

CALIFORNIA'S LANTERMAN ACT 45 YEARS LATER

A STUDY OF SERVICE RECIPIENTS' AND PROVIDERS' EXPERIENCES WITH THE LAW'S LEGACIES

**CASTER FAMILY CENTER
FOR NONPROFIT AND PHILANTHROPIC RESEARCH
IN COLLABORATION WITH
CALIFORNIA DISABILITY SERVICES ASSOCIATION**

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EXECUTIVE SUMMARY

The Lanterman Act was a truly trend-setting piece of legislation when it was passed in 1969. It moved people with disabilities out of institutions and into the community to live, learn, and work. It also established structures and standard operating procedures to assist persons with disabilities and their families' in accessing needed services and support.

The California Disability Services Association (CDSA), an association of community-based nonprofit and for-profit organizations that provide assistance to people with intellectual and developmental disabilities, decided in 2013 that it was time to take a close-up look at the impact of the legislation 45 years after the act became law. It collaborated with the University of San Diego's Caster Family Center for Nonprofit and Philanthropic Research (the Caster Center) to conduct a focus group study exploring perceptions of, and experiences with, disability services in California.

In total, 328 individuals participated in 43 focus group meetings throughout eight of the nine Caucus areas throughout California. The majority of focus groups were composed of representatives from one of the following: service providers (including Regional Center staff¹, clients/consumers, and parents/guardians/ conservators. In addition, there were also hybrid groups that were made up of a mix of people from the above groups, as well as a number of individuals who did not fit into the above categories such as advocates, grandparents, interns, school district employees, siblings, and vendors.

CDSA was responsible for conducting the focus groups, recording what was said during focus group sessions, and providing a preliminary analysis of the data generated by each focus group using an analysis template developed by the Caster Center. The template was included in a manual created by Caster Center personnel that provide directions for CDSA members to use in collecting and analyzing data. Caster Center personnel also were responsible for the overall analysis of the data and for writing this report.

¹ Although in the field of Disability Services it is customary to distinguish between service providers and Regional Center personnel, for the purposes of this study the two types of employees were both referred to as service providers. The use of a single term was required because many focus groups were composed of both those who are traditionally characterized as service providers and those who are classified as Regional Center personnel. Most recorders' notes did not distinguish between the two types of focus group participants.

Research Questions

Both the focus group discussions and this report have been organized around three questions:

- 1) What is working?
- 2) What is *not* working?
- 3) What changes are needed?

What Is Working?

Responses to the what-is-working question suggest that focus group participants strongly supported the goals of the Lanterman Act, and many felt supported by the structures and organizations established as a result of the law. Many participants were positive about the programs that are currently being offered and the personnel who offer these programs. There were also positive comments about Regional Center personnel who facilitate the process of identifying and accessing needed services.

Other positive comments focused on independent living, the opportunity for service recipients to be employed and receive a modest paycheck, and the perceived increased sensitivity of the education system to clients/consumers who are still in school. Participants often attributed their positive perceptions to the Lanterman Act and the Regional Centers throughout the state that the law established to assist people with disabilities and their families.

What Is *Not* Working?

When participants were asked to discuss what is *not* working, many were able to articulate a different view of the state of the Lanterman-generated system of support and services.

Many comments, not surprisingly, related to recent budget cutbacks. According to participants, cutbacks and inadequate financing were responsible for a variety of problems, including (but not limited to): frequent staff turnover, low staff wages, and inadequate professional development opportunities for staff. Fiscal issues also involved insurance companies' barriers to service such as the denial of treatment and the cumbersome, time-consuming and frustrating referral system (particularly when service recipients need to see specialists).

Participants also spoke of a bureaucracy that was portrayed as inconsistent with and unresponsive to the needs of people; they also discussed a perceived lack of interagency cooperation. The lack of cooperation was attributed, in part, to a lack of understanding of the

different cultures and different rules and regulations of different agencies, as well as to a desire to “pass the buck” so that the cost of services would be incurred by other agencies.

During the *what-is-not-working* part of discussions, some focus group participants balanced the positive comments about education, employment, independent living, and transportation made during an earlier part of the discussion with comments that were decidedly negative. Yet, most participants who made critical comments about these four matters were not necessarily challenging or disagreeing with the Lanterman Act's community-integration goals; rather, they criticized the way those goals were being implemented.

What Changes Are Needed?

Participants also were asked to discuss what changes are needed. Their comments were translated in the report into the following succinct recommendations:

- (1) Convene cross agency meetings to develop understanding of different organizational cultures and minimize the “passing the buck” phenomenon.
- (2) Provide training to those who are not directly involved with helping client/consumers but, nevertheless, often have significant contact with people with disabilities.
- (3) Develop mechanisms to share good ideas with others in the “Lanterman system.
- (4) Conduct a study to determine when consistency across the Regional Centers should be mandated and when local discretion is appropriate; develop mechanisms to enforce consistency when consistency is judged to be desirable and appropriate.
- (5) Lobby to no longer reduce social security benefits for individuals with developmental disabilities with jobs that pay less than the minimum wage; reduce other penalties for working, as well.
- (6) Develop education programs for parents (especially new parents) that provide either in-person or virtual training about how to access services and negotiate the system.
- (7) Communicate changes in regional center policies and options via newsletters and/or email messages.
- (8) Create directories of services that parents and conservators can access themselves.

(9) Create public service commercials and, if possible, multi-faceted public relations campaigns to educate both the general public and specific populations about the strengths and contributions of persons with disabilities.

(10) Increase staff training, especially for low-wage workers whose education and work backgrounds often are not a good match for the responsibilities they have.

(11) Improve oversight of group homes and those in charge of them.

(12) Educate parents, guardians, and conservators about long-term options for taking care of the person with disabilities for whom they are responsible.

(13) Provide assistance and incentives (including, possibly, tax credits) to businesses that employ persons with disabilities.

(14) Increase services to improve the transition from the school years to adulthood.

(15) Upgrade technology as a way to improve communication, enhance efficiency, impose consistency (when appropriate), and increase oversight of the system.

(16) Increase funding for a variety of reasons and purposes.

The idea of forming foundations to help increase the availability of services when government funding is far from adequate was only mentioned in passing (and by only one service provider) in the discussion of what is needed. This idea, however, appears to have real potential in an era of government retrenchment and, arguably, should be given greater attention than the data from the third part of the focus group interviews suggests. One item that received significant attention during the *what-is-not-working* part of the discussion, but that was not discussed when the conversation turned to needed changes, involved the cumbersome medical referral process and insurance companies' perceived blocking of needed services.

INTRODUCTION

California's Lanterman Act was a landmark piece of legislation when it was passed in 1969. It promoted the integration of individuals with developmental challenges into the larger society before such thinking was codified into law elsewhere. More specifically, the act embraced the idea of moving individuals with developmental disabilities out of institutions and into the community to live, go to school, and work. The concept of community integration was later embraced by legislation in other states, as well as in federal legislation.

De-institutionalization can only be successful if support systems are put in place to aid individuals with developmental disabilities who are attempting to function beyond the doors of the institutions in which they were once housed. The Lanterman Act established such support systems. For example, it established a network of Regional Centers throughout the state that were charged with assisting those with disabilities and their families with access to services through an array of service providers. The law also informed service recipients what to do when they were not able to access the services they needed.

The Lanterman Act has now been in place for 45 years. Not surprisingly, there is currently an effort to update the law. The California Disability Services Association (CDSA), an association of community-based nonprofit and for-profit organizations that provide assistance to people with intellectual and developmental disabilities, decided in 2013 to participate in the updating process. The organization's System Modernization Committee decided to do this, at least initially, by studying what is working, what is problematic, and what changes in the law and related rules and regulations may be required to better serve California's disabled population now and in the future.

THE STUDY

Research Design and Methodology

The study's design used a focus group methodology to gather perceptions and experiential information about disability services in California from a wide range of stakeholders. The stakeholder groups that participated in the study included both different types of service providers and different groups of service recipients. The emphasis on interviewing different stakeholders reflected a commitment to employ a version of maximum variation sampling in generating study participants; however, the study also relied on convenience sampling. Interviews were conducted only with volunteers who knew about, and were willing to attend, meetings that were scheduled at particular times and places.

Because of the qualitative nature of the study's design and, especially, the study's reliance on participant groups that were established, at least in part, on the basis of convenience, the study was not designed to determine the precise percentage of people who agreed with each idea raised during the study. Gathering this type of information would require translating the results of this study into items on a survey instrument that would then be administered to a representative sample of individuals throughout California. The purpose of *this* study was simply to surface thinking about the services associated with the Lanterman Act, thinking that may or may not be typical of the thinking of similar stakeholders who have had experience with the Act. Of course, with the type of design employed in this study, if the sample of participants is relatively large and an idea is endorsed by a large number of sample participants, commonsense suggests that the idea is *likely* to be shared by others who did not participate in the study.

To generate a relatively large sample with a relatively small budget, CDSA opted to contract with the Caster Family Center for Nonprofit and Philanthropic Research (the Caster Center) at the University of San Diego to *jointly* design and execute the study. To contain costs, the plan was for data collection to be done by CDSA members throughout the state. After each interview, those who facilitated and recorded data from a focus group discussion were expected to engage in a preliminary analysis of the data generated by the focus group. This preliminary analysis entailed using a template provided by the Caster Center to analyze the key issues raised during each focus group meeting.

In addition to designing the template to be used in the preliminary analysis of data from each focus group, Caster Center personnel designed a manual that CDSA members could use to guide data collection, as well as the preliminary data analysis. The manual, which can be found in the Appendix, specified that a facilitator and recorder (i.e., note taker) should be assigned to each focus group; the manual also detailed what those who took on these roles should do. Later pilot work, which was observed by Caster Center personnel, revealed the need for someone to take on a third role, that of a scribe who recorded the discussion on flip charts that members could refer back to during the course of the discussion. Piloting the procedures outlined in the manual also revealed the need to modify the interview questions for clients. CDSA volunteers later developed a modified version of the interview protocol.

In addition to creating the manual, Caster Center personnel were assigned the task of providing professional development on the use of the procedures outlined in the manual. Professional development was delivered in two ways: (1) presentations by Caster Center personnel during the Southern and Northern regional meetings of CDSA in the Fall of 2013 (each presentation included an actual example of a service provider focus group)² and (2) a video of a focus group that was put on the CDSA website for those conducting focus groups to view prior to doing their work.³

Finally, Caster Center personnel were responsible for analyzing the data after those who conducted the focus group sent focus group materials to the Caster Center. These materials included (a) the recorder's notes, (b) forms filled out by focus group participants prior to the start of focus group discussions (see the manual in the Appendix), and (c) the preliminary analysis sheets produced by each focus group's leadership team immediately after the focus group ended. Caster Center personnel also prepared this report.⁴

² Both examples were conducted by CDSA's Executive Director and included selected CDSA members. Because issues arose, especially during the first presentation at the Northern California meeting, the examples of the focus group sessions that were part of the presentations also served as a preliminary pilot of the procedures outlined in the manual and contributed to the revision of the manual. As previously noted, Caster Center personnel also functioned as observers for additional piloting, which assessed the different types of focus groups employed in the study.

³ The website was being revised at the time this report was written. Consequently, the link to the instructional video is no longer available.

⁴ The report was written by Dr. Robert Donmoyer and Christina E. Mitchell and reviewed by representatives from the CDSA's System Modernization Committee.

Participant Profile

Type of Groups

A total of 328 individuals participated in 43 focus groups. Some individuals self-identified with more than one group. For example, a service provider also listed herself as a parent to a client/consumer on the form that all participants filled out individually before the actual focus group discussion began.

As Table 1 indicates, there were 16 Service Recipient and 15 Service Provider groups. The 16 Service Recipient groups included nine Client/Consumer groups and seven Parent/Guardian/Conservator groups. Two Regional Center groups participated as part of the Service Provider groups. There were also 12 Hybrid groups, defined as groups consisting of a heterogeneous mix of individuals. Hybrid groups consisted of clients/consumers, parents/guardians/conservators and service providers, as well as individuals such as advocates, grandparents, interns, school district employees, siblings, and vendors.

Table 1. Types of Focus Groups

Type of Focus Group	Number of Groups	Number of Participants
Clients/Consumers	9	82
Parents/Guardians/Conservator	7	37
Service Providers	15	109
Hybrids	12	100
Consumers		19
Parents/Guardians/Conservators		38
Service Providers		39
Other		17
TOTAL	43	328

Demographic Profile

Table 2 summarizes the demographic profile of participants. At times the totals do not equal 100 percent because a small number of participants did not provide demographic information.

Table 2. Demographic Profile of Participants

Demographic Category	Number	Percentage
Gender		
Male	120	37%
Female	202	62%
Ethnicity		
American Indian/ Alaska Native	4	1%
Asian	7	2%
Black/African American	21	6%
Hispanic/Latino	60	18%
Native Hawaiian/ Other Pacific Islander	2	1%
White (Non-Hispanic)	235	70%
Other	7	2%
Age		
Age Range of Participants	14 - 81 years old	
Average Age of Participants	44 years old	
Years Providing or Receiving Services		
Range	0 - 54 years	
Average	18 years	

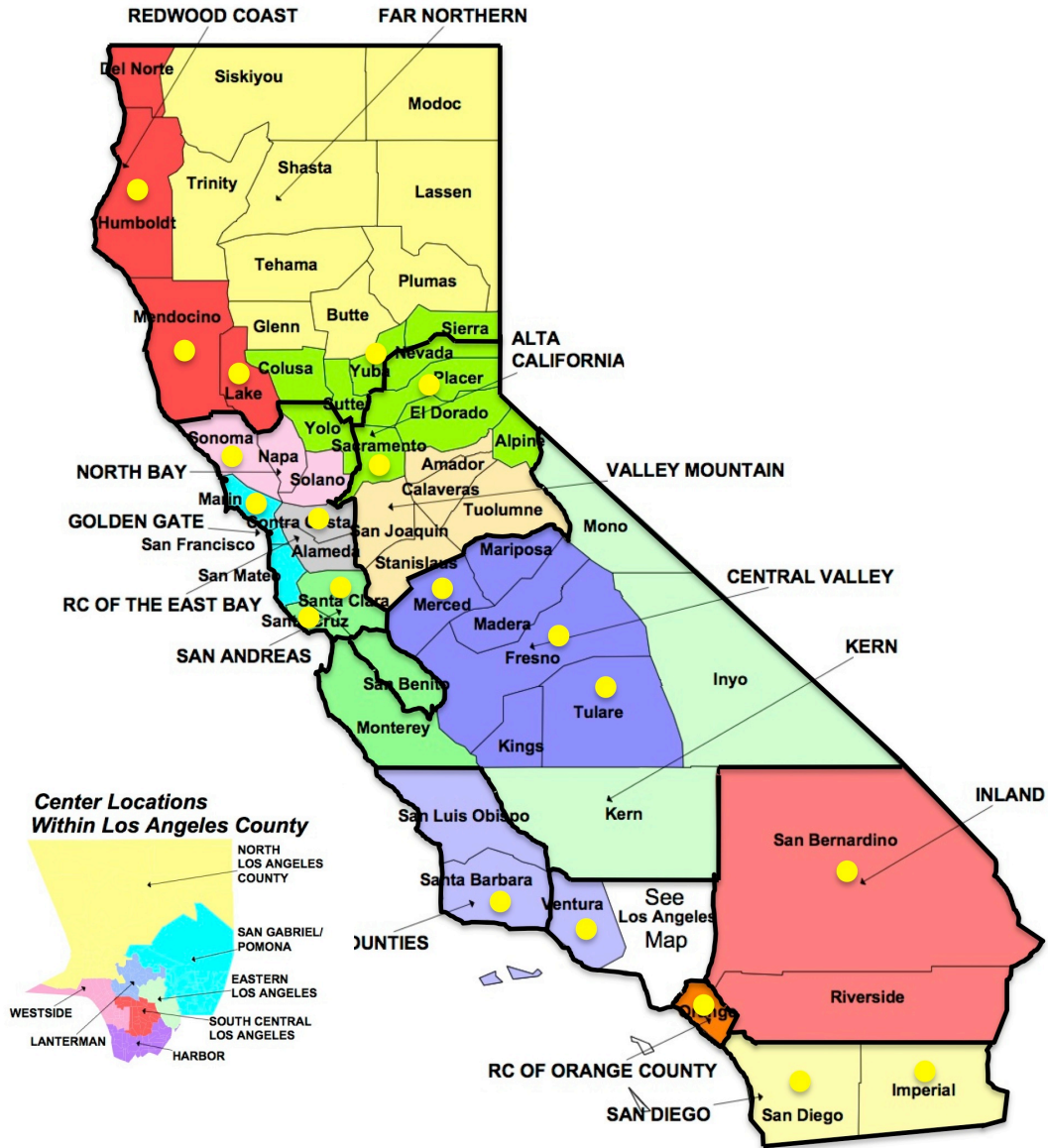
CDSA Caucus and Regional Service Areas

The CDSA is divided into nine caucuses throughout California (see Figure 1). These caucuses correlate to the service areas of the Regional Centers, the state-contracted nonprofit agencies established by the Lanterman Act to oversee client/consumer services. All caucuses participated in the study except Central Coast (San Luis Obispo and Santa Barbara). As Table 3 demonstrates, the number of focus groups in each caucus varied, ranging from a high of 12 in the Bay Area to a low of one in Orange County.

Table 3. Overview of CDSA Caucus and Regional Service Areas

Caucus Service Area	County	Regional Center Service Area	Total
Bay Area			
	Marin	Golden Gate	1
	Contra Costa	East Bay	2
	Sonoma	North Bay	4
	Santa Clara	San Andreas	3
	Santa Cruz	San Andreas	2
			12
Capitol			
	Placer	Alta	1
	Sacramento	Alta	4
			5
Central Valley			
	Fresno	Central Valley	2
	Merced	Central Valley	1
	Tulare	Central Valley	1
			4
Inland Empire			
	San Bernardino	Inland	6
			6
Los Angeles			
	Ventura	Tri-Counties	1
			1
Orange County			
	Orange	Orange County	1
			1
San Diego			
	Imperial	San Diego	2
	San Diego	San Diego	6
			8
Upstate			
	Yuba	Alta	1
	Humboldt	Redwood Coast	1
	Lake	Redwood Coast	2
	Mendocino	Redwood Coast	2
			6

Figure 1. CDSA Caucus Service Areas, Regional Center Service Areas, and Focus Group Locations



FINDINGS

The study was organized around the following three research questions, which also became focus group interview questions:

1. What is working?
2. What is *not* working?
3. What changes are needed?

This discussion of findings is structured around focus group participants' answers to these three questions.

Question # 1: What is Working?

Programs, Activities, and Services

The detailed notes from the majority of all types of focus groups (i.e., parents/conservators, clients/consumers, service providers, and hybrid groups) contained positive comments about programs, activities, and services offered for those with disabilities. Participants in the focus groups composed of parents, guardians, and conservators were especially positive and lauded specific programs ranging from direct care and day programs to services tailored to the specific needs of clients/consumers. One participant, for example, took note of how much the clients/consumers love the day program; “they are upset when they can’t go,” she told the group. Another participant in a parent/guardian/conservator group noted that her daughter “would come to the program sick” if she could, because she loved the program so much.

Similar sentiments also were expressed in the client/consumer groups. One client/consumer, for example, noted that the day program “allows me to make my own decisions, be more independent, get work experience, and have real friends.”

There were also a number of positive comments about a range of socialization activities that were designed to integrate clients/consumers into the larger community. One participant in a parent/guardian/conservator group, for example, talked about her sister being active in a group home; she noted that her sister “enjoys social activities and is in the choir.” Another parent talked about the opportunity for the parent’s daughter “to get out of [the] home and out from four walls” and go into “the community where there is integration and she can mingle in the world.” One of the more compelling comments came from a parent who had lived out of state with a

daughter with a developmental disability. “It was a nightmare,” this parent recounted, “and [we] moved back to California....Out of state, she was at home and not doing anything. Here her attitude has changed; she’s happy....,has friends.”

Respite services seemed to be especially appreciated. “It takes the load off of parents when my son goes to the day program,” one parent stated. This parent also noted that “the experience of life with someone outside the family is important” for the client/consumer as well.

When clients/consumers had an opportunity to speak for themselves, they, too, said many positive things about the socialization activities in which they participated. In fact, the only negative comments found in the notes for the clients/consumers group related to wanting even more activities in which to participate. Presumably these comments were prompted, at least in part, by the elimination of some programs and activities due to recent cutbacks in recreational/societal integration activities because of cuts in state funding.

The storyline about programs and activities was also positive in the groups composed of service providers. They often praised the creative, innovative, and broad-range of programs designed to meet changing needs and noted that “people are generally happy.”

Program Personnel

Parents/guardians/conservators and clients/consumers were also very positive about the people who ran programs, activities, and services. Clients/consumers recognized and appreciated the support they received from staff members, and parents/conservators also had positive things to say about the staff members who provided services. One parent, for instance, talked about being “very pleased with program staff,” while another stated that the “personnel [who ran programs] were terrific.”

Clients/consumers also had positive things to say about the assistance staff members provide. Here is a sample of client/consumer comments about program personnel:

My worker helps me.

People listen to me.

People help me start my day; [without them] I would not be able to start my day.

Some of the positive comments were about Regional Center personnel who worked with clients/consumers and parents/guardians/conservators to develop each service recipient's Individual Program Plan (IPP). One guardian stated that the "caseworker is [always] supportive and informed when creating the IPP." Another noted, "The case manager knows what is best for my son, and he knows appropriate resources and can advocate." Even a parent participant who indicated that he had a high functioning son for whom many programs and activities were not optimal seemed to understand the limits confronted by IPP preparers: "I understand that they can't tailor one program to everyone involved."

There were also positive comments from clients/consumers about the professionals who helped develop IPPs. One client/consumer noted "I agree with the advice I get from my social worker." Another comment related to the service orientation of those who facilitate the IPP process: "I like that my worker comes to my home and wants to get you guys [presumably service providers attending the focus group session] together to talk."

At times it seemed as if personnel were effective in spite of, rather than because of, the policies and organizational structures that defined and bounded what personnel could do. The problematic nature of policies and organizational structures will be discussed more in the what-is-not-working section below.

Independent Living/Support for Independent Living

The closing of the residential centers that often housed individuals with developmental disabilities, which dates back to 1967 and the passage of the Lanterman-Petris-Short Act, meant that new forms of housing had to be created. The new forms emphasized independent living. Some clients/consumers who participated in the focus groups lived in group homes; others had their own apartments.

Independent living was mentioned positively in a number of client/consumer focus groups. Many of the comments that could be counted as criticisms of independent living related to clients/consumers wanting to be *more* independent by moving from group homes (where noise and interpersonal problems existed, according to some clients/consumers) to their own apartments.

Of course, independent living requires support and scaffolding, and a number of individuals in the client/consumer groups mentioned the support they were receiving or had received. One client/consumer said, "I love my ILS [Independent Living Services] instructor." Another

client/consumer was quite specific about the ILS instructor does: “My I[H]SS [i.e. In-Home Supportive Services worker] helps me pay my rent and bills. She helps me stay independent.”

Comments about the value of independent living and the support individuals living independently receive from service providers also came from parents. One parent, for example, commented about the ways In-Home Supportive Services (IHSS) personnel supported independent living: “They help [people] clean, learn to cook, take folks to Wal-Mart when busses don’t run. This is huge for people with disabilities.”

Service providers also endorsed the independent living strategy. One provider, for example, described the strategy as versatile and cost effective.

To summarize, the comments about the general strategy of independent living during the what-is-working part of the discussion were all exceedingly positive. Any comments that could be coded as negative related either to wanting to live even more independently or to seemingly minor irritations with living in a group home situation. The number of groups in which independent living was mentioned, however, was relatively small (though the topic did come up in at least one of the parent/guardian/conservator, client/consumer, and service provider groups). It is conceivable that independent living was not mentioned more often as something that is working because it is now so well-established; therefore, focus group participants may have viewed independent living as something that is natural and inevitable rather than the policy innovation that it once was.

Transportation Services

Transportation services not only support independent living; they also can be a key to greater societal integration, generally. Most individuals with developmental disabilities, for example, do not own or even drive cars, so if they are to get to and from a job, for example, they need transportation.

Given the importance of transportation, it is not surprising that transportation services were mentioned in all types of groups as something that is working. One client, for example, stated, “I like getting the free bus passes. It really helps a lot.” Positive comments from parents and conservators were almost always focused on the special transportation provide by disability service organizations.

Van service works....We live out in the boonies. If it were not for People Services, I would spend a fortune on gasoline. The driver couldn't be nicer. If he is running late, he calls. My son can't wait to get to the van.

Another parent/conservator suggested that drivers were not just nice, they also “are careful and they observe good safety rules.” A third parent commented on both the people skills and the technical competence of van drivers:

The driver is the kindest man I've ever met. He gave CPR. If we have problems we get calls back and track anything that is important. It [van transportation] has been a godsend; they watch medical issues.

Service providers did not say a great deal about transportation. The comments they did make tended to be logistical and technical. One service provider, for example, noted that providing adequate transportation for clients/consumers required considerable collaboration with Regional Center personnel. There will be more on the issues of collaboration and coordination below. The discussion below also will indicate that transportation services are not working for everyone.

Employment and Education

The Lanterman Act encourages students to become part of the workforce through its pay-for-productivity initiative. Clients/consumers indicated they liked having jobs, including volunteer jobs. Not surprisingly, however, clients/consumers were most enthusiastic about jobs that netted a paycheck, a point that also was reinforced in some parent/guardian/conservator focus groups. One guardian said: “My brother loves to work, and I’m very appreciative that the Lanterman Act found work for my brother.”

Both parents/guardians/conservators and clients/consumers had positive things to say about the job coaching and employment services that were being provided. Some service providers also mentioned the value of employment services. Service providers also emphasized the benefits associated with having individuals with developmental disabilities in the work force, as well as the benefits to the client of working:

Clients are involved in Meals on Wheels, and they love it—going to people's doors and having contact they did not have otherwise, and they enjoy [this contact] and get free lunch if they work. [It is also] wonderful for the people they are serving to have that contact, and this agency made that contact and connection.

Of course, many of the individuals served by the Regional Centers and other organizations that provide services were still students and, consequently, were not yet ready for the labor force. There were some comments about schools, and many of them suggested that things were working—or at least improving—in the school domain. One parent/guardian/conservator

commented that meetings about their child's Individualized Educational Plan (IEP) (the schooling equivalent of the more comprehensive IPP developed in consultation with Regional Center personnel) were carefully monitored and held consistently. One hybrid group participant noted that there were better services for individuals with disabilities now than in the past, while another participant noted that "schools [today] are servicing people until [they are] 22 years [old]." One parent/guardian/conservator group also noted that there was "increased discussion about college," and one participant in the client/consumer group talked about taking college classes.

Legislation

Many participants who articulated positive comments specifically attributed the positive things they talked about to legislation, the Lanterman Act, and the Regional Centers that emerged as a result. One parent/guardian/conservator focus group member, for example, talked about "strong legislative support for our community," while another specifically attributed the positive things that happen in California to "the fact that we have Lanterman and Regional Center services." Service providers were even more likely to reference the Lanterman Act by name. Here is what one service provider said:

California [is] unique...I push the Lanterman entitlement. I don't think people realize how unique the service delivery system is in California. I know a person who went to Colorado and waited 4 years for services and never received them. This is a person that returned to California and right now they are working and socializing in the community...Let people know that if you go to another state, people are wait listed and many have never received services. Here people get services; in 30 days they can become a Regional Center client, which is unheard of in other states. People in other states end up going to homeless shelters and prisons because they are not receiving services, which is a huge difference in California.

Question #2: What is *Not* Working?

Not all the thoughts expressed during the various focus groups conducted throughout the state were positive. In fact, when asked to talk about what was not working and what things required modification, focus group participants had a great deal to say.

Budget Cuts

Given the budget cuts of the recent past, it should come as no surprise that many of the identified problems could be traced back to inadequate funding. Facilitators asked focus group participants to limit their comments about recent budget cuts because this is a problem that is already on most people's radar screens. Nevertheless, many groups commented on the direct toll that budget cuts have taken. One parent, for instance, noted, "the change in IHSS [In Home Supportive Services] operating hours have hurt. In the summer, when school is out, we're caring for him [the parent's son] 10 hours a day, and it's hard. We need more time." Another said, "Medi-Cal was taken from us. We have cuts in dental and vision."

Service providers also commented on the toll that budget cuts have taken. One service provider, for example, noted that legislation no longer provides much in the way of funding for socialization and recreation programs. "Camp and [other] socialization and recreation programs need to come back...the lack of this causes depression."

Arguably, however, the most poignant comments about the recent budget cuts came from some of the clients/consumers who expressed real concern about the possible consequences of the cuts. One client/consumer, for instance, stated: "We might lose our jobs and where we're living at and our services." Another noted that her sister died of cancer and her ILS vendor would not let her go to the funeral because transporting her to the funeral would cost too much.

Insurance Problems and the Referral Game

Most of the participants seemed to heed the facilitator's request not to focus too much on the negative consequences of recent budget cuts, but, even when they did this, the problems raised often were connected to financing in some manner. Many of the less-than-positive comments about programs and services, for instance, were related to insurance claims, which of course, are all about dollars. One consumer/client, for instance, noted, "When I needed a new [wheel] chair, I was turned down three times because the insurance company didn't believe I needed a power wheel chair. So insurance and budget cuts is what I see is wrong." Ironically, a service provider in an entirely different focus group noted, "Sometimes when they [finally] get their wheel chairs, they have outgrown them."

Another client/consumer commented: “You should have seen the heck me and mother went through for this stinking polyp in my nose, and we had to fight...to get a referral for me to see an ENT [ear, nose and throat specialist], and I was so flippin’ sick.” This comment about the need to fight to have a client/consumer’s polyp problem attended to was one of many complaints about the perceived nonsensical and unnecessary referral game that client/consumers and their families constantly had to play. The game often involved needing to go back to the medical professional who originally referred a client/consumer to a second medical professional after the second medical professional indicated the client/consumer needed to see a third medical professional.

Of course, it is possible that this referral game does not seem nonsensical and unnecessary to insurance company representatives who were not interviewed as part of this study. In short, figuring out whether the bureaucratic impediments to accessing services that both clients/consumers and parents/guardians/conservators complained about are in some way defensible is beyond the scope of this study. All that can be said for certain here is that service recipients and the parents, guardians, and conservators who are directly responsible for service recipients’ care tend to see the referral game as evidence that medical services are not working.

Insurance-related complaints were not just about the referral process and battles about eligibility. One parent, for example, noted that “local doctors [are] not accepting Medi-Cal; [especially] for specialists, we have to go far away and still pay for services.” This parent talked about “the good old days” when a mobile unit organized and, presumably, funded by a Regional Center came to the area once a month and patients were seen by the same doctor visit after visit. “Everyone who was there,” this parent noted, “was developmentally disabled, but that was all the doctor saw. It was very helpful...[Now] instead of a doctor coming here, we have to go to...[the city] and wait two months for an appointment.” There were other comments about the need to travel relatively long distances to be treated by physicians, especially physicians who were specialists, as well as comments about wait lists that prevented clients/consumers from receiving care in a timely fashion.

Problems with Inter-Agency Cooperation and Collaboration

Focus group participants, especially those who were service providers, identified other problems with medical services. Some of these problems centered on a lack of interagency cooperation. A number of focus group participants, for example, talked about agencies trying to “pass the buck” (in this case quite literally since expenditures were involved) to another agency. One service provider, for example, described being

irritated, to say the least, when I call a funder and state that a consumer needs help and the person says, “Let me call the other agency.” If a consumer is needing help, there needs to be ownership of the issue.

According to a number of service providers, the lack of interagency collaboration is really problematic when there is a dual diagnosis, especially when part of the diagnosis involves mental health problems. One service provider, for example, noted, “It used to take four months, now it is taking 10 to 17 months, to access psychiatric service.” Another service provider explained that it is difficult even to get a client/consumer in the mental health services queue: “Mental health providers say the issue is due to [client/consumer] behavior and Regional Centers assert that is the issue is based on mental health. The client is left in limbo.” A third service provider got more specific:

I spent 300 hours on a case. Mental health [agencies] would not have any part of it. Trying to get other agencies in, it's almost criminal. They're saying no to dealing with [clients/consumers who have] dual diagnoses and other agencies....I was in court with seven attorneys for one kid....Agencies are not held accountable....[There is a] lack of training and collaboration when people have complex needs.

Accessing service is even more problematic when a client is violent. As one service provider said: “There are no resources to support violent clients.”

Another service provider suggested that dual diagnoses involving mental health issues become even more complicated when clients/consumers transition to adult services because adult clients with mental health issues often refuse mental health services: “Once they exit the [transition] program...clients say, ‘I’m fine. Leave me alone.’ I’m not sure if it is a civil rights issue or the taboo of mental illness.”

Comments by other service providers revealed that the problem of interagency collaboration and cooperation extended well beyond dual diagnoses that involved mental health issues. Some service providers suggested that while financial concerns about who will pay certainly contribute to a lack of collaboration, there is at least one other source of the problem: a lack of understanding of different organizations' different organizational cultures. The following quote from one service provider identified both cultural and fiscal factors as sources of interagency collaboration and cooperation problems:

Triple check on collaboration [problems] with the dually diagnosed. I see it over and over again with Mental Health, Probation, Child Welfare Services, Regional Center [people]. They don't understand each other's regulations and [this lack of understanding] interferes with getting needs met. [Also,] agencies that should be serving people are saying, "It's not our job." It's an argument of who will pay. When it happens, it's not about the individual served. [It's] a lot of finger pointing.

To summarize, there were many comments about a system that intentionally or unintentionally does not work collaboratively to respond to client/consumer needs. One service provider may have captured frustrations about the lack of interagency collaboration and cooperation best: "Stop the runaround! Stop the Swiss-cheese system!"

Staff Inadequacies

There were not only complaints about a system that appeared to be uncoordinated and composed of sub-units that did not understand the rules and regulations of other sub-units and/or that were predisposed to abrogate responsibility. There also were quite a few complaints about the people who worked in the system. Below are some staff-related complaints:

They allow individuals to smoke on facility grounds, and that is a health issue. I get it: people have to have choices. But with Special Olympics I watched caregivers smoke and I saw athletes smoke because they want to be like the staff.

Direct care staff are not qualified employees...[but they] work with folks that need someone who knows what they are doing.

The lowest level staff are always turning over, and they are the ones with the most face time with the clients.

In 25 years, one person had worked with 200 staff.

We expect staff to be going to medical appointments with clients that have extreme very complicated medical needs, and staff do not understand it and cannot report back and information gets lost.

Once again, clients/consumers offered some of the most telling comments about staff problems. One client/consumer, for example, talked about being treated like a number rather than a person. Another complained about “having to attend a program where people yell and scream,” a statement that could be perceived as an indictment of the staff members who run the program and are unable or unwilling to control the people who participate in it. Another client/consumer said, “I want the same staff all the time,” while another client/consumer made clear that this seldom happened: “My job coaches don’t understand me because they keep changing.”

Often, staff-related problems are not necessarily problems with individuals. Rather, they can be traced back to the overall system and the policies that govern that system.

System and Policy Problems

Even as certain focus group participants acknowledged that direct care staff often “are not qualified employees that work with folks that need someone who knows what they are doing,” they also noted that organizations “cannot recruit when you pay eight dollars an hour; salaries across the board are low.” Another participant noted that the “lack of pay to staff limits the number of people coming into the field. It’s all based on...money.”

Low wages also were blamed for the large amount of staff turnover, considered by many to be a major problem. “It’s hard when my staff leaves all the time,” one service provider stated. Some participants, however, suggested that the problem of staff turnover was not simply the result of low wages. A lack of training and support was also cited as a source of the employee turnover problem. One service provider who noted, “.People want to quit due to lack of training,” stating that the field “need[ed] a foundation for staff to work with.”

Other system-related comments included the generic observation that the “system is not user friendly” and a much more specific observation that there is “no statewide data base [of resource materials].” Service providers also suggested that technology problems went far beyond the absence of a statewide database: “There is a lack of new and more efficient technology within the system,” a service provider noted.

Some individuals pointed to system problems that seemed to be largely rooted in problematic attitudes and a failure to appreciate the need for a business perspective: “Supported Living Services [SLC] is not viewed as a business as much as a side project... The concept of SLC is not valued. We need to be able to balance the business aspects of the work with the work practices and principles.”

Other participants highlighted more concrete system and policy problems. One service provider, for example, highlighted the need “to have a line of credit. It is really hard [sometimes] to make payroll, to make ends meet.” A parent complained about the pay caps that state policy imposed on disabled people who have jobs: “They should be able to make more than \$1000 a month. We are forced to keep our children poor in order to be able to keep medical services. They cannot own anything.” Another participant noted, “Individuals are not willing to get married because of the fear of losing benefits,” and a client/consumer got concrete about the social-security-based incentive not to work: “Before I got my job, I was making \$8.50 from social security. [After I got a job], I went down to \$2.30.”

Parent Problems

Some of the problems that were identified related to parents' inadequacies. Most of the time, it was the parents, themselves, that raised the topic of parental inadequacies. Below are some comments from parents about this topic:

Services are not heard about or told about. Where are services that are available?

Sometimes I feel like [I need] more help in learning how to redirect inappropriate behavior. I know what I'm doing at home, but is that the same [things that] they do at program?" There is a lack of communication on the best way to manage inappropriate behaviors, and consistent communication with program [personnel] would help, so we know we are working together.

I would appreciate a better understanding of resources. I don't know and I don't know where to go.

Sometimes, staff members spoke for parents. One staff member, for example, was quite concerned about foster parents' lack of knowledge about how to access services: “Anyone who has foster children falls through the cracks” this service provider said. Other service providers suggested that the inability to understand the system and access services was not confined only

to foster parents or those who recently adopted a child with disabilities. A quite different perspective was articulated by one service provider, however: “When they [parents] become educated,” this staff member lamented, they start “begging for services. We don’t have the resources to provide the services.”

Finally, some of the most poignant parental concerns were about the future, including the time when parental caretakers would no longer be alive. One parent, for instance, spoke of “not being clear about my son’s future. Right now he is living with us. We are concerned about what services he may need in the future.” In addition, a number of focus groups explicitly took note of the fact that there was no assistance with end-of-life planning. One parent indicated that his family was “trying to do a special needs trust so...[his son] doesn’t end up homeless because of inheritance. If they are not poor, they don’t get anything.”

There was also some criticism of parents from some service provider groups. This criticism at times involved parents’ perceived over-protectiveness: “Parents and family members...are reluctant to let clients move out and be independent,” one service provider stated:

They hold close and do not allow them [clients/consumers] to thrive. I’ve seen it a few times and it is destructive to the client’s growth. And you have empathy for the family. They have grown up with that as their jobs, and they may believe that is the best thing, and yet we [service providers] see the potential, but parents can’t see the potential. Sometimes family is dependent upon the money and it’s [not just] their job but also their income and will go to great lengths to keep a client at home.

Other service providers seemed to describe the opposite problem and complained that parents and other family members had “unrealistic expectations” of how independent and integrated into the larger society a client/consumer could become.

Service providers’ comments about parents sometimes linked to the system and policy issues that were discussed above. An example is the loss of social security benefits after a consumer begins working and receiving even a modest income. As one service provider said, “Once they see that a family member will make too much money [to qualify for full social security benefits], they say they don’t want the consumer to work. But it is better to work than to [just] collect money [for doing nothing]. We need to get families to understand this.”

The Client/Consumer Idiosyncrasy Problem

In addition to comments that portrayed staff and parents as the source of problems, some participants also suggested that the clients/consumers were, at times, a reason why the system was not working as well as it should. Those who cited clients/consumers as a source of difficulties, however, were not criticizing them. They were simply taking note of the fact that people—including people with disabilities—are often quite idiosyncratic.

One parent, for example, stated, “My son is a round peg in a square hole. And he has to fit into that hole.” This parent went on to state that the son “was on the borderline between moderate and mild mental retardation. Living services don’t fit; employment doesn’t fit. There is not enough variety of jobs out there for him to choose from.”

Another parent echoed the sentiment about a client/services mismatch for those who are not the ideal typical client for whom programs and services were designed. This parent also spoke specifically about and the need for a wider variety of jobs:

We want some alternatives...[My child] needs to be busy, and he wants a job, but he is medically fragile and he has some other issues that prevent him from doing anything else, and we need alternatives. When he was in school, he worked and went to school....I don't know how the schools did it. In school, he went to a nursing home and folded laundry and a cabinet shop and swept the floors, and he loved it. We are trying to work with the Regional Center. We need some alternatives for vocational services for people who are not just high functioning.

One wonders, given the idiosyncratic nature of human beings (including human beings with disabilities), whether there will ever be a sufficient number of alternatives to accommodate all that is individual uniqueness. Could it be that the values embedded in the Lanterman Act are what philosophers refer to as *regulative ideals*, i.e., things that can never be achieved, at least not achieved completely, but that are still things we should strive for and attempt to achieve to the extent possible?

Education/Employment/Independent Living/Transportation Reconsidered

The earlier discussion of what participants believed was working revealed many positive comments about the Lanterman-related goals of mainstreamed education, employment in the community, independent living, and transportation services. There were also many negative comments about these topics when focus group participants were asked to talk about what was

not working. The comments almost never challenged Lanterman goals related to education, employment, independent living, and transportation; rather negative comments focused on implementation issues.

Education. Some parents, for example, indicated that they had limited opportunities to consult with school district officials; for these individuals, meetings to develop and approve their children's Individualized Educational Plans (IEP) were largely procedural display. Parents also described excessive paperwork and what they reviewed as an unnecessarily complex system that intentionally or unintentionally kept parents at bay.

One parent of a Down Syndrome child suggested that there actually is less social integration of children in schools when students get older: "They have him on a separate lunch hour. He needs the social interaction. It's 2013. It was actually better with the second and third graders. They were more comfortable with him."

Service providers suggested that education problems do not disappear when students leave high school because, according to them, there is a lack of education services available during the transition to a post-high school world. One service provider noted that budget-related cuts at community colleges resulted in clients/consumers being barred from taking classes more than once, a common practice in the past for clients/consumers who needed more time to master the educational content of particular courses.

Employment. At this point in time, most clients/consumers do not attend community college after high school. For them, integration into the larger society happens through employment. Much like those who identified employment as something that was working in a post-Lanterman-Act world, those who complained about employment liked the idea that adults with developmental disabilities should be integrated into the workforce. Their complaints related to limited job opportunities, as well as compensation limits and the impact of even modest compensation on benefits. Here is a sample of employment-related comments made during a number of focus group interviews:

The big companies have downsized so much....My son was with [a company] almost seven years, and somebody bought them out and cut that part of the contract first. They are there to make business, and all they want is money. My son is high functioning and has been at three [work]places this year, when before he was there [i.e., in the same workplace] forever.

-- Parent/Conservator

Lost [my] job at Round Table in 2010. Returned to Day program to get more job skills, and haven't been able to get a job since.

-- Client/Consumer

Employers are reluctant to hire employees with full wages and benefits.

-- Service Provider

There were other disincentives for clients/consumers to work for less than full pay, according to a number of participants. A loss of medical benefits was mentioned by participants, as was the reduction in social security payments when clients/consumers were employed. This reduction occurs, according to participants, even though a client/consumer, by law, is paid much less than minimum wage. Here are some of the client/consumer comments about the reduction of social security benefits that the low-wage workers experience:

Government should stop taking funds when we're on a fixed [income].

I am unable to get social security [because I am working, but] I'm barely afford my bills.

I can't work because of my SSI [i.e., social security insurance].

If I get a job in the community, they [the government] should not pick on me.

Independent Living. Like the idea of employment in the community, the idea of independent living was appealing to virtually all participants in all participant groups. But, as was the case with employment and education, the devil was in the implementation details for the participants who listed independent living as something that was *not* working. Focus group participants complained about a lack of affordable housing, the poor quality of some group homes, and poor oversight of group homes.

One parent, for example, talked about “having to go out of the county to find a placement,” and a service provider stated, “Limited funds and incomes severely limit the individual’s choices of where to live.” Another parent said, “My son was placed in a group home 12 to 13 years ago. At first, homes were a great experience. When he became an adult, homes were horrible.” Another parent told of a group home that had operated for 11 years without a license: “We were called on a Thursday and said we have to have him out the next day.”

Many of the client/consumer complaints about group homes focused on staff members. “My staff [member] doesn’t care about me,” one client/consumer stated; “she doesn’t listen to me.” Another said, “Staff doesn’t see us as people.”

Transportation. Negative comments about transportation often were related to one or more of the other topics discussed in this section of the report. One service provider, for example, noted that the “opportunity to work was lost because of no transportation.” Another noted, “Transportation does not work well because buses stop at 4:30. That impacts work socialization. It’s big!”

Clients also had a great deal to say about transportation. They complained about chronically late buses, insensitive bus drivers, not being able to talk on the bus which makes the client/consumer feels like she is not being treated as an adult, and long bus rides. Some bus rides reportedly were so long, in fact, that bathroom accidents sometime occur before clients/consumers reach their destinations.

Bureaucracy

Finally, a theme that cut across many of the discussions is bureaucracy. The idea that the bureaucracy that was established to implement the Lanterman Act is highly problematic was articulated in all of the different types of groups that were part of this study.

Many of the bureaucracy comments were focused on the Regional Centers. Although there were many positive comments about the Regional Centers and some participants noted that the services provided by the Regional Centers were improving, there were also many negative comments that suggested the Centers were highly problematic bureaucracies. Below are some parent comments:

[It’s a] bloated bureaucracy. Regional Centers are focused on pacifying the paper gods.

Families feel uninformed. There is “log jamming” when families have a real need before they’re in the system...[Service coordinators] are gatekeepers.

[They are] running parents through the ringer. They push out the purchase of service till the end.

Who is my case manager? [I am] having to stalk.

A parent that hasn't been through the system doesn't know how to start using the system. When my daughter started with getting employment, it took five months to get an interview, and she sat and stared at the wall for five months. Parents don't know how to access DOR [Department of Rehabilitation]. They call, leave a message, and...[are told] someone will get back to them. They never do...they are so overworked and have so many cases; the ratios are way out of whack!

Parents were not the only participants who specifically identified bureaucracy-related problems. Service providers, including Regional Center employees, also often suggested that the system was not working and often mentioned some of the same indicators of bureaucratic problems (e.g., excessive paperwork, high caseloads) that parents discussed. As insiders, however, they also raised additional issues. One service provider, for example, said

My concern with the Regional Center is that we have not had a cost of living adjustment (or any sort of raise) in years, and our expenses have gone up a great deal. We still provide some level of service; we would never not take care of people.

Service providers were also in a position to identify reasons other than excessive caseloads for why the bureaucracy was not working as well as it should. One service provider, for instance, noted that “multiple levels of oversight cause confusion and mixed messages,” while others suggested that, despite the fact that there were many layers of oversight, “quality control has not been there across the entire service system.” Another service provider talked about a “lack of follow-up...to check up on workers and direct service staff,” a theme that was also discussed in the parent group discussions.

Finally, there were comments about a lack of consistency and standardization in the system. Both consistency and a sensible amount of standardization normally are considered hallmarks of a well-organized bureaucracy. One service provider, however, stated, “There are 21 regional centers...21 accounting departments doing things 21 different ways—The Lanterman in 21 Acts.” Another participant claimed: “Each region is different. What is missing across regional centers is consistency of services. People can be denied at one and accepted at another. They need to do a better job of educating their employees.” Another person even suggested that “regions get different amounts of funding”; this person did not comment on the possibility that funding level differences might be justifiable.

Question #3: What Changes Are Needed?

After focus group participants were asked to discuss what was and was not working in terms of disabilities services today, they were asked to respond to one additional question: What changes are needed? Not surprisingly, most of the responses to this third question were already at least implicit in what participants had said earlier in the focus group said. To avoid redundancy with previous sections, detailed data from discussions of the third question have been reduced to a list of recommendations for action. After each recommendation listed below, there is a sample verbatim comment that was mentioned in one of the focus groups during discussions of the third interview question.

1. Convene meetings of different regional centers, agencies, and departments for the purpose of understanding the organizational cultures and responsibilities of different groups and minimizing “passing the buck.”

*Stop the turf wars....[We need] more sit downs, more roundtables.
-- Service Provider*

2. Provide training to those who are not directly involved with helping clients (e.g., bus drivers, employers, public defenders) but who often have significant contact with people with disabilities.

*There needs to be organized training between departments and agencies involved in services. That includes public defender, district attorney, first responders, so they would know what to do and don't assume [things that are inappropriate]. There are huge assumptions that occur and it's an amazing waste of resources, time and money. Interagency training [is needed] so assumptions aren't made.
-- Service Provider*

3. Develop mechanisms to share good ideas with others in the “Lanterman system.”

*I worked at different regional centers and there was a foundation created at one that enabled them to provide startup funds for businesses and sex education, real life [things]. Good ideas [like this] are not being disseminated in the state. Agencies focus on their own turf. Managers get together, but why can't there be more communication/collaboration among regional centers to get systems that work in place.
-- Service Provider*

4. Conduct commissioning a study to determine when consistency across the Regional Centers should be mandated and when local discretion is appropriate; develop mechanisms (e.g., a state-level appeal process or an ombudsperson) to enforce consistency when consistency is judged to be desirable and appropriate.

I know regional centers need to reflect the areas [in which they are located], but there are some basic things, [e.g.] job development, IT, best practices. Consistency among regional centers [is needed,] with a bottom line of best practice.

-- Service Provider

5. Lobby for the government to no longer reduce social security benefits for individuals with developmental disabilities with jobs that pay less than the minimum wage; lobby to change other penalties for working, as well.

We need] changes in social security to make up the difference in my pay check to be able to make things [i.e., ends] meet.

-- Client/Consumer

6. Develop education programs for parents (especially new parents) that provide either in-person or virtual training about how to access services and negotiate the system.

I mentor new moms and they do not even know how to start. Having a child with a disability is a blow.

-- Parent

7. Communicate changes in regional center policies and options via social media, newsletters, and/or email messages.

It would be great if someone there [i.e., at the regional center] would pass along changes. We never get told, and they could send out newsletters and they could send mass e-mails.

-- Parent

8. Create comprehensive service directories that parents and conservators can access easily themselves.

They [service providers] don't make it easy for us [to know about services]. Providers could make information about services they offer available, a directory of services.

-- Parent

9. Create public service announcements, commercials, and, if possible, multi-faceted public relations campaigns to educate both the general public and specific populations (e.g., bus drivers, secondary school students who might be inclined to bully other students with disabilities, etc.) about the strengths and contributions of persons with disabilities and the benefits of helping rather than hurting them.

We must] show [the] community that people with disabilities are producers, not consumers.

-- Parent

10. Increase staff training, especially for low-wage workers whose education and work backgrounds often are not a good match for the responsibilities they have.

Training would be a great improvement and funding to do training throughout the system [is needed].

-- Service Provider

11. Improve oversight of group homes and those in charge of them.

In some homes, staff are afraid of my son and the regional center social worker is stumped as to how to handle the situation.

-- Parent

12. Educate parents, guardians, and conservators about long-term options for taking care of the person with disabilities for whom they are responsible.

I had no idea that special needs trusts existed. [We need] education on planning the future of our child. The biggest mistake you can make is leave anything to your child.

-- Parent

13. Provide assistance and incentives (e.g., tax credits) to businesses that employ persons with disabilities.

We need to] fund community employment, help people get jobs, work with employers to help place students, and support people in getting jobs.

-- Service Provider

14. Increase services to improve the transition from the school years to adulthood.

We want our adult children to maintain skills learned when they were young.

-- Parent

15. Upgrade technology as a way to improve communication, enhance efficiency, impose consistency, and increase oversight of the system.

Use...grants to fund transition to [a] paperless system.

-- Service Provider

16. Increase funding for a variety of reasons and purposes (e.g., improving salaries and minimizing turnover, reinstating cost-of-living increases, re-establishing recreational activities for the disabled including the opportunity to participate in the Special Olympics, reducing often overwhelming case loads, etc.).

Increase funding by 40 percent!

-- Service Provider

CONCLUSION

A Glaring Omission and an Underplayed Potential Solution

At the end of reports such as this one, the authors normally generate a list of recommendations based on the findings that were reported. In this case, focus group participants did most of this work for those of us who put this report together when they addressed the what-is-needed question. There are, however, two issues that appear to have either fallen through the cracks or were underplayed as focus groups transitioned from talking about what is not working to talking about what is needed.

One issue involves complaints about the cumbersome referral system and other perceived impediments to receiving services because of insurance companies' rules and regulations. The reasons this issue did not surface during the final third of focus group discussions is a bit of a mystery, given the intensity of some of the comments during the what-is-not-working part of the discussion. Might the reason have something to do with the fact that insurance companies normally are part of the business sector rather than the government or nonprofit sector? In short, did focus group participants consciously or unconsciously conclude that cumbersome insurance-related processes and other impediments to services imposed by insurance companies were only something to complain about and not problems that can actually be solved?

A second issue that seems to have been underplayed in the translation from perceived problems to needed solution is the intriguing suggestion to establish foundations to help fund programs for those with disabilities. One participant mentioned this option in passing, but this novel idea may deserve greater attention in an era of government retrenchment when dollars are almost certainly inadequate to meet the very real needs of clients/consumers. In short, the foundation option seems to be a change that should be given greater consideration than it received in the what-changes-are-needed portion of the focus group interviews.

Final Observations

As the breadth of stakeholder comments generated by this study were reviewed and analyzed, the appreciation that virtually all of the focus group participants had for the vision embedded in the Lanterman Act became readily apparent. Also striking was the fact that most participants seemed to understand, at least intuitively, how difficult it is to implement that vision, especially in an era when funds for state and federal programs are limited and there is a growing distrust of government and an ever-increasing desire to limit government expenditures. Nonetheless, the majority of the participants wanted to make the Lanterman Act work as intended, and they provided insightful suggestions about how a 45 year-old system might be improved so that it better serves California residents with disabilities.

APPENDIX

MANUAL FOR
FACILITATORS AND RECORDERS
IN THE
CALIFORNIA DISABILITY SERVICES
ASSOCIATION'S
MODERNIZATION STUDY

This manual has been prepared by the University of San Diego's Caster Family Center for Nonprofit and Philanthropic Research in consultation with the System Modernization Committee of the California Disability Services Association.

INTRODUCTION

Thank you for agreeing to serve as either a group leader or recorder for the California Disability Services Association's (CDSA) system modernization study. This is a study of stakeholders' perceptions of what is currently working, what is not working, and what might be missing in current efforts to provide government-funded services to people with disabilities. The study, also, hopefully, will identify ideas about how to improve disability services in the future.

Because this is an initial exploration of the topic, it is appropriate to use a qualitative, focus-group research design. Consequently, the study is not designed to identify the precise percentage of professionals and service recipients who hold similar views about the current system and how to improve it. If such percentages are needed, the findings from this study can, at a later date, be used to formulate a survey instrument that can be administered to a representative sample of disability services professionals and recipients in the state. Here the goal is more modest: to surface a range of ideas from people who have expertise about the disability services system in California, either because they *provide* services within the state system or because they *receive* state-supported services.

Although this study's research design employs maximum variation rather than random sampling, the study, because of volunteers like you, will gather data from a relatively large number (and, hopefully, a diverse group) of service providers and recipients. If many of these participants say the same or similar things, it is reasonable to conclude that the identified strengths and weaknesses of the current system are not merely figments of someone's imagination. In short, wide-spread agreement about an issue should provide an impetus for action (or, at the very least, further study).

This sort of study design also pays attention to outliers and, consequently, can reveal novel thinking. An idea need not have widespread support to be useful; out-of-the-box ideas contributed by outliers can be especially useful for generating ideas about how to improve the current service-delivery system.

In short, because of the efforts of people like you, this study will be able to identify what large numbers of people say is working in the disabilities services field, what is currently problematic, and, hopefully, how the delivery of disability services can be improved in the future. The

remainder of this manual will focus on the following: (a) procedures to engage in prior to actual data collection; (b) data collection procedures; (c) what you should do after data collection.

PRE-INTERVIEW PROCEDURES

As noted above, data collection in this study will be built around focus group interviews. It is preferred that the same one or two facilitators be used throughout the process rather than a fleet. Before facilitators can actually conduct focus-group interviews, they will have to do the following things: (a) recruit someone to play the recorder role if a recorder has not already volunteered; (b) schedule a place and time for the focus group interview; (c) select participants; (d) copy and organize handouts. Please have pens or pencils on hand for recorder as well as participants, and ensure flip chart sheets and markers are available to chart the comments. Please make certain the facilitation team is identified with name tags. Each of these tasks is described briefly in this section of the manual.

Recruit Someone to Play the Recorder Role

In advance of the session, facilitators should arrange for at least one other volunteer to play the role of the recorder. The recorder is responsible for taking as close to verbatim notes as possible. The recorder can be used to engage participants. It is recommended that notes be taken on a laptop if possible, or handwritten and then typed into a Word document. If a recorder cannot be found, a facilitator could attempt to play both the recorder and facilitator roles, but playing both roles is not recommended.

If additional personnel are available, a facilitator may want to add an additional person to the team to simply watch the process and take more abbreviated notes than the close-to-verbatim notes the recorder will be taking. The observer would share what he or she observed during the post-interview analysis process that is discussed in a later section of this manual.

Schedule a Place and Time for the Interview(s)

The facilitator, ideally in consultation with the recorder, also should decide when and where the focus group interviews will take place. *A space with movable chairs should be selected so chairs can be arranged in a circle (or, possibly, around a round table) during the interview.*

If possible, make arrangements to provide light refreshments for participants.

Meetings with service recipients should be arranged close to major public transportation routes and should be accessible. The space should be large enough to accommodate participants in wheelchairs comfortably.

A related decision is how many focus group interviews will be conducted at the time and place stipulated. Generally, focus groups should have no more than eight participants and should last approximately one and a half hours. If there is only one facilitator and one recorder, the team will only be able to conduct one focus group interview at a time. Of course, a facilitator/recorder team could do a number of interviews sequentially in the same location and on the same day, but at different times. If this is the game-plan, interviews *should not* be scheduled back to back, but rather, they should be arranged *with at least an hour and fifteen minutes* in between so the team has time to complete the analysis task described below after each interview.

If multiple facilitator/recorder teams are available to conduct multiple focus group interviews at the same time and there is adequate space to accommodate multiple focus group interviews simultaneously, multiple interviews can be scheduled for the same place and time. Remember, however, the optimal number of participants for any focus group is eight, so be sure you have enough facilitators and recorders to accommodate the number of participants you schedule for any given time.

Select Participants

After interviews are scheduled, the facilitator/recorder team must invite people to participate. A flier that can be used to recruit participants can be found in Appendix A of this manual. This flier should supplement an oral request to participate and an acceptance by the person who has been asked to participate. Do not simply post the flier and hope that people will see it and show up at the focus group interviews. Do try to recruit a broad spectrum of individuals and not just those who always support your organizations. Even if people show up, you will not know how many people will come to the interviews and whether you will be able to stick to the eight-person-per-focus-group game-plan designed to make the focus group interview effective. Therefore, in addition to issuing personal invitations, make sure you devise a process to keep track of who has indicated they will participate in each session.

There are two types of participants and, consequently, two types of focus groups in this study: service providers and recipients of services. First, decide which type of focus group you will be conducting. Then, invite eight participants per focus group to be part of the study. Attempt to get as diverse a group as possible. If you are conducting a service provider focus group interview, for example, you would want to invite both experienced professionals and professionals who are new to the system. You also should consider inviting people who work in small, medium-sized, and large organizations. Of course, you also should strive for demographic diversity and a collection of people who provide different types of services. It is recommended that you start the invitation process early enough so that you can recruit a full group.

Groups made up of service recipients and their families also should be diverse. Participants should vary in terms of age, gender, ethnicity, and the types of services received.

There are additional considerations when forming a service recipient group. For example, if a participant is under 18 and/or is conserved the facilitator will need to get a signed waiver for the individual to participant to be a part of the focus group from their parent/Conservator (Please see appendix B).

Remember, the design of this study stipulates that maximum variation sampling is to be used to identify participants. Consequently, whether you are setting up focus groups of service providers or service recipients, strive to gather as diverse a group of participants as possible. Because maximum variation sampling is driving premise, individual interviews can be substituted to obtain perspectives from individuals whose needs do not allow group participation.

Copy and Organize Handouts

The final thing to do in advance of conducting the actual focus group interview is to be sure you have made copies of the data collection and analysis documents found in the appendices of this manual (See Appendices B, C, and D). Immediately before the interview, be sure they are organized in such a way that you will have easy access to the documents at appropriate times during the focus group interviews.

Summary

This section has reviewed the procedures that should be followed to prepare for the focus group interviews. These procedures are summarized in Figure 1.

TABLE 1: Summary of Pre-interview Procedures

1. Arrange for someone to serve as a recorder. If personnel are available, you may also want to add an additional person to your team to play the role of observer, though doing this is not required and may not be feasible in all cases.
2. Schedule a place (with moveable chair that can be arranged in a circle) and time for the interview(s).
3. Decide whether the interview will be with service providers or service recipients.
4. Recruit a diverse group of participants.
5. Copy and organize the documents to be used during the focus group interview.
6. Immediately before the focus group interview, arrange ten chairs (for the eight participants and the recorder and facilitator) in a circle.

Interview Procedures

Recorder's Role

As the name of the role being played suggests, the recorder's role during focus group interviews with both service providers and service recipients is to write down—in as much detail as possible—what happens and, especially, what was said during the interview. The recorder should strive to record potentially significant quotes as accurately as possible and put quoted material in quote marks to differentiate verbatim material from the recorder's descriptions of what happened and what was said. Generally, recorders should describe rather than interpret, but if a recorder feels he or she needs to include an interpretation of what is happening in the notes he or she is

taking, recorder interpretations should be put in parentheses to differentiate interpretation from descriptive material.

Facilitator's Tasks

The procedures to be followed by those playing the facilitator role can best be communicated by providing a script of what facilitators should say and do. Know, however, that the script below is not meant to be read to focus group participants or even memorized and repeated precisely as written. Facilitators have discretion to tailor scripts to their style and to a group's needs.

Here is a script that can be used to guide what happens in focus groups of service providers:

Facilitator: Thank you all for agreeing to participate in this focus group interview about the state of disability services in California. As a service provider you have expertise about what is working well, what is problematic, and what could be done to improve the service to our clients.

We have asked you to participate today in a study in cooperation with the University of San Diego. The purpose of this study is simply to know what is working, what is not working, and what is missing within the current system. The University of San Diego will be the recipient of today's outcomes. These outcomes form the basis for a report outlining our System Modification proposal.

Before we begin our work, I would like you to review the contents of the form I am passing out. *(Facilitator passes out consent forms copied from Appendix B.)* Please read the form and, assuming you agree with what is stated in it, sign two copies, keep one copy for your records, and return a signed copy to me. *(Facilitator allows time for participants to read, ask questions about, and sign the form. Facilitator collects one copy of each signed form. These should be returned with the other materials that are generated during the interview and post-interview analysis process.)*

Now, we can begin our work. I am passing out another form that includes the three questions we will be talking about today. *(Facilitator passes out Participant Preliminary Note-taking Forms that were copied from Appendix C.)* Before we talk about Question # 1, take a few minutes to think about the question and jot down the ideas you might want to share during our group discussion of Question #1. You should also write anything that is important but do not want to share during the discussion. I will be collecting (but not reading) these forms at

the end of the interview and sending them to the people who are writing up the results of this and other meetings being held throughout the state. So, even if you do not mention an idea during our discussion, if you write it on the form, the people who are writing about what people throughout the state are thinking will see it. So use your best penmanship and express your thoughts as completely as possible in the five minutes I will give you to complete this task. (*Facilitator provides approximately five minutes for participants to record their thoughts about Question # 1).*

Now it is time to share with the group one idea you wrote down. We will go around the circle and let each person share, in no more than a minute or two, the point they want to make. We will not interrupt the person speaking. Then we will go around the circle again for another round of uninterrupted comments which might focus on what someone else has said during the first round of comments or on a new idea that you had written down but did not share during your first time to speak. After going around the circle twice, I will open things up for a less structured discussion. Throughout the sharing process, however, be concise so others will have time to speak. Also, be sure you listen to what others say. And always be respectful of others, even if you strongly disagree with them. So, the first question is about what is currently working well.

(The facilitator repeats the process for the second and, then, the third question. The facilitator, in other words, first, asks people to jot down notes for the second and then the third question, and after each jotting period, gives participants time to share their ideas, first in a relatively structured format and then in a less structured way. Each of the three segments should last approximately 15 minutes. In addition to following the procedures outlined in this script, the facilitator should also follow the general guidelines for facilitation summarized in Table 2.)

TABLE 2: General Guidelines for Facilitators

1. Be upbeat and positive.
2. Signal that everyone's perspective should be respected, even if one disagrees with it. When disagreements are voiced during the unstructured parts of the discussion, comments should be diplomatic and respectful.
3. Do not let anyone monopolize the response and sharing time. It is appropriate to gently interrupt people during the structured part of the interview if their comments go over the two-minute time frame. Also remind participants during the unstructured parts of the interview that there is limited time and there is a need to let everyone speak. If need be, institute a rule that nobody speaks a second time until everyone wants to speak has had an opportunity to be heard.
4. Given the difficult budget situation the state has been in for the past several years, there may be a tendency, especially when answering the second question focused on problems with delivering services, for people to persevere on funding issues. If this happens, let people talk about money—or the lack of it—but then indicate that the recorder has made note of the fiscal concerns and ask people to address problems that are not necessarily—or at least not completely—related to money problems.
5. Adjust your language and interview procedures to communicate effectively with the members of the particular focus group you are interviewing.

You have provided important insights about each of the three questions you have been asked to discuss. To conclude our time together, I would like everyone to state, in one breath, the most important idea they heard today. I'll ask for a volunteer to start us off and then we will go around the circle clockwise, starting with the person who is to the left of the first speaker.

(Participants provide their one breath response to the most-important-idea task.)

Thank you, again, for participating. Our job is to summarize your ideas and send the summaries, along with the notes you made and the recorders' notes to the University of San Diego where professional researchers will analyze and report the your ideas along with ideas generated in many other focus groups around the state.

Facilitator Procedures for Service Recipient Interviews

The script for focus group interviews with service recipients is similar to the script presented above. Depending on the service recipients being interviewed, however, the language and possibly even some of the processes described in the script, may need to be modified. For example, with some service recipient groups, you may need to read and explain the consent from to service recipients and have a conservator sign the form. You might also need to have prompts prepared to help clarify the meaning of questions and the kind of answers that would be appropriate. Again it should be noted that there is no expectation that the script presented above should be presented verbatim to groups, even groups of service providers. Facilitators should always tailor what they say to their own style of interacting and, especially, to the needs and special characteristics of particular focus group members.

Post-interview Procedures

After the focus group interview ends, the facilitator's and recorder's work is not over. The facilitator and recorder (and, also, the observer, if a third person is added to the team to play the observer role) need to sit down and complete the Interview Analysis Form found in Appendix D of this document. Whenever possible, this form should be completed on a laptop or computer. If that is not possible on-site, then the facilitator or recorder may elect to transcribe it to an electronic format at a later time. This form asks you to list the three to five most frequent responses to each of the three major questions discussed during the interview. Whenever possible, use the recorder's notes to add a quote that represents what most people were saying and also indicate the number of people who appeared to endorse the idea.

You also are asked to summarize any interesting novel thinking that surfaced during the interview that may not have had widespread support. Outlier thinking can be especially useful in figuring out what to do to improve services in the future, but include outlier responses to any of the three questions that are potentially useful. Quotes from the recorder's notes also should be included in this part of the form whenever possible.

When you are finished filling out the form, the facilitator or his or her designee should put the form in the data-return envelope that has been provided, along with the participants' and the recorder's notes. (See Appendix E for a list of materials to be put in the envelope.) The envelope should then be sent to the address that is on the return envelope.

APPENDIX A

MEETING INFORMATION FLIER

Appendix A includes a flier that can be used when inviting people to participate in focus group interviews. If desired, a notation indicating the purpose of the focus group interviews can be added to the bottom of the flier. Make sure you extend a personal invitation to people to participate and determine whether they have committed to show up at the focus group interview. Do not simply post the attached flier and hope people will see it and show up. The attached flier, in other words, should be used as a supplement to a verbal invitation.

The Developmental Disabilities System in California



What's Working?

What's Not?

What's Missing?

Be a part of a **Community Conversation** about how to modernize the California Developmental Disabilities System. Our system is nearly 50 years old, and like most 50 year olds may need a bit of attention where it is sagging, creaking or looking a bit tired.

When:

Where:

For more information or to RVSP please call:

Hosted by developmental services providers and the California Disability Services Network (CDSA)

APPENDIX B

CONSENT FORM

This appendix contains the consent form to satisfy requirements of the Institutional Review Board. Two copies should be distributed to each focus group participant and the participant should read and sign the two copies at the start of a focus group interview. When clients are being interviewed, they may need to be accompanied by a conservator. If this is the case, the conservator also signs on the appropriate line. The facilitator should collect the consent forms and include them in the already-addressed envelope of materials being returned to the Caster Family Center for Nonprofit and Philanthropic Research at the University of San Diego.

**University of San Diego
Institutional Review Board**

Research Participant Consent Form

For the research study entitled:
California Disability Services Association's System Modernization Study

I. Purpose of the research study

The California Disability Services Association is conducting a System Modernization Study. Professor Robert Donmoyer, Ph.D. and Director Laura Deitrick, Ph.D. at the Caster Family Center for Nonprofit and Philanthropic Research at the University of San Diego have been engaged to help design the study and analyze and report the results. You are invited to participate in a study. The purpose of this study is: to understand stakeholders' perceptions of what is currently working and what is problematic with current efforts to provide government-funded services to persons with developmental disabilities.

II. What you will be asked to do

If you decide to be in this study, you will be asked to:

- Participate in a focus group discussion about your perceptions, feelings, and thoughts about, or your experiences with, the current efforts to provide government-funded services to persons with disabilities.
- As a part of the focus group, write your answers to three questions regarding your perceptions.

You may be audiotaped/videotaped during the interview.

Your participation in this study will take a total of 90 minutes.

III. Foreseeable risks or discomforts

Sometimes when people are asked to think about their feelings, they feel sad or anxious. If you would like to talk to someone about your feelings at any time, you can call toll-free, 24 hours a day:

San Diego Mental Health Hotline at 1-800-479-3339

OR _____ (Facilitator to provide local hotline number)

IV. Benefits

While there may be no direct benefit to you from participating in this study, the indirect benefit of participating will be knowing that you helped the public better understand stakeholders' perceptions of what is currently working and what is problematic with current efforts to provide government-funded services to persons with disabilities.

V. Confidentiality

All information provided to the Caster Center and/or identifying records will remain confidential and kept in a locked file and/or password-protected computer file in the researcher's office for a minimum of five years. All data collected from you will be coded with a number or pseudonym (fake name). Your real name will not be used. The results of this research project may be made public and information quoted in professional journals and meetings, but information from this study will only be reported as a group, and not individually. Quotes from focus group participants may be used but the person who said it will not be identified.

VI. Compensation

You will receive no compensation for your participation in the study.

VII. Voluntary Nature of this Research

Participation in this study is entirely voluntary. You do not have to do this, and you can refuse to answer any question or quit at any time. Deciding not to participate or not answering any of the questions will have no effect on any benefits you're entitled to, like your health care, or your employment or grades. You can withdraw from this study at any time without penalty.

VIII. Contact Information

If you have any questions about this research, you may contact either:

1) Nancy Batterman

Email: nbatman@communityoptions.org

Phone: 858-565-9870 x104

2) Robert Donmoyer, Ph.D.

Email: donmoyer@sandiego.edu

Phone: 619-260-7445

3) Laura Deitrick, Ph.D.

Email: LauraDeitrick@sandiego.edu

Phone: 619-260-2903

I have read and understand this form, and consent to the research it describes to me. I have received a copy of this consent form for my records.

Signature of Participant Date

Name of Participant (**Printed**)

Signature of Conservator (**when appropriate**) Date

Name of Conservator (**Printed**)(**when appropriate**)

Signature of Investigator Date

APPENDIX C

PARTICIPANT NOTE TAKING FORM

This appendix contains the form that is to be handed out to each focus group participant near the start of each focus group interview. (See the sample script for the appropriate time.) Participants will fill in the different parts of the form at different times in the interview. The facilitator should collect the forms at the end of the interview, use the information on them as input during the interview summary/analysis process that follows the interview, and return the forms in the already-addressed envelope that has been provided.

Participant Note Taking Form

Date: _____ Focus Group Leader: _____

Location: _____

Are you: ___ male ___ female How old are you? _____

How do you identify:

___ American Indian or Alaska Native ___ Asian
 ___ Black or African American ___ Native Hawaiian or other Pacific Islander
 ___ White (non-Hispanic) ___ Hispanic or Latino
 ___ Other

Are you:

___ Service Provider(Including Regional Center Staff)
 ___ Client (service recipient)
 ___ Parent
 ___ Conservator
 ___ Other (Describe: _____)

For how many years have you been providing or receiving services? _____

Instructions: Today we will be discussing three questions about delivery of services to people with disabilities. Before you discuss each question, list your ideas on this form. This process will allow you to collect your thoughts before each part of the discussion begins. Also, if there is anything you are uncomfortable saying during the discussion, you can write it here. The discussion leader will collect, *but not look at*, what you have written at the end of the meeting and send your notes to the people who will be writing up the results of this and other meetings.

Question #1: What is currently working well?

1.

2.

3.

Comments:

Question # 2: What is currently not working well?

1.

2.

3.

Comments:

Question # 3: How could things be changed in the future to improve the delivery of services?

1.

2.

3.

Comments:

APPENDIX D

INTERVIEW ANALYSIS FORM

Immediately after a focus group interview has been completed, the facilitator and recorder (and also the person playing the observer role if an observer was included on the team) should review the notes of the meeting and complete the form that is on the next pages.

Interview Analysis Form

To be Filled Out by Facilitator and Recorder Immediately after Each Focus Group Interview

Date of Focus Group: _____

Location: _____ **Caucus:** _____

Number of focus group participants: _____

Type of focus group participants:

____ Service Providers

____ Clients (including service recipients and, when appropriate, parents and/or conservators)

____ Parents

____ Conservators

____ Combination (Name types of participants): _____

____ Other (Name type of participants): _____

Focus Group Facilitator: _____ **Facilitator's Organization** _____

Facilitator's email/phone number _____ / _____

Focus Group Recorder: _____ **Recorder's Organization** _____

Recorder's email/phone number _____ / _____

Instructions: After completing a focus group, the facilitator and recorder (and also the person playing the observer role if such a person was part of the process) should review the recorder's notes and, for each of the three questions asked, list up to five responses that received the most support during the interview. After each item, please estimate the approximate number of focus group participants who agreed with the item (e.g., 5 of 8). Also, for each item listed include a direct (or, if necessary, a reconstructed) quotation that captures the essence of the item. The final part of this document also asks you to list any novel responses that did not receive widespread support but may, never-the-less, be potentially important. (Novel items may be especially important in figuring out ways to improve the system.) Whenever possible, please type your responses rather than write them out by hand.

After you have completed this and the following pages, please return the document, along with the recorder's notes and the note-taking forms completed by participants

to: _____

Question #1: What is currently working well?

1. _____

Approximate number of participants who agreed: ____ of ____

Sample quotation:

2. _____

Approximate number of participants who agreed: ____ of ____

Sample quotation:

3. _____

Approximate number of participants who agreed: ____ of ____

Sample quotation:

4. _____

Approximate number of participants who agreed: ____ of ____

Sample quotation:

5. _____

Approximate number of participants who agreed: ____ of ____

Sample quotation:

Question # 2: What is currently not working well?

1. _____

Approximate number of participants who agreed: ____ of ____

Sample quotation:

2. _____

Approximate number of participants who agreed: ____ of ____

Sample quotation:

3. _____

Approximate number of participants who agreed: ____ of ____

Sample quotation:

4. _____

Approximate number of participants who agreed: ____ of ____

Sample quotation:

5. _____

Approximate number of participants who agreed: ____ of ____

Sample quotation:

Question # 3: How could things be changed in the future to improve the delivery of services?

1. _____

Approximate number of participants who agreed: ____ of ____

Sample quotation:

2. _____

Approximate number of participants who agreed: ____ of ____

Sample quotation:

3. _____

Approximate number of participants who agreed: ____ of ____

Sample quotation:

Please use the space below to record any additional novel responses that did not get widespread support. Include quotations whenever possible.

APPENDIX E

CHECKLIST OF MATERIALS THAT MUST BE RETURNED TO

UNIVERSITY OF SAN DIEGO'S CASTER CENTER

Checklist of Materials to be Returned in the Envelope That was Supplied In This Packet

- € All Signed Participant Consent Forms
- € All Participant Note Taking Forms
- € Interview Analysis Form (Completed by Facilitator, Recorder, and, When Appropriate, Observer)

Checklist of Materials to be Returned Electronically be emailing to:

- € Interview Analysis Forms that have been typed into a Word document. (Completed by Facilitator, Recorder, and, When Appropriate, Observer)