, over time, these families developed tremendous trust in us, as we interviewed them every year or two. We expected that they might be more willing to disclose details about their service needs and satisfaction, or to be more candid, than typical survey respondents.

We examined how the services these families received related to their perceived needs and well-being, in addition to the more obvious demographics derived from surveys (e.g. child age, ethnicity). As one important illustration, consider the earlier POS finding relating expenditures to ethnicity – for example, slightly lower per capita service expenditures for Hispanic families. We know that costs vary widely depending upon where a client or consumer lives – in her own home or in a community residence. We also know, from previous studies, that Hispanic families are much less likely to seek out-of-home placement than European American families. Direct interviews, however, helped us determine whether the inclination to keep the son or daughter at home is because Hispanic families know less about residential options (an access issue) or because cultural values such as familism make placement unthinkable (a cultural issue). Thus the non-equivalence in spending may result indirectly from responsiveness to parental desires, rather than from some type of ethnic bias in delivery of services by DDS.

Expressed service needs

The highest needs for information, expressed by at least ¾ of the combined sample, were in the following areas: Information about regional center services, and information about recreational services. The highest needs for resources that were expressed by at least ¾ of the combined sample were help in finding: access to SSI, access to Medi-Cal, medical services for the young adult, in-home respite care, and transportation. In almost all cases in which there was a significant difference between European American and Hispanic groups, Hispanic parents expressed greater need.

The highest expressed needs tended to be among the lowest with unmet needs, indicating that regional center services are responsive to the most commonly expressed needs. Yet many of the other service needs were being met for a remarkably low percent of families. Among the greatest unmet needs, for the European American and Hispanic samples combined, were information about sexual development (84.5% of those who

expressed these needs did not receive the service), information about recreational services (74.8%), help in behavior management (80%) or in handling stress (78.6%) and help in finding the following resources: home health agency (90.2%), specialized autism programs (85.7%), behavioral intervention (82.7%), and social skills program (82.1%). Overall, about half of the expressed needs were not being addressed.

Comparing European American and Hispanic families, Hispanics had greater needs in every case where the difference was significant, and some striking differences in unmet needs were found. Among the highest, in the domain of support needs, were: meeting regularly with regional center service coordinators, and financial help to purchase services such as speech therapy for the young adult. It should be noted that Hispanic mothers reported higher unmet needs than European American mothers in every category of support. Hispanic mothers also expressed higher unmet need for information about recreational services, and higher unmet resource need in the area of speech therapy. We note that in every category but one (in-home respite care) Hispanic mothers had higher unmet resource needs. When we examined satisfaction with the services that they did receive, however, Hispanic and European American mothers did not differ.

Hispanics and unmet needs: An artifact of demographic differences?

Hispanic respondents reported significantly greater unmet needs than European Americans. In attempting to understand this difference, we first considered the other ways that these samples differed. As indicated in Report #2, the samples differed significantly on child age, whether or not the young adult had exited from school, mother's education, family income, reported depressive symptoms by mother, and reported positive impact of the young adult on the family. All but the last of these variables also correlated significantly with the "unmet needs" variable, suggesting that differences between the two samples could be accounted for entirely by these demographic and well-being variables, where the Hispanic group was clearly disadvantaged. However, when we examined the influence of all of these variables, the ethnicity variable (Hispanic) still accounted for significant variance in "unmet needs."

How do "unmet needs" relate to maternal well-being?

To further understand service needs within the Hispanic sample, correlations were run between FNSS totals needs and selected child and parent variables, including acculturation. The total needs score was related significantly to acculturation, socioeconomic variables, and child behavior problems, as well as to respondent psychological well-being (e.g., parenting stress, morale, depression). That is, Hispanic mothers who were less acculturated, and/or were of lower education/income, and/or who had sons or daughters with more severe behavior problems, and/or who experienced more parenting stress and depressive symptoms *reported more total service needs*. These results are correlational **but not causal;** that is, they simply indicate what other variables related to total expressed service needs. Furthermore, while caregiver mental health needs were highlighted in some of these analyses, the delivery of such services does not appear to be under the purview of regional centers. Nonetheless, service coordinators might want to be

aware of, and make appropriate referrals for, mothers experiencing acute stress or expressing symptoms of depression, as those mothers are less likely to contribute positively to their children's development.

Summary

In summary, the respondents to the FNSS expressed a high number of needs they would like regional centers to meet. They were satisfied with the services they were receiving, but only about half of their expressed needs were being met. Hispanic families expressed significantly greater needs than European American families, and also received significantly fewer services. Thus, the percentage of unmet service needs was twice as high for Hispanic families in this sub-sample. Two of the highest support needs identified by Hispanic mothers were regular meetings with regional center service coordinators, and help for purchasing services such as speech therapy for the young adult. The Hispanic and European American samples differed on a number of variables that related to unmet service needs; however, when these were controlled in statistical analyses, Hispanic status still accounted for significant variance in unmet service needs.

There are implications for the regional center system from these findings. First, it is clear that the Hispanic families in this sample desired more interaction with their service coordinators. Obviously, these meetings should involve staff who are sensitive to the cultural context and who themselves are bilingual. That, in itself, may resolve several other areas of unmet needs because parents are likely to feel more comfortable requesting specific services, or participating in the prioritizing of existing services. Even in lean fiscal times, having some direct input and involvement in setting priorities can be empowering.

Second, it is important to note that most of the sons and daughters of these mothers were going through "transition," the process of leaving public high school, a stressful time for parents. This volatile period can elicit new worries for families and challenges for their young adult consumers, such as finding work or day programs in the community, developing new friends or socialization opportunities. This may have caused respondents to perceive more "unmet needs," and to less often want "what's on the menu" of services provided by regional centers.

C. Focus Group Analyses

The POS II study also involved the conduct of focus groups to explore needs, attitudes and beliefs of parents/consumers about services for individuals with developmental disabilities. Focus group members were asked to express their viewpoints or opinions about service delivery – a topic on which they had particular experience, and in some cases, expertise. The focus group leader did utilize a list of guiding questions, and she encouraged participants to provide candid and complete responses. By definition, focus group participants are not representative of all consumer families in the regional center system. Rather, their viewpoints were sought for one main reason: *To gather information or opinions that may not be reflected in the larger survey, which required short responses to questionnaire-type items.*

Sixteen focus groups were conducted for the purpose of the POS II study, and a detailed review of findings is contained in Report #2. Eight of these groups were held at high-per-capita expenditure regional centers and eight at low-per-capita expenditure centers; four were with parents/consumers, and four were with service providers. Groups were led by a trained focus group facilitator and were based on a questioning route that was designed to elicit concerns about information dissemination as well as service access, equity and costs. Thus, although focus group methodology is not intended to be representative, several common themes were identified, as follows:

(1) *Uniform access to information about regional center services*: Access to information was equally noted across staff and parent/consumer groups, regardless of participant ethnicity or regional center. Typical sources of information dissemination were provided by participants, including professional referrals (e.g., physicians, teachers) as well as "the grapevine" of neighborhoods and informal social groups.
(2) *Recognition that services are not the same everywhere and for everyone*: Of significance, some parents viewed themselves as at the mercy of the service coordinator: "a good caseworker" (i.e., service coordinator) makes "all the difference." Too, they emphasized that the "squeaky wheel" gets attention AND gets services. The staff members' perspective on this issue was that they do not always have the resources or ability to mete out services as they would like.
(3) *Fighting with school districts is often necessary to assure that the consumer receives appropriate services*: Both staff and parents noted that parents of higher income and educational background seemed to get more and better services. Staff, in particular, were concerned about fighting with schools at the transition age (e.g., transition to kindergarten or first grade.)
(4) *Staff and parent concern about the increase in autism spectrum disorders and the concomitant demand for services*: Access to services seemed to be affected by the frequency of the disorder, according to staff and parents, who repeatedly referred to autism. Staff referred to autism as the "label of choice," or the "chic disorder right now." Parents referred to it as "a rich man's disease."
(5) *Lack of transportation limited the accessibility of services*: As obvious as this sounds, transportation needs were mentioned repeatedly by service coordinators. The issue of physical accessibility to services was mentioned especially with respect to rural areas.
(6) *There was some evidence that cultural differences affected access to services*: Staff repeatedly mentioned the reluctance of some Hispanic families to ask for services, in part because of a general feeling of intimidation and in part because they perceived a stigmatizing aspect to requesting services. Of course, language issues were paramount for both Asian and Hispanic families. Some parents noted that service coordinators could "only translate words," but did not have the cultural sensitivity or language facility to really find out what parents needed. Finally, both parents and staff noted a service provider bias that Hispanic families wish to "take care of their own" and do not want services. This assumption by providers may have contributed to Hispanic families receiving fewer services. To the extent that

staff felt parents with more education and income were more likely to get services, one can surmise that less acculturated families also would be at a disadvantage.

Summary

Overall, the participants in the focus groups expressed a number of concerns that reflected some of the issues addressed in POS Report #1 regarding ethnicity, consumer characteristics, and regional center. However, most sentiments were expressed by only a handful of participants and cannot be interpreted as widely representative. The affect expressed during the groups was generally upbeat -- neutral to positive; negative comments were relatively rare. For the most part, both the staff and parents/consumers felt that services were provided on the basis of need whenever possible, and opinions expressed indicated that participants found the process of service delivery to be equitable.

However, the constant reference to services unique to autism spectrum disorder (which was not a focus of this particular study) indicates how concerned consumer families and service coordinators were about the fiscal implications of meeting this particular need. Indeed, parents of children with other types of disorders were not as confident that their (and their consumers') needs would be adequately met.

Finally, there are implications for Spanish-speaking families and for some Asian, non-English-speaking families as well. As in the survey findings from the Hispanic subsample, these concerns might readily be dealt with by increasing the use of bilingual service coordinators who spend additional time assessing family needs and prioritizing their concerns.

III. HOW DOES THE STORY END?

In designing POS II, our goal was to try to examine "equity" in service delivery within the DDS system. While equity, in this context, seems like it should be a concrete concept – equal amounts of this or that service, equal numbers of dollars spent – it is, to some extent, in "the eye of the beholder." To over-simplify, if each consumer family in the DDS system received the same exact amount of funding from DDS (i.e., equal purchase of services), equity would not be achieved, because each person with a developmental disability has different needs, and families have different desires for types of services. A "one size fits all approach" is not the way to achieve equity in service provision.

Similarly, a single methodological approach to the POS II study would not help us achieve our goal of determining whether there was equity in the system. Thus, we developed a study that involved four different component parts, each of which is a chapter, with the whole story hopefully told in this Final Report. With this analogy in mind, how did the story come out?

Chapter 1, The Statewide Analyses: Using the statewide database, and examining not one year of data but five, we were able to search for systematic trends or biases in

purchase of services. In a series of carefully controlled statistical studies, we found no systematic bias. We did find that consumer-related characteristics drive service delivery, as they should. When we examined the potential bias factors of consumer gender, ethnicity and regional center, we found that the latter two had small, but statistically significant effects.

Chapter 2, The Statewide Survey: The statewide analyses involved looking at numbers on a database; the survey involved gathering new numbers -- from consumers, guardians or consumer families themselves. Here, the sample logically dropped from over 100,000 to just over 1,000. We were able to learn that, overall, the needs of families were met, although less so in some specific cost categories than others. We also learned that, overall, consumers/families were relatively satisfied, despite the fact that there were some unmet needs. Too, service coordinators agreed reasonably well in their ratings of consumer/family needs and satisfaction. Nonetheless, there were some small, but statistically significant differences by ethnicity; for example, African American, Asian American and Hispanic respondents had higher reported needs for additional resources than White or European American respondents.

Chapter 3, The Subsample Survey: Here, the sample dropped to just under 100 for Spanish-speaking Hispanic families. While this sample constituted a unique group, by all having young adult offspring (ages 18-28) with severe disabilities, they contributed a more personal and comprehensive view of the impact of service provision. Their particular part of the "story" is more detailed, because they were part of a larger study and more information was available for them. Here, too, respondents were satisfied, overall, with the services provided. However, only about half of their expressed needs were being met, and they expressed twice the percentage of unmet needs as their Anglo counterparts. Furthermore, the mothers who expressed more total service needs had more stress and depression, less acculturation, and sons or daughters with more behavior problems. The picture obtained from this intensive look at the subsample suggested that these mothers were certainly in need of services.

Chapter 4, The Focus Groups: This chapter is perhaps the most "up close and personal" part of the overall study. We amassed a huge amount of information from relatively few individuals. All participant comments had validity, and many speak to areas of service delivery that might be improved. For the most part, though, the focus group data did not suggest any crisis in the system. However, while the participants were generally positive, their comments were constructively critical of current needs and policies.

We do not view any of the above findings as discrepant or contradictory. Nor is any one chapter in this story more "important" or more "correct." Rather, each methodology that we incorporated addressed a slightly different question. There can always be a *perception* of bias due to a "squeaky wheel" (as noted in the focus groups), or due to the failure to take *all* relevant variables into account (something nearly impossible to do in any study.) What is important here is that the different components of POS II took these issues into account, and provided us with multiple perspectives on the service delivery process.

IV. IMPLICATIONS FOR SERVICE DELIVERY

The implications of the POS II study are consistent with prevailing literature and wisdom in the field. In order to meet the range of needs experienced by families with children who have disabilities, service delivery systems must do more than simply provide services without guidance and go beyond just creating isolated, generic services. While families appear to appreciate regional center services, based on the relatively high satisfaction levels reported on our surveys, focus group data suggest that *some* families continue to experience areas of unmet needs, such as advocacy, sensitively trained staff, and service coordination, particular from one agency to another.

Focused discussion with staff from regional center, the Department of Developmental Services, and Stakeholders for the purpose of digesting these study findings would be useful. Here, we note major discussion points, some of which have practical implications:

(1) Given the massive budget operation of the DDS and regional center system, the delivery of services is surprisingly equitable and smooth. Theoretically, there could have been some differential allotment of services due to one factor or another. If, in fact, there were major inequities to be found, we likely would have found them, and we would have pointed them out. However, our analyses, either over the short term or across the five years (using a variety of acceptable statistical techniques) revealed virtually no systematic bias**. Implication:** The system "works."

(2) The analyses presented over five years indicated that there were fewer Hispanics being served in the adult categories, which are often the most expensive. Put another way, the younger generations of consumers contain different proportions of ethnic groups than the older generations. This suggests that over time, as the current consumers age, there will be increased purchase of service need for particular ethnic groups, primarily Hispanic. **Implication:** Planning for future delivery and purchase of services should take changing demographics of the DDS consumer population into account.

(3) There are other fiscal implications of these studies. One is that any across-the-board budget cuts for the regional center system would more negatively affect some consumers and their families than others (i.e., those at the lower expenditure centers, and those who are non-English speaking.) **Implications:** This potential for differential impact implies that special effort should be made to preserve services for affected families and consumers.

(4) Overall, the vast majority of parents/consumers were generally satisfied with the services that they currently receive. However, there were many unmet needs, especially among Hispanic families. This finding became apparent in our subsample analyses, where the availability of additional measures enabled

us to examine unmet needs more closely, by relating service provision to other aspects of family well-being. **Implication:** It is imperative that regional center service coordinators pay better attention to these unmet needs, particularly when they occur in families who do not speak English (and, thus, would be less likely to advocate for their own needs).

(5) There is a perception of an emphasis on meeting needs in the area of autism spectrum disorder (ASD), as noted by participants in our focus groups, especially if they occur in low expenditure regional centers and in non-English speaking populations. **Implication:** Parents of non-English speaking ethnic groups are less likely to demand services for their child with ASD, and regional centers may want to be proactive on behalf of these children.

(6) Regional centers may need to be more culturally sensitive to issues that will emerge over the next decade or so, and to be ready for a growing population of certain ethnic groups. It is possible, too, that over time service patterns and priorities may need to change to meet the needs of these groups. Toward this end, there will be need to develop better outreach to these communities to assure that families are aware of the services available through regional centers. Outreach efforts may reveal particular areas of unmet family support as well as consumer needs. **Implication:** If nothing else, the need for more bilingual service coordinators will be necessary

(7) Finally, how can the system best meet the needs of families? This is a difficult question to answer, especially in tight fiscal times. Focus group findings suggested that some families don't want what's on "the menu" of current regional center services, yet they want things that are not available. For example, the subsample analyses (and related work with that sample) clearly suggest that Hispanic families are not interested in out-of-home placement, but they are very interested in having a case manager who has the time to be more personal and who will "listen." Other clinical issues also affect family needs, such as the increased maternal stress of having a child with multiple disabilities or the behavioral challenges of children with ASD. Regional centers are not currently structured (or funded) to deal with all of these collateral issues. Moreover, the evolution of the case manager role, from more of a "clinician" or social worker to a consumer-driven fiscal manager, may not be the best model for meeting family needs. **Implication:** Perhaps less of a one-size-fits-all approach would allow regional centers to better meet the needs of diverse groups. This may require additional personnel with more clinical skills, who might relieve some of the caseload of current service coordinators.

There are likely many more implications of this study that might be revealed through continued dialogue. We look to public policy makers to place greater emphasis on interagency collaboration, thorough staff training, and support to consumer families. Perhaps, too, service coordinators at regional centers could continue to systematically identify which specific aspects of consumer services are particularly helpful and in what

areas (e.g., stress reduction, or in-home support, ability to keep child at home). Finally, continuing efforts to isolate areas of service need, to provide for those needs, and to evaluate parent/consumer satisfaction with services received are paramount.

V. UNRESOLVED QUESTIONS

As with most major research projects, the more we know, the more we need to know. Thus, in this concluding section, we identify several unanswered questions or areas of concerns. We note that most of these can be answered by further study of the existing database (which is a tremendous resource); others might require some reallocation of current priorities.

(1) We propose some trend analyses that examine expenditures for Hispanics and other recently immigrated groups, as they currently exist on the statewide database. Furthermore, we propose some modeling of future expenditures, using census data and reliable estimates of birth and immigration rates.

(2) We propose a study of purchase of service costs for children with autism spectrum disorder. Currently, we understand that no one cost category covers these services entirely and that they are covered under a variety of categories, some unique to certain regional centers. It is imperative that we get a reliable and usable handle on these services, and identify service patterns for meeting the needs of consumers with autism spectrum disorder across regional centers and ethnicities. It would be possible to anticipate future expenditures using recently published prevalence rates and statistical modeling.

(3) Finally, we recognize that many regional centers have some specialized initiatives for developing more effective ways to deliver services to Hispanic and other non-English speaking groups. It would be useful to gather data from each regional center on how this is being done to determine if one model is more effective than another. In particular, proposals from service coordinators to better meet unmet family/consumer needs and to better assess family/consumer satisfaction may go a long way to resolve questions of equity in service provision.