

APPENDIX

Methodology

Survey Background and Design

XenologiX was asked to conduct the *2001 Early Start Program: Family Satisfaction Survey* based on consumers who were currently receiving Early Start program services from the Department of Developmental Services. The parameters given to XenologiX for the satisfaction survey were:

- 1) Sample to consist of DDS Early Start population with status codes 1 (prevention), 2 (active client), and 3 (genetics).
- 2) DDS requested a sample size sufficient to provide results at the 95 percent confidence level. Subject to the DDS requirements, XenologiX proposed an initial sample size of 7,234 children to reach the target of 1,585 completed interviews: an expected response rate of 22.0 percent.

In developing the questionnaire, one area of interest was transition services. To include transition services, the redefined population included children over age three who had recently transitioned out of the Early Start program. The new population numbered 31,585 and included all children age 39 months or less as of September 1, 2001 and children who were status 1, 2, or 3 during one or more of the preceding 12 months. Consistent with this change in methodology, the initial sample size increased to 9,802 and the target number of complete interviews increased to 1,706.

Interview Instrument Development

Initial design, development, review and revisions took place in July 2001. Questionnaire content was guided by State and Federal requirements. All reviews and inputs were provided by DDS program management, research staff, Family Resource Center Network, and two subcommittees of the Interagency Coordinating Council: 1) the Quality Assurance Subcommittee; and 2) the Family Services Support Subcommittee. The questionnaire received final approval during November 2001.

Methodology Sampling

The Department of Developmental Services drew the sample based on demographic considerations. The sample required 10.0 percent of those age 36 months and 24.0 percent of each age group from birth through 24 months of age.¹ Based on the sampling criterion, there were three regional centers that had sample sizes below 100. The samples for those three centers were augmented proportionately by age to bring them above 100.

Sample data for two regional centers had no telephone numbers recorded for more than five percent of their sample. The sample for those two regional centers was augmented to meet a five percent sampling minimum.²

The samples were then combined and compared to the total Early Start population distribution. Based on this analysis, two subpopulations were not captured: Native Americans and children whose case status was “D” (Closed-Eligibility Not Determined). The samples were augmented so the sample included the total population for these two subpopulations.

As some questionnaire items specifically asked respondents to recall details of the IFSP meeting, XenologiX recommended excluding families who had an IFSP meeting more than four to six months prior to the survey using their assumption that the IFSP meeting occurred close to the child’s birth date. In addition, a large number of telephone numbers provided were not in service. Preliminary analysis of the initial sample data by XenologiX indicated that augmenting sample size by 30 percent should permit reaching target response levels for most centers. Later, additional sample augmentation was included for three regional centers based on actual experience. The final augmented sample size was 9,802, which XenologiX used as follows:

Initial sample	9,802
Unusable telephone numbers	1,161
Unused sample	3,349
Used sample	5,292

Although conventional calculations of response rate equals 17 percent, based on the used sample of 5,292, and a total of 1,706 survey participants, the final response rate for this effort was 32.2 percent.

¹ Age as of September 1, 2000, rounded to the last whole year.

² For example, if numbers were missing for seven percent, the sample size increased by 12 percent.

Methodology

Data Collection

On November 2, 2001, DDS mailed pre-notification letters to the Executive Directors and Early Start Program Managers at each regional center. The letters provided information about the *2001 Early Start Program: Family Satisfaction Survey*.

Data collection commenced on November 5, 2001. Interviews were conducted via telephone (and not via postal mail, in-person interviews or the internet) based on the following factors:

- 1) *No literacy requirement*, which could prohibit some individuals who cannot read or write from participating in mail or web-based efforts;
- 2) Flexibility to conduct the interviews in the respondent's preferred language (in mail and internet efforts, survey language is often limited and translations are not always reliable);
- 3) *Speed of data collection* - telephone interviews can be conducted at a faster pace over fewer days;
- 4) *Cost* - telephone interviewing tends to be less expensive than face-to-face or mail modes of data collection;
- 5) *Understandability* – telephone interviews offer the respondent the opportunity to ask questions if they do not understand an item or abbreviation;
- 6) *Reliability* – because a telephone interview may enhance understandability, reliability also may be enhanced; and
- 7) *Response Rate* – the response rates may be better than mail surveys when all sample members are appropriately contacted.

A total of 1,706 telephone interviews were conducted between November 5th and 28th and December 21st and 22nd, 2001. The average telephone interview lasted 15 minutes, 27 seconds.

A total of six attempts were made to contact each family or primary care provider. Interviews were conducted in the respondent's language of choice for each survey participant and were scheduled at a convenient time for the individual responding on behalf of the child.

Interviews were conducted by professional interviewing staff who had received at least two weeks of specialized training. All interviewers were monitored for quality assurance and respondent confidentiality was maintained.

Methodology

Survey Notes

Although the initial analysis plan called for a random sample with a 95 percent confidence level, several factors resulted in the sample not meeting the planned sample criteria. Over sampling was necessary to achieve adequate representation of ethnicities and ages.

As with any survey methodology, the families with the lowest socio-economic status may be under-represented. This phenomenon may be attributed in part to the difficulty of contacting families who may not have telephones, registered addresses, or who move frequently. Suggestions for addressing this issue would include conducting special studies, planning for secondary methods of contact (e.g., non-telephone methods), and using tracking strategies common to follow-up studies to locate persons no longer reachable at telephone or address on file.

Data Demographics

The following tables illustrate the degree to which the respondent survey data represents California's Early Start (ES) population:

For each regional center: the participant data represented between 4.45 and 5.10 percent of their total ES population;

By residential type: the participant data was representative within less than one percent (0.84 percent);

Within ethnicity: the participant data was representative within seven percent, with each ethnicity representing at least one percent of the ES population included;

For primary language: the participant data was representative within 4.33 percent, with all primary languages representing at least one percent of the ES population included;

By consumer status: the participant data distribution was within 18 percent, with all status codes representing at least one percent of the ES population included; and

For gender: the participant data was within two percent of the ES population.

Data Demographics

Regional Center	Population		Survey Participants	
	Count	Percent	Count	Percent
Lanterman	860	2.7%	79	4.6%
Golden Gate	1,027	3.3%	79	4.6%
San Diego	2,804	8.9%	83	4.9%
Far Northern	536	1.7%	76	4.5%
Alta	1,689	5.3%	82	4.8%
San Andreas	1,773	5.6%	82	4.8%
Tri-Counties	1,734	5.5%	82	4.8%
Central Valley	1,586	5.0%	80	4.7%
Orange	2,713	8.6%	86	5.0%
Inland	2,540	8.0%	85	5.0%
Redwood Coast	329	1.0%	75	4.4%
North Bay	1,024	3.2%	79	4.6%
Kern	684	2.2%	79	4.6%
East Los Angeles	1,117	3.5%	79	4.6%
South Central LA	1,373	4.3%	83	4.9%
Harbor	1,892	6.0%	82	4.8%
Westside	1,292	4.1%	83	4.9%
Valley Mountain	1,465	4.6%	81	4.7%
North Los Angeles	2,061	6.5%	84	4.9%
San Gabriel/Pomona	1,225	3.9%	80	4.7%
East Bay	1,861	5.9%	87	5.1%
TOTAL	31,585	100%	1,706	100%

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Data Demographics

Type of Residence	Population		Survey Participants	
	Count	Percent	Count	Percent
Out of State	20	0.1%	0	0.0%
Parent	28,747	91.0%	1567	91.9%
Own Home	1	0.0%	0	0.0%
Correctional Institution (Prison)	1	0.0%	1	0.1%
CCF (RCFE)	4	0.0%	1	0.1%
CCF (1-3 Beds)	11	0.0%	0	0.0%
CCF(4-6 Beds)	43	0.1%	2	0.1%
CCF	3	0.0%	0	0.0%
CCF	1	0.0%	0	0.0%
CCF Special Health Care Needs/Childre	5	0.0%	0	0.0%
Health Facility	1	0.0%	0	0.0%
Health Facility	5	0.0%	0	0.0%
ICF-DD/N (4-6 Beds)	31	0.1%	0	0.0%
ICF-DD/N (7-15 Beds)	5	0.0%	0	0.0%
Health Facility	1	0.0%	0	0.0%
ICF-DD H (7-15 Beds)	1	0.0%	0	0.0%
SNF/NF Nursing	11	0.0%	0	0.0%
CCF (obsolete)	12	0.0%	1	0.1%
Child Foster	1,932	6.1%	97	5.7%
Adult Foster	1	0.0%	0	0.0%
Child Foster-Certified	288	0.9%	23	1.3%
Health Facility	4	0.0%	0	0.0%
Acute Hospital	42	0.1%	1	0.1%
Other	1	0.0%	0	0.0%
Sub-Acute Pediatric	16	0.1%	0	0.0%
Community Treatment Facility	3	0.0%	0	0.0%
Transient/Homeless	2	0.0%	0	0.0%
Other	393	1.2%	13	0.8%
TOTAL	31,585	100.0%	1,706	100.0%

Data Demographics

Primary Ethnicity	Population		Survey Participants	
	Count	Percent	Count	Percent
Asian	1	0.0%	0	0.0%
African American	2,176	6.9%	96	5.6%
Filipino	310	1.0%	18	1.1%
Native American	69	0.2%	18	1.1%
Spanish/Latin/Hispanic	10,457	33.1%	520	30.5%
White	7,386	23.4%	522	30.6%
Other Asian	523	1.7%	9	0.5%
Cambodian	35	0.1%	0	0.0%
Chinese	175	0.6%	7	0.4%
Guamanian	2	0.0%	0	0.0%
Native Hawaiian	4	0.0%	0	0.0%
Asian Indian	66	0.2%	0	0.0%
Japanese	28	0.1%	0	0.0%
Korean	46	0.1%	0	0.0%
Laotian	8	0.0%	2	0.1%
Hmong	28	0.1%	4	0.2%
Other Pacific Islander Group	30	0.1%	1	0.1%
Samoan	20	0.1%	0	0.0%
Thai	1	0.0%	0	0.0%
Vietnamese	103	0.3%	4	0.2%
Other/Mixed	1,839	5.8%	97	5.7%
Unknown	8,278	26.2%	408	23.9%
TOTAL	31,585	100.0%	1,706	100.0%

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Data Demographics

Primary Language	Population		Survey Participants	
	Count	Percent	Count	Percent
ASL (American Sign Language)	9	0.0%	0	0.0%
Other Sign Language	2	0.0%	0	0.0%
English	23,896	75.7%	1366	80.1%
Armenian	10	0.0%	0	0.0%
Somali	1	0.0%	0	0.0%
Amharic	2	0.0%	0	0.0%
French	3	0.0%	0	0.0%
Portuguese	3	0.0%	0	0.0%
Spanish	6,760	21.4%	339	19.9%
Other Latin	1	0.0%	0	0.0%
Cantonese Chinese	102	0.3%	0	0.0%
Mandarin Chinese	46	0.1%	0	0.0%
Japanese	17	0.1%	0	0.0%
Vietnamese	148	0.5%	0	0.0%
Korean	28	0.1%	0	0.0%
Laotian	9	0.0%	0	0.0%
Cambodian	30	0.1%	0	0.0%
Other Asian	26	0.1%	0	0.0%
German	1	0.0%	0	0.0%
Miao (Hmong)	33	0.1%	0	0.0%
Thai	1	0.0%	0	0.0%
Mien	3	0.0%	0	0.0%
Other Germanic	1	0.0%	0	0.0%
Hungarian	1	0.0%	0	0.0%
Russian	36	0.1%	0	0.0%
Other Uralic-Slavic Languages	4	0.0%	0	0.0%
Samoan	2	0.0%	0	0.0%
Tagalog	42	0.1%	1	0.1%
Other Pacific Island	4	0.0%	0	0.0%
Arabic	23	0.1%	0	0.0%
Hebrew	5	0.0%	0	0.0%
Farsi	14	0.0%	0	0.0%
Hindi (Northern India)	26	0.1%	0	0.0%
Urdu (Pakistan India)	8	0.0%	0	0.0%
Other Indo-Iranian Language	13	0.0%	0	0.0%
Danish	1	0.0%	0	0.0%
Other Scandinavian	1	0.0%	0	0.0%
All Other Languages	253	0.8%	0	0.0%
Unknown	20	0.1%	0	0.0%
TOTAL	31,585	100%	1,706	100%

Data Demographics

Client Status	Population		Survey Participants	
	Count	Percent	Count	Percent
Intake and Assessment	75	0.2%	1	0.1%
Prevention (High Risk Infant)	18,093	57.3%	1283	75.2%
Active Client	5,321	16.8%	264	15.5%
Genetics (at Risk Person)	13	0.0%	1	0.1%
Inactive	1,481	4.7%	29	1.7%
Closed Transfer	95	0.3%	5	0.3%
Closed Not DD	4,262	13.5%	70	4.1%
Closed Deceased	209	0.7%	0	0.0%
Closed Not Determined	616	2.0%	33	1.9%
Closed Out of State	194	0.6%	1	0.1%
Closed Other	1,207	3.8%	19	1.1%
Other	19	0.1%	0	0.0%
TOTAL	31,585	100%	1,706	100%

Gender	Population		Survey Participants	
	Count	Percent	Count	Percent
Male	19,096	60.5%	1065	62.4%
Female	12,489	39.5%	641	37.6%
TOTAL	31,585	100%	1,706	100%



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Questionnaire

Department of Developmental Services 2001-02 Early Start Family Satisfaction Survey

“Hello, my name is _____. I am calling on behalf of the Department of Developmental Services and _____ Regional Center. Am I speaking to? **ASK FOR ONE OF THE NAMES ON THE LIST. USUALLY THIS WILL BE A PARENT – EITHER PARENT, OR IN SOME CASES A GUARDIAN ARE ALL QUALIFIED RESPONDENTS. WE ARE LOOKING FOR THE PARENT OR MAIN CARE PROVIDER. IF THIS INDIVIDUAL IS NOT AVAILABLE, ARRANGE FOR CALLBACK. IF THE PERSON YOU SPEAK TO ON THE PHONE ASKS YOU TO SPEAK TO ANOTHER REPRESENTATIVE, YOU ARE ALLOWED TO DO SO, BUT PLEASE MAKE NOTE OF WHO THE RESPONDENT IS – RELATIONSHIP TO THE CHILD.** As part of an annual audit, the Department and _____ **Regional Center** is gathering information from families about the services the regional centers provide to the community. This information will help the Department and _____ **Regional Center** better understand how well families are being served. In order to help improve their services, they need to know what you think about their performance. This effort is very important to the Department and the regional center. We are not trying to sell you anything and we will not ask you for any personal information. We just want to know what you think of _____ **regional center’s** services.”

“This survey should be fun and interesting and will only take about ten minutes” (If “No” – “**Would you like me to call back later?**” – **Find out when a good time is and call back.**) There are no right or wrong answers, please feel free to answer all the questions according to how you feel. You won’t get into any trouble for your answers. Your answers will be kept confidential. As we go through the survey, if you do not understand something I say, please let me know and I will try to say it in a different way.

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First, I would like to ask you a couple of general questions. There are no right or wrong answers; please feel free to answer all questions according to how you feel. Your answers will be compiled with that of other families and then given to the Department and the regional center in a report. No names will appear anywhere in this report.

A. Just to verify, can you please tell me what your relationship is to (child's name)?

- Mother (includes step-mother)
- Father (includes step-father)
- Foster Parent
- Residential Care Provider
- Sibling
- Grandparent
- Other Family (Aunt/Uncle, etc.)
- Other _____

B. Can you please tell me how old (child's name) is, in years and months?

Years Months

Early Start Services

The next set of questions asks you about the early start services you and your family may be receiving. Again, there are no right or wrong answers and no one will get in trouble as a result of this survey.

1. What early start services are you and your family currently receiving? (multiple responses allowed)

- | | |
|---|--|
| <input type="checkbox"/> Physical Therapy | <input type="checkbox"/> Occupational Therapy |
| <input type="checkbox"/> Parent Education/Family Support/Counseling | <input type="checkbox"/> Speech and Language Services |
| <input type="checkbox"/> Developmental/Psychological Assessment | <input type="checkbox"/> Family Training and Education |
| <input type="checkbox"/> Transportation | <input type="checkbox"/> Behavior Intervention |
| <input type="checkbox"/> Respite | <input type="checkbox"/> Other _____ |

2. Who provides these services? (Note to Interviewers: This refers to the organization that performs the service, not necessarily who funds the service.) (multiple responses allowed)

- The Regional Center
- Family Resource Center
- A private or non-profit Early Start/Intervention Provider (CCS, private physical therapist, etc.)
- Local Education Agencies (SELPA/LEA Infant Program, etc.)
- Physician/Medical Staff/Pediatrician/Family Doctor, etc.
- Other _____
- Don't Know

3. Who had the most say in choosing these services?

- "My family did" (I did, my family did, my spouse and I, etc.)
- The IFSP or Planning Team (Decided at the IFSP or Planning Meeting)
- The Regional Center/Service Coordinator
- Service Provider/Program "told us what we needed"
- Physician/Medical Staff/Pediatrician/Family Doctor, etc.
- Other _____
- Don't Know
- "We didn't have a choice", "They just told us what we would receive"*

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4. Did your family receive all of the Early Start services that were specified in your IFSP?
 (If Necessary: The Individualized Family Service Plan - IFSP - and the planning team meeting is organized by the regional center and focuses on the abilities and needs of your child and your family, as well as what services may be appropriate for your child. The IFSP meeting is held every year, with a review of the plan occurring every six months. *(If necessary: Your regional center service coordinator should have coordinated this meeting with you to discuss your child's and family's progress, wants and needs, as well as how well services are meeting your family's needs.)*
 Yes, we received all of the services stated in the IFSP
 No, we have not received any of the services specified in the IFSP
 No, we only received about one-quarter of the services stated in the IFSP
 No, we only received about half of the services stated in the IFSP
 No, but we received most of the services
 Don't Know/Remember
5. Using a 1 to 10 scale, where 1 is Unacceptable, 10 is Outstanding, and 5 is Average, how would you rate the amount of service (number of service hours) you and your family receive?
6. Using a 1 to 10 scale, where 1 is Unacceptable, 10 is Outstanding, and 5 is Average, how satisfied are you with the quality of the services you and your family receive?
7. Did the services outlined in your family's IFSP start on time or when you were told they would (as specified in the IFSP)?
 Yes, all of the services started on time (skip to q10)
 No, but most services started on time
 No, very few services started on time
 No, none of the services started on time
 Don't Know/Remember (skip to Q10)
- If they did not start on-time continue to Q8.
8. (If they didn't start on time) What services were delayed? (open-end)
9. Approximately how much of a delay was there in the start of services?
 Less than one week
 Between 1-2 weeks
 2-4 weeks
 More than one month, but less than two months
 More than two month, but less than three months
 More than three month, but less than four months
 More than four month, but less than five months
 More than five month, but less than six months
 More than six months
 Don't Know/Remember
10. Using a 1 to 10 scale, where 1 is Unacceptable, 10 is Outstanding, and 5 is Average, how would you rate how well services have been designed to fit into your everyday family schedule or routine?

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11. Have service providers demonstrated how you can work with your child between intervention sessions?

Yes No

12. Using a 1 to 10 scale, where 1 is Unacceptable, 10 is Outstanding, and 5 is Average, how would you rate the services in meeting your IFSP outcomes [goals]?

13. Using a 1 to 10 scale, where 1 is Unacceptable, 10 is Outstanding, and 5 is Average, overall how would you rate the services you receive?

Information

The next couple of questions ask about early start information you and your family may have received from the regional center.

14. Using a 1 to 10 scale, where 1 is Unacceptable, 10 is Outstanding, and 5 is Average, how sufficient is the information you have received to plan for your child's needs?

15. Do you know what to do if you disagree with a decision made by the regional center or by the LEA? (For example, decisions regarding eligibility or need for specific services.)

Yes No

16. Using a 1 to 10 scale, where 1 is Unacceptable, 10 is Outstanding, and 5 is Average, how would you rate the ease of finding information about what services may be available to you?

17. When you were first looking for assistance, was culturally relevant information available to you? (For example, was information provided to you in your language of choice? Was the information ethnically relevant to you? Was the information relevant to your culture's value system?)

Yes, all of the information we needed was available in culturally relevant formats

Yes, a great deal of culturally relevant material was available

Yes, but only some culturally relevant material was available

No, culturally relevant materials were not available

Don't Know/Remember

IFSP

The next set of questions asks about your family's Individualized Family Service Plan and the planning team meeting. The planning team meeting is organized by the regional center and focuses on the abilities and needs of your child and your family, as well as what services may be appropriate for your child. The IFSP meeting is held every year, with a review of the plan occurring every six months. (If necessary: Your regional center service coordinator should have coordinated this meeting with you to discuss your child's and family's progress, wants and needs, as well as how well services are meeting your family's needs.)

18. Were things that are important *to you* discussed at your most recent planning team meeting (IFSP)?

- Yes, we discussed all of the issues that were important to us
- Yes, most important issues were discussed
- Yes, but only a few important issues were discussed
- No, important items were not discussed
- Don't Know/Remember

19. During the planning team (IFSP) meeting, did the service coordinator discuss your family's needs and wants with you?

- Yes, we discussed all of our family's needs or wants
- Yes, most of our family's needs or wants were discussed
- Yes, but only a few of our family's needs or wants were discussed
- No, none of our family's needs or wants were discussed
- Don't Know/Remember

Personal Outcomes

Using a 1 to 10 scale, where 1 is Much Worse, 10 is Much Better, and 5 is the Same, how would you rate your child's progress towards meeting the _____ outcomes (goals) identified by the planning team?

20. Social and Emotional (the child's ability to interact with and relate to others)

___ ___ No Intervention Needed Don't Know

21. Cognitive (the level of cognitive functioning, including problem-solving, learning, processing information)

___ ___ No Intervention Needed Don't Know

22. Speech and Language (Ability to communicate)

___ ___ No Intervention Needed Don't Know

23. Physical/Motor (including vision, hearing, mobility, coordination)

___ ___ No Intervention Needed Don't Know

24. Adaptive Skill (child's ability to take care of him/herself)

___ ___ No Intervention Needed Don't Know

25. Overall Quality of Life

___ ___ No Intervention Needed Don't Know

26. (If family receives family supports, services and resources - Q1, Parent Education or Parent Training options only) Do you believe the family supports, services, and resources have enhanced (improved) your child's quality of life?

Yes No

27. Overall, do you feel that the early intervention services you have received have increased your family's capacity to enhance (improved) your child's development?

Yes No

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Overall

These last couple of questions ask about your overall satisfaction with the regional center's early start services.

28. (If Child is older than 3 years of age and exiting Part C):
Did your child receive all of the services identified on his or her IFSP by his or her third birthday?
- Yes No Don't Know/Remember
29. (If Child is younger than 3 years of age and eligible for Part B):
Did your child receive all of the special education and related services identified on his or her IEP by his or her third birthday?
- Yes No Don't Know/Remember
30. (If Child is younger than 3 years of age and eligible for Part B): Did your child receive all of the appropriate services identified on his or her IFSP by his or her third birthday?
- Yes No Don't Know/Remember
31. (If Child is older than 3 years of age): Using a 1 to 10 scale, where 1 is Unacceptable, 10 is Outstanding, and 5 is Average, how would you rate the help (in planning, etc.) you received from the regional center in transitioning your child and his/her services when he/she turned 3 years of age?
- —
32. Using a 1 to 10 scale, where 1 is Unacceptable, 10 is Outstanding, and 5 is Average, how would you rate the services the regional center provides for your family?
- —

"Thank you for participating in this effort and answering these questions. The Department of Developmental Services and _____ Regional Center wants to give you the best service possible and your information is very important in helping them serve you better. Thank you again for talking to me."