

**STAKEHOLDERS' FEEDBACK ON EARLY START AND LANTERMAN ACT SERVICES
STANDARD INFORMATION PACKETS (SIPs)
EXECUTIVE SUMMARY**

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STAKEHOLDER REPRESENTATION IN THE FEEDBACK FOR SIPS

On-Line Survey:

The stakeholder feedback on the formats and modes of communication (primary area) and the content (secondary area) of the Early Start and Lanterman Act services Standardized Information Packets (SIPs) was collected via an On-Line Survey. An invitation to participate in the survey was posted on the Department of Developmental Services' website and shared with the 21 regional centers, family resource centers network, disability rights organizations, Office of Clients' Rights Advocates, State Council for Developmental Disabilities, community-based organizations, and other agencies. The On-Line Survey was posted from 7/8/2021 to 9/28/2021. The survey was ended when the submission of responses stopped. The survey was administered in English, Spanish, Traditional Chinese, Vietnamese, and Tagalog.

Stakeholders' racial and ethnic self-identification:

English: The *optional* question about the survey respondents' race and ethnicity was answered by 636 and omitted by 497 individuals. Additionally, 69 survey respondents (10.85% of all who answered this question) checked the option 'prefer not to state'. Thus, racial and ethnic self-identification information was reported by only half, or 567 (50%) survey respondents, and not available (either omitted or not reported by choice) for 566 (50%), the other half of all survey respondents. Thus, the race / ethnicity representation data below should be interpreted with an understanding that it reflects *only half of those who responded to the race / ethnicity survey question*. Of those who responded to the racial and ethnic self-identification question, the racial and ethnic group representation was as follows:

Race / ethnicity	Number of respondents	Percent of all who answered the optional race /ethnicity question	Percent served in the DDS regional center system 2019/2020
African American	43	6.67%	8.77%
Asian	69	11.01%	6.85%
Hispanic / Latino/Latinx	166	26.10%	38.96%
Native American or Alaska Natives	14	2.2%	Not reported
Native Hawaiian or Other Pacific Islander	3	0.47%	Not reported
Other	33	2.2%	Not reported
White	300	47.17%	31.56%
Prefer not to state	69	10.85%	N/A

Total respondents to the racial and ethnic self-identification question: 636

Racial and ethnic self-identification information available: 636-69 = 567 (50% of all who responded to the survey)

Stakeholders group representation:

English: In total, 1,133 individuals responded to the survey in English. Seven (7) of these individuals did not share their stakeholder group affiliation(s) (e.g. whether they are a self-advocate, a parent or a legal guardian, a family support professional such as a family resource center staff member, or a regional center staff member, see the types of stakeholder groups below). Some of the respondents were affiliated with more than one stakeholder group, thus they were counted as representing all the stakeholder groups that they marked in their response. Of the 1,126 individuals who shared their stakeholder group affiliation (*potentially more than one*), the following stakeholder groups were represented in completing the On-Line Survey.

Spanish: In total, 71 individuals responded to the On-Line Survey in Spanish. Of the 59 individuals who shared their stakeholder group affiliation (*potentially more than one*), the following stakeholder groups were represented in completing the On-Line Survey

Chinese: In total, 10 individuals responded to the On-Line Survey in Traditional Chinese. Of the 9 individuals who shared their stakeholder group affiliation (*potentially more than one*), the following stakeholder groups were represented in completing the On-Line Survey

Vietnamese: In total, 6 individuals responded to the On-Line Survey in Vietnamese, and all 6 shared their stakeholder group affiliation (*potentially more than one*)

Tagalog: 1 individual, a parent, responded to the On-Line Survey in Tagalog.

TABLE: On-Line Survey: Stakeholder group representation by category and language

Language	English	Spanish	Chinese	Vietnamese	Tagalog	All languages
Number in the stakeholder group (% of all who filled out the survey in that language)						
Consumer or Self-Advocate	50 (4.44%)	1 (1.69%)	1 (11.11%)	0	0	52
Parent, legal guardian, or conservator of a consumer	676 (60.4%)	48 (81.36%)	6 (66.67%)	3 (50%)	1 (100%)	734
Family member or friend (who is not a parent or legal guardian)	24 (2.13%)	3 (5.08%)	0	0	0	27
Total self-advocates and family members	750 (66.97%)	52 (88.13%)	7 (77.78%)	3 (50%)	1 (100%)	813

Service provider	118 (10.48%)	7 (11.86%)	3 (33.33%)	1 (16.67%)	0	129
Clinician	106 (9.3%)	1 (1.69%)	0	0	0	107
Paid advocate	76 (6.6%)	4 (6.78%)	0	0	0	80
Regional Center Staff	61 (4.53%)	2 (3.39%)	0	0	0	63
Family support professional	20 (1.78%)	6 (10.17%)	1 (11.11%)	2 (33.33%)	0	29
Other Professional	7 (0.62%)	0	0	0	0	7
Total Professionals	388 (33.31%)	20 (33.89%)	4 (44.44%)	3 (50%)	0	415
Total number of stakeholder roles	1,138	72	10	6	1	1,227
Total number of survey respondents	1,126	71	10	6	1	1,214

Note: Because the survey respondents were asked to 'check ALL that apply', one person could be counted more than once if they were, for example, a parent and a professional, or a parent, a self-advocate, and a professional. The **total number of stakeholder roles** represents all the roles the respondents marked. The **total number of respondents** represents the number of people, and is less than the total number of stakeholder roles in the table above.

On-Line Survey results:

1. "Where should the following information be located?"

Answer: **to be included in the information packet (versus the resource guide)** Number of respondents (Percentage of all respondents)

Topic	English	Spanish	Chinese	Vietnamese	Tagalog
Eligibility for regional center services:	512 (79.75%)	55(84.62%)	9 (100.00%)	6 (100%)	1 (100%)
Referral for intake	404 (63.72%)	43(67.19%)	8 (88.89%)	2 (33.33%)	1 (100%)

Intake process and its timelines	520 (81.12%)	53(82.81%)	8 (88.89%)	6 (100%)	1 (100%)
Types of assessments or tests to show eligibility	443 (69.33%)	51(79.69%)	8 (88.89%)	5(83.33%)	1 (100%)
Whom to contact for intake-related questions	458 (71.34%)	49(76.56%)	9 (100.00%)	5(83.33%)	1 (100%)
How to prepare for intake	432 (68.03%)	53(82.81%)	8 (88.89%)	6 (100%)	1 (100%)
Information about the results of the assessment	441 (69.23%)	54(84.48%)	7 (77.78%)	5 (83.33%)	1 (100%)

2. *“Where should the following information be located?”*

Answer: **to be included in the information packet (versus the resource guide)**

Topic	English	Spanish	Chinese	Vietnamese	Tagalog
An overview of services	473 (75.20%)	52(81.25%)	9 (100.00%)	5 (83.33%)	0
How to request services	466 (73.04%)	49(76.56%)	9 (100.00%)	3 (50.00%)	0
Individual program plan (IPP) or individual family service plan (IFSP)	422 (65.94%)	52(81.25%)	8 (88.89%)	3 (50.00%)	1 (100%)
Who is on the planning team	401 (62.75%)	56(87.50%)	7 (77.78%)	3 (50.00%)	1 (100%)
Process for approving services	416 (65.62%)	55 (85.94%)	9 (100.00%)	4 (66.67%)	1 (100%)
Preparing for the IPP and IFSP	367 (57.98%)	54(84.38%)	7 (77.78%)	4 (66.67%)	1 (100%)
Person-centered planning	324 (51.18%)	55(85.94%)	8 (88.89%)	3 (50.00%)	0

Answer: **to be included in the resource guide (versus the information packet)**

Topic	English	Spanish	Chinese	Vietnamese	Tagalog
How to plan for future care	385 (59.43%)	51(79.69%)	7 (77.78%)	2 (33.33%)	0
Information on community resources	359 (55.56%)	51 (79.69%)	7 (77.78%)	5 (83.33%)	1 (100%)
Information regarding emergency situations	446(68.93%)	47 (74.60%)	5 (55.56%)	1 (16.67%)	1 (100%)

3. "Where should information about consumer / parents' rights be located?"

Answer: **to be included in the information packet (versus the resource guide)**

Topic	English	Spanish	Chinese	Vietnamese	Tagalog
Rights of consumers' and their families	457 (71.63%)	53(82.81%)	6 (66.67%)	4 (66.67%)	1 (100%)
Who can help to resolve problems with services	359 (56.18%)	57(89.06%)	5 (55.56%)	4 (66.67%)	1 (100%)
Information on the formal complaint process	345 (54.50%)	54(85.71%)	6 (66.67%)	4 (66.67%)	1 (100%)
An overview of the appeal process	332 (52.28%)	55(85.94%)	7 (77.78%)	5 (83.33%)	1 (100%)
What to do if unhappy with services or service provider	353 (55.94%)	54(85.71%)	6 (66.67%)	5 (83.33%)	0

4. When asking how **to rank the different ways the information should be provided**, the ranking was as follows:

Topic	English	Spanish	Chinese	Vietnamese	Tagalog
Hard copy for the 1 st ranked	256 (42.11%)	34 (52.31%)	3 (30.00%)	2 (33.33%)	1 (100%)
for the 2 nd ranked	198 (32.57%)	18 (27.69%)	2 (20.00%)	1 (16.67%)	0
Electronic delivery for the 1 st ranked	233 (37.76%)	14 (21.88%)	4 (44.44%)	1 (16.67%)	0
for the 2 nd ranked	197 (31.93%)	25 (39.06%)	3 (33.33%)	2 (33.33%)	1 (100%)
In-Person for the 3 rd ranked	198 (32.57%)	20 (30.30%)	3 (33.33%)	1(16.67%)	1 (100%)
A video of someone presenting the information					
for the 4th ranked	274 (44.77%)	35 (53.03%)	3 (33.33%)	3 (50.00%)	1 (100%)

Open-ended answers to the On-Line Survey:

Additional stakeholder feedback was derived from narrative open-ended answers of the On-Line Survey in English, Spanish, Traditional Chinese, and Vietnamese. **A total of 545 open-ended answers**, including 527 in English, 6 in Traditional Chinese, and 12 in Vietnamese were collected and thematically analyzed using NVivo 12 analytic software. There were no open-ended answers in the online survey in Tagalog.

Key Informant Interviews and Focus Groups:

Key Informant Interviews (KIs) were conducted 11/2/20 – 2/12/21. Focus Groups (FGs) were conducted 8/31/21 - 9/31/21.

The stakeholder feedback on the content (primary area for KIs and FGs) and format (secondary area) of the Early Start and Lanterman Act services Standardized Information Packets (SIPs) was summarized from the following:

English:

20 individual and group Key Informant Interviews with 24 participants: 3 parents; 3 parents and self-advocates; 1 parent and a UCEDD staff member; 1 self-advocate and a UCEDD staff member and an advocacy professional; 5 regional center staff members; 2 State Council for Developmental Disabilities members; 2 Disability Rights California staff members, 1 Association of Regional Center Agencies staff member; and 6 Department of Developmental Disabilities staff members.

4 focus groups with 20 participants: 8 parents; 3 parents and family support professionals; 2 parents and regional center professionals; 7 regional center and other professionals

American Sign Language: One focus group with 2 participants, both professionals

Spanish: 2 Focus Groups with 5 participants, all 5 were parents; **One Key Informant Interview** with 1 participant who is a self-advocate and advocacy professional)

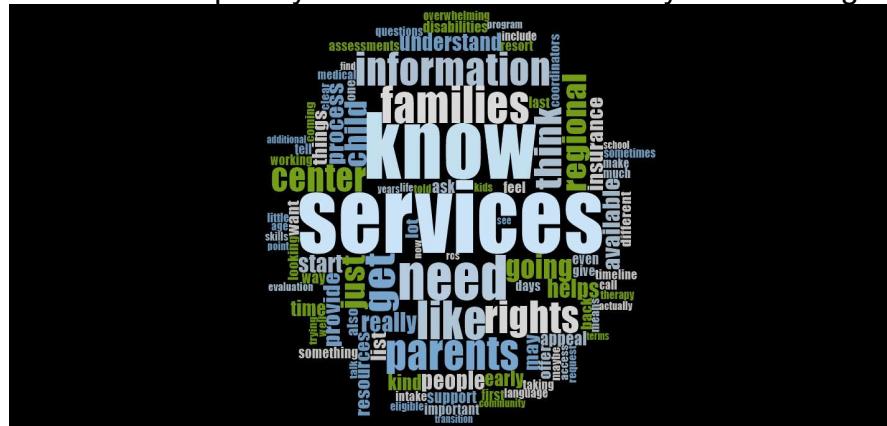
Traditional Chinese: One focus group with 5 participants: 3 parents and 2 professionals

Vietnamese: One focus group with 6 participants: 3 parents, 1 sibling, 2 professionals

In total for all languages, 63 individual stakeholders, many with multiple stakeholder group affiliations, participated in 21 Key Informant Interviews and 9 Focus Groups. Of note, although focus groups in Tagalog were planned, there were no participants who expressed interest in participating after being contacted by a Filipina focus group facilitator.

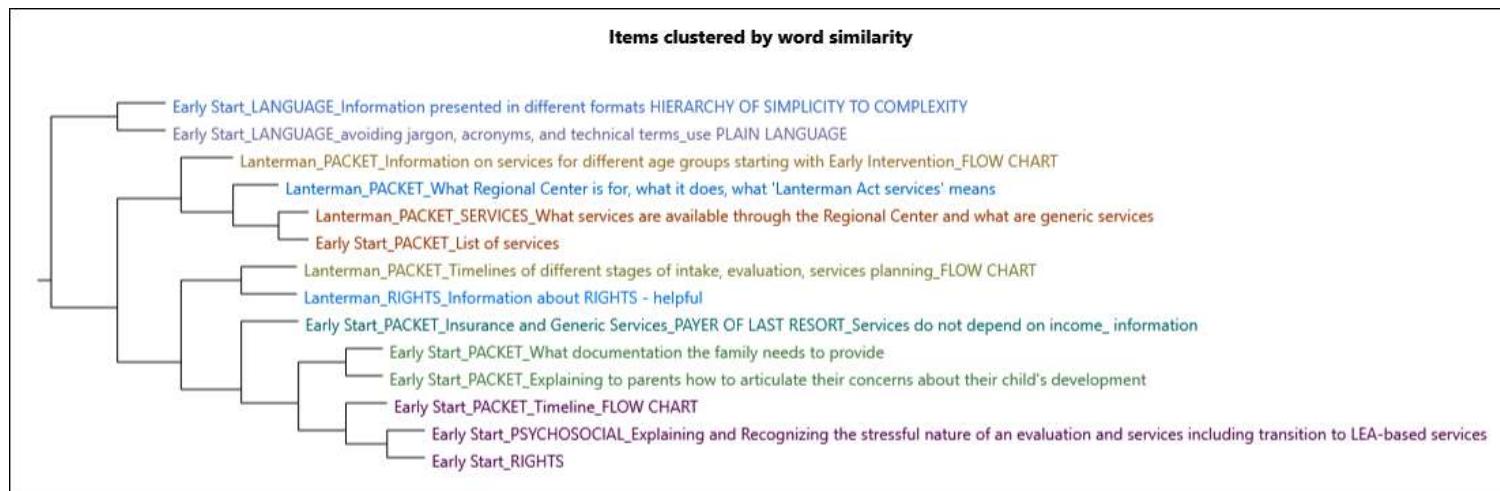
Data analysis summary

Word cloud of 100 most frequently used words: the centrality of knowledge about services



This word cloud illustrates the most frequently used words in the transcripts of Key Informant Interviews and Focus Groups uploaded to NVivo, a data analytic software, for analysis. The larger the size of the word, the more frequently it appears in the data. As can be seen in the word cloud image above, "SERVICES" is the most frequently used word, followed by "KNOW", "FAMILIES", "INFORMATION", "NEED", "RIGHTS", and "PARENTS".

2) Cluster analysis of most frequent themes: access to information is linked to rights, plain language, timelines, checklists



NVivo generates a cluster analysis to visualize patterns of word use in the transcripts by grouping themes that have similar words. This provides a picture of what themes are related because of the similar meaning of the words they contain.

3) Stakeholder recommendations

- Families' psycho-social challenges during and after intake and evaluation:

- ✓ One of the most frequent themes in the parent stakeholders feedback is that SIPs need to reflect a **caring and compassionate response from the regional center staff**. Family members described their need for regional center staff's recognition of the stressful and often traumatic nature of intake and evaluation. As one parent shared, '*I wanted somebody to hold my hand and walk me through it because I didn't know where to go next and what to do*'.
- ✓ Professional stakeholders suggested that regional center staff's communication with families should be '**relationship-based**'. As one professional shared, "*All we talk about should have an overarching theme of relationship-based encounters. Set the platform in relationship-based. Walk this journey with you rather than set a set amount of time*". Another professional shared: '*It's not helpful to not listen. I think that's the biggest problem sometimes when we're listening in a conversation, we're just listening for the information that we can respond to and I think some families need to tell you their story. Yes, because that's what they want, us to witness to their pain, they want empathy and they want to witness and they want to tell their story. And you got to understand, you got to let them tell their story. If you don't have time for them to tell the story, you say, "you know, this is not, I don't have, you know, we have to bring this conversation to a close, I would like to talk with you further, can we figure out a time and a date when I could talk to you a little bit further. Right now I've got a meeting coming up. Can we talk later on this afternoon?*".
- ✓ Professional stakeholders formulated the **appropriate response to the challenges families have** when receiving new information under emotionally difficult, stressful circumstances of a developmental delay or a developmental disability diagnosis. As another professional shared: '*When families go through intake they're in a time of incredible stress and transition. And they're not good at taking in information, you know certain parts of your brain shut down and our system is very complicated, so one of the things that came up was that if you really want people to understand and retain information, a really good way to do that is to give them the information in the most clear, concise, relevant way. And then deliver it to them once when they're going through it and circle back you know, three months later, six months later, just with a check-in "Hey, did you, do you understand, do you have any additional questions now that you're kind of settling into a routine?" and so those are some of the challenges that we discussed*'.
- ✓ Information packets should provide information about resources that would **meet the needs for emotional as well as informational support**. Information on Family Resource Centers, parent support groups, and advocacy groups should be included to assure that families entering the regional center system have access to support, mentorship, and knowledge of other, more experienced families. As one parent shared, what is needed in the SIPs is *Parent psychological resources for themselves and parent /caregiver peer support groups in local area of the center. This is needed right away*.
- ✓ The SIPs should support families' **hope**. SIPs should help parents to, as one parent said, '*dream big and train for independence*'. SIPs should include families' real-life stories of success, with photographs. As one professional shared:

Regional Centers training for independence. With appropriate support services in place, create a stable growing experience and involvement experiences which is based on everyone's strengths. This type of framing is beneficial to parents to dream big for their kids.

- ✓ Families want to feel that the SIPs talk to them. AS one parent shared, 'make **the tone of the packets more personal** and less technical'.

Early Start – specific content recommendations

- ✓ Early Start services are provided **in the natural environment** such as family home.
- ✓ Explain **what Early Start is**
- ✓ Early Start is **voluntary**, it has no relation to DCFS
- ✓ What **the role of regional center is in Early Start**, what Early Start is for in the regional center system
- ✓ What an Early Start **evaluation will be like**
- ✓ **Referral process**; what a self-referral is
- ✓ What is involved in **intake, assessment, and receiving services**
- ✓ **What is IFSP** and how parents can prepare and participate
- ✓ Expectations regarding **parents' participation** in Early Start
- ✓ Estimate of **time commitment** for the parents to participate in ES with their child
- ✓ An explanation of **how parents should describe their concerns** about their children's development to help the professionals identify a need for services.
- ✓ Include information on **developmental milestones**
- ✓ What to do if the child **does not qualify for Status 1**
- ✓ **Families can return to RC for an evaluation** if the child's developmental gap widens
- ✓ An explanation about **generic services and the role of insurance** in Early Start services
- ✓ A **timeline from referral to services** in a flow chart
- ✓ What **documentation** parents need to provide to have their child evaluated for Early Start; a **CHECK LIST** of what parents need to bring for intake
- ✓ Parents need to be explained that **Early Start is temporary and ends at age 3**
- ✓ Preparing for transition planning at 32 months the latest
- ✓ Who is on the Early Start team, **the role of different professionals**
- ✓ The role of **Service Coordinator**
- ✓ **Eligibility** for Early Start
- ✓ Provisional eligibility for Lanterman services
- ✓ Avoiding jargon, acronyms, and technical terms, use **PLAIN LANGUAGE** in SIPs
- ✓ Present simple information first, then more complex information
- ✓ **Responsibilities of the parents, the RCs, and the school districts** during transition from Early Start: A **CHART**
- ✓ Early Start SIP should **support hope**: *Nothing that says "we hope this will help but it might not"; reassure parents that they will receive individualized supports and intervention for their children*
- ✓ Each service needs to have an evaluation to be authorized

- ✓ Having the right to request another Service Coordinator; having the right to know who is Service Coordinator's supervisor is
- ✓ Have a list of other systems such as CCS

Lanterman - specific content recommendations

- ✓ **A list of all types of services potentially available** through the Early Start and Lanterman Act programs, separated into core services and a link to a complete list. What services are provided through the regional center, what are generic services, and what services are provided by the school district.
- ✓ An explanation that **services are linked to specific individual needs**.
- ✓ An explanation that **regional center services are voluntary** and not linked in any way to child protective services.
- ✓ An explanation that **regional center services do not depend on documented status**
- ✓ **Destigmatize eligibility criteria**; explain eligibility criteria in simple, plain language rather than in clinical terms.
- ✓ Include **personal stories and other examples with photographs to describe positive outcomes** (independent living, employment, education).
- ✓ Visuals for describing different **professionals' roles** on the team; especially the role of service coordinator.
- ✓ Understanding **what is involved in intake, assessment, IFSP / IPP**, and receiving services.
- ✓ What **information and documents** families should prepare for an evaluation: **CHECKLIST**
- ✓ What **eligibility requirements** are for Early Start and Lanterman; what diagnoses automatically qualify a child for Lanterman services. Explain the differences between Status 0, Status 1 and Status 2.
- ✓ What to do if the child **does not qualify for Status 2**.
- ✓ What '**payer of last resort**' means; health insurance use; generic services; regional center services are not based on income; healthcare coverage does not always mean services are accessible.

Stakeholder recommendations regarding SIPs language and format

- ✓ Use plain language (6th grade reading level) so that families with lower reading level are able to comprehend
- ✓ Packets must be adapted for the deaf community
- ✓ Avoid technical language, acronyms, codes, and legal jargon
- ✓ Include a Glossary of Terms, including in Spanish and other languages
- ✓ Create CHECK LISTS, e.g., for the documents to bring at different stages; forms a family needs to fill out
- ✓ Use FLOW CHARTS for timelines (e.g. of the intake and evaluation process)
- ✓ Hyper-links or QR codes to more detailed information so people can absorb and retain, and not get overwhelmed
- ✓ Information in different formats so that SIPs are accessible for different processing styles
- ✓ Information in digestible bits, from simple to more complex

Stakeholder recommendations regarding SIPs content on families' rights to appeal and fair hearing

- ✓ Parents can challenge a RC's decision and appeal
- ✓ Parents' right to request another service coordinator
- ✓ Parents need to be explained what their rights are, not just be given a hand out
- ✓ The right to be evaluated for Lanterman services 6 months before the child's 3rd birthday

- ✓ The right to return to RC for an evaluation if the child's developmental gap widens

Non-English-speaking stakeholders' feedback

- ✓ Address cultural factors that impact how comfortable parents are to appeal: **APPEAL NEEDS TO BE NORMALIZED**
- ✓ Glossary of terms in different languages
- ✓ Non - English-speaking families need to know that they have a right to an interpreter
- ✓ Interpreters must be trained on what technical terms mean in order to convey information: Informed Interpreters needed for parents to understand ES services correctly
- ✓ Watching a video may be preferable to reading information
- ✓ ES services are provided to address specific, individual needs of the child and the family
- ✓ SIPs need to address parents' challenges to understanding and acting upon their rights
- ✓ The right to bring others to the meetings with regional center staff
- ✓ An explanation that Early Start services do not depend on documented status
- ✓ Immigrant families need to know about developmental milestones
- ✓ Parents need to know how to articulate their concerns about their child's development: a list of problematic behaviors
- ✓ Include information on developmental milestones in Spanish and other languages
- ✓

Input from Stakeholders in the development of SIPs was mandated by the Amendment to the Welfare and Institutions Code, Senate Bill No. 81 CHAPTER 28 SEC. 21. Section 4642 of the Welfare and Institutions Code is amended to read: 4642. (3) (A) The department (Department of Developmental Services) shall create, with input from stakeholders, standardized information packets to be provided to any person seeking services from a regional center. There shall be one information packet related to services provided under the California Early Intervention Services Act and another information packet related to services provided under the Lanterman Developmental Disabilities Services Act. The information packets shall be translated to provide language access, as required by state and federal law, shall be available in alternative formats and alternative modes of communication, as required by federal law, and shall include, at a minimum, all of the following: (i) An overview of the regional center system. (ii) A resource guide for consumers and their families. (iii) Consumer rights. (iv) Contact information for the regional center, the department, the office of clients' rights advocacy, and the protection and advocacy agency specified in Division 4.7 (commencing with Section 4900). [Approved by Governor June 27, 2019. Filed with Secretary of State June 27, 2019].

Full text of the amendment can be accessed at: leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201920200SB81