



Attachment 1 Focus Group Outline

FOCUS GROUP OUTLINE FOR CONSUMERS OF RYAN WHITE TITLE IV

Los Angeles County

July 14, 2003

GUIDE	CONCEPT/ INSTRUCTIONS
<p>1. Hello, my name is _____ and I work for the Los Angeles Family AIDS Network, an organization that is assessing the care needs of families affected by HIV and AIDS in Los Angeles. Our discussion is entirely confidential. Only the analysts on this project will know your name -- no provider of your care will ever be able to link your comments to your name or penalize you for what you say. Therefore I ask that you be as honest and candid as you can. Feel free to compliment or criticize any program or provider.</p> <p>How many of you have been in focus groups before? For those you who have not, it is a discussion – in this case about your HIV and AIDS care. By discussion I mean that you should feel free to voice your opinion on a subject or respond to something someone else says – you don't have to raise your hand, and feel free to ask a question or respond directly to something someone else has said.</p> <p>There are a few ground rules:</p> <ol style="list-style-type: none">1. Because we are taking notes [or taping], please speak clearly and do not speak at the same time someone else is.2. Don't criticize or attack another person in the group. If you disagree with something someone has said, wait until they are done and give your opinion on the subject.3. And last, talk from your own experiences. What things you have experienced, and what are your needs. Don't talk about what everyone needs – we are interested in your experience. <p>If I cut you off, I apologize in advance. Because we only have 60 to 90 minutes and I have several topics to discuss, I may have to move on to new topics – often times these groups get bogged down so my task is to make sure that doesn't happen.</p> <p>So, before we begin, I want to confirm that you are willing to discuss your HIV and AIDS care needs.</p> <p>As a token of our gratitude for your time, I have a \$20.00 food voucher that I will give you at the end of the group.</p>	INTRO, ground rules



GUIDE	CONCEPT/ INSTRUCTIONS
2. Please introduce yourself – first name only --and tell the others in the group a little about yourself, including age, mode of transmission, and how long you have known that you have been HIV positive? <i>[Place in notes the gender and ethnicity of each participant.]</i>	Warm up, stage of infection
3. Are you living with a partner or husband (wife)? Is he (she) HIV positive? How is their health?	Husband (wife) and their status
4. Do you have any children? Are they HIV positive or negative? How is their health?	Children and their HIV status
5. IF HIV+ CHILDREN: And what is the first name of your infected child(ren)? <i>(USE FIRST NAME(S) THROUGHOUT INTERVIEW)</i>	Name of Children for personalizing interview.
6. Where do you (all) go for medical care of your HIV infection or AIDS? <i>(Probe for all members of the family?)</i> How far is that from where you live? Do you think it would be better if you could all go to the same place for care? What would be the advantages and disadvantages for you?	One-stop care
7. Provided you could get the same level of care, how important is having a clinic in your neighborhood instead of traveling outside you neighborhood for a clinic? How difficult is it for you to travel to clinic? <i>(Probe for reasons)</i>	Proximity
8. How is your treatment paid for? <i>(Probe for own and family's)</i>	Reimbursement
9. How many of you are on medications /for your HIV infection – show of hands? How many are on some type of combination therapy? <i>(Record number in notes.)</i>	Medication
10. IF HIV+ SPOUSE AND/OR CHILDREN How many of you have a spouse or child on medications <i>(show of hands)</i> ? Do you know if the medication includes an antiviral or protease inhibitors? <i>(Record number in notes.)</i>	Medication
11. How would you describe your current physical and emotional health? What symptoms or opportunistic infections related to your HIV infection have you had? What are your current symptoms? <i>(PROBE FOR BOTH PHYSICAL AND EMOTIONAL – SUCH AS DEPRESSION, BIPOLAR)</i>	R's physical and emotional health
12. IF HIV+ SPOUSE OR CHILDREN How would you describe your partner's [and children's] current physical and emotional health? What symptoms or opportunistic infections related to their HIV infections have they had? What are their current symptoms? <i>(PROBE FOR BOTH PHYSICAL AND EMOTIONAL – SUCH AS DEPRESSION, BIPOLAR)</i>	Family's physical and emotional health



GUIDE	CONCEPT/ INSTRUCTIONS
13. Many people living with HIV/AIDS find it difficult to adhere to the schedule of taking drugs. How many of you have had any problem keeping your medication on schedule (<i>show of hands</i>)? Why? (PROBE FOR REASONS, INCLUDING DENIAL, KNOWLEDGE, FEAR, SIDE EFFECTS)	Adherence & compliance
14. IF HIV+ SPOUSE OR CHILDREN Have you had any problem maintaining your child's medication schedule? (PROBE FOR REASONS, INCLUDING DENIAL, KNOWLEDGE, FEAR, SIDE EFFECTS)	Family's adherence & compliance
15. Are there times when some of you can't get your medication [or medication for your family]? Why?	Barriers to getting medications
16. Are the instructions for taking the medication clear? If not, why? Does anyone help you with understanding instructions? Who? [IF FAMILY , Is that true for you family members as well?]	Instructions

Medical Care: Delayed Care Seeker / Unconnected To Care

17. How often do you think you should see a doctor? Do you go that often? Are there any problems in going to a doctor that often?	Delayed care seeker
18. IF HIV+ CHILDREN How often do you think your child(ren) should see a doctor? Does he or she go that often? Are there any problems in taking your HIV positive kids to a doctor that often?	Family delayed care seeker
19. Since 1995, has there ever been a period of more than 6 months when any of <u>you</u> have not seen a doctor (<i>record show of hands</i>)? Has there ever been a year of more when you haven't seen a doctor or gone to a clinic? Why? (PROBE FOR INDIVIDUAL, ORG, STRUCTURAL REASON)	Initial access to services Newly diagnosed
20. Has any of your <u>children</u> ever gone for more than 6 months without seeing a doctor or going to a clinic for their HIV infection (<i>record show of hands</i>)? How long did it take you to start regular appointments after your child was diagnosed with HIV infection?	Family initial access to services Newly diagnosed
21. [IF DELAYED CARE] Why did you wait to take your child to see a doctor	Newly diagnosed

Health Insurance / Benefits

22. I would like to talk for a few moments about insurance coverage. Who has insurance (<i>record show of hands</i>). [PROBE FOR SCHIP (State Childrens' Health Insurance Program), COBRA, insurance through work, Medicare, Medi-Cal/Medicaid]? Do you think you should be getting [better] insurance? Does the insurance adequately pay for your child's HIV/AIDS health care?	Insurance
23. What type of benefits and supplementary income do you get, including Social Security Disability Insurance (SSDI), SSI, TANF, Emergency Assistance, Section 8 housing, etc? Are they sufficient to meet your [and your child's] needs?	Benefits



GUIDE	CONCEPT/ INSTRUCTIONS
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Housing and Direct Financial Assistance

24. How many of you have inadequate housing (record show of hands)? What are the barriers to finding good housing? (Pay particular attention to criminal justice history, difficulty obtaining a security deposit, and landlord discrimination, problems finding safe and acceptable housing for children.)	Housing barriers
25. Since being diagnosed with HIV, have any of you been homeless? Can you tell me how that came about?	Homelessness
26. Have any of you had to leave your housing? Why? What could have prevented it?	Housing loss
27. For you, has having stable housing been necessary before you could start scheduling and maintaining appointments with a doctor or a clinic for child regularly?	
28. Do you have any problems paying the electricity and other utility bills? Have you ever sought financial assistance to pay those bills? What was the outcome?	Financial assistance

HIV Services

29. I am now going to pass out a list of HIV services. As I read each service, check the box that says whether you needed the service in the past year, asked for the service, and received the services (<i>Go through and example, for each major category probe for problems in accessing the service or quality of service</i>).	Need, demand, utilization
30. (AFTER THE LIST) Are there any other HIV or AIDS services that you feel you need but aren't available? Why do you think the service(s) aren't available?	Demand and unmet demand.
31. In general, how would you describe the quality of HIV care services that you receive? What services work well? What services work poorly?	Quality of services
32. In general, how would you describe the quality of HIV care services you receive for your child? What services work well? What services work poorly?	Family quality of service
33. Was there anything in particular that made getting services easier for you or your child(ren)?	Organizational facilitators

Additional Needs

34. Is there anything else that you would like to tell us about your service needs or gaps in services, or barriers to care?	Considered open end
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Focus Group Outline for Providers of Title IV Target Populations
Los Angeles County
July 14, 2003

GUIDE	CONCEPT/ INSTRUCTIONS
<p>1. Hello, my name is _____ and I work for the Los Angeles Family AIDS Network, an organization that is assessing the care needs of families affected by HIV and AIDS in Los Angeles. Our discussion is entirely confidential, only those on our analyst team will ever be able to link your comments to your name. Therefore I ask that you be as honest and candid as you can in our discussion.</p> <p>How many of you have been in focus groups before? For those you who have not, it is a discussion – in this case about the HIV and AIDS care of adolescents, women and their families. By discussion I mean that you should feel free to voice your opinions on a subject or respond to something someone else says – you don't have to raise your hand, and feel free to ask a question or respond directly to something someone else has said.</p> <p>There are a few ground rules:</p> <p>4. Because we are taking notes [or taping], please speak clearly and do not speak at the same time someone else is.</p> <p>5. Don't criticize or attack another person in the group. If you disagree with something someone has said, wait until they are done and give your opinion on the subject.</p> <p>6. And last, talk from your own experiences. What things you have experienced, and what your patients and clients need. We are most interested in your direct experiences.</p> <p>If I cut you off, I apologize in advance. Because we only have 60 to 90 minutes and I have several topics to discuss, I may have to move on to new topics – often times these groups get bogged down so my task is to make sure that doesn't happen.</p> <p>So, before we begin, I want to confirm that you are willing to discuss your clients' HIV and AIDS care needs.</p>	INTRO, ground rules
<p>2. Please introduce yourself – first name only --and tell the others in the group a little about your practice or clinic.</p>	Warm up, stage of infection
<p>3. First I would like to talk about reimbursement for services. What are the different sources of funds you receive? About what percent comes from Medical? Medicare? OAPP (or Ryan White Title I and II?) Title III? LAFAN (Title IV)? Other sources?</p>	Funding
<p>4. What is the current state of collaboration between Title III and Title IV recipients? Are you satisfied with this model of collaboration? If not, what changes should be made?</p>	Collaboration



GUIDE	CONCEPT/ INSTRUCTIONS
5. Can you describe how the LAFAN (Title IV) funds are spent? How critical is it for your continued services to adolescents, women and their family with HIV or AIDS?	Importance of Title IV funding
6. How satisfied are you with the administration of these funding sources? Can you think of anything that would make the administration more effective or efficient?	Satisfaction with Admin of funds from different sources.
7. For your patients, what do you feel are the most important medical and mental health services they need, outpatient visits, including dental, 1-1 and group counseling?	Medical service Needs
8. How important do you think that case management is for these women and their families? What is the most important service case managers provide?	Importance of case-management
9. How often, on average, do you treat women who are HIV positive?	Average number of times a year
10. How critical would you say wrap-around services are to adolescents, women and their children, including transportation, childcare, housing, financial assistance for housing....	Wrap-around service needs
11. Now, what do you think are the largest gaps in services – that is services you feel are needed but not adequately provided? Why? What are the barriers to care for these women? How can they be overcome?	Gaps in services
12. Among children, adolescents, women of childbearing age, and families are there any risk-groups, ethnic populations, or geographic areas you perceive as under- or over- served?	Geographic and subpopulation needs.
13. For the services you provide to women, children, families, and youth, can you make any recommendations on how they could be provided better? Are there other models of service delivery that you think would work better?	Quality of care
14. Typically there is a request for proposal for providers who wish to receive Title IV funding. Do you like that process? Can you think of any other process that would work better for you?	RFP process
15. Is there any other thing you would like to tell me about the needs of children, adolescents, women of childbearing age, and families?	Other comments



Attachment 2 Key Informant Guide

KEY INFORMANT INTERVIEW FOR PARENTS AND CHILDREN LIVING WITH HIV AND AIDS FOR TITLE IV TARGET POPULATIONS

Los Angeles County
July 14, 2003

QUESTIONS	CONCEPT/ INSTRUCTIONS
1. Hello, I would like to talk to [NAME REFERRED BY LAFAN]. (IF NOT THERE – Can you tell me when I can contact her/him?)	Be sure you are talking to the right person
2. Hello, [NAME OF REFERRAL] gave me your name and said you would be willing to talk about the HIV care needs. My name is _____ and I am calling from Los Angeles Family AIDS Network, an organization that is assessing the care needs of families affected by HIV and AIDS in Los Angeles. I want to confirm that you are willing to discuss your HIV and AIDS care needs.	INTRO and confirmation
3. Our discussion is entirely confidential. No provider of your care will ever be able to link your comments to your name.	
4. As a token of our gratitude for your time, I have a \$20.00 food voucher that I will give you at the end of this interview.	
5. Before we begin I want to confirm that you are HIV positive?	Confirm status
6. Do you mind if I call you by [FIRST NAME]? Can you tell me your race, age, modes of transmission, and how long you have known that you have been HIV positive?	Demographics and stage of infection
7. Have you been diagnosed with AIDS or are you HIV positive, but don't have AIDS?	Stage of disease
8. Are you living with a partner or husband (wife)? Is he (she) HIV positive?	Husband (wife) and their status
9. Do you have any children? Are they HIV positive or negative?	Children and their HIV status
10. IF HIV+ CHILDREN: And what is the first name of your infected child(ren)? (<i>USE FIRST NAME(S) THROUGHOUT INTERVIEW</i>)	Name of Children for personalizing interview
11. Where do you (all) go for medical care of your HIV infection or AIDS? (<i>Probe for all members of the family.</i>) How far is that from where you live? Do you think it would be better if you could all go to the same place for care? What would be the advantages and disadvantages for you?	One-stop care



QUESTIONS	CONCEPT/ INSTRUCTIONS
12. Provided you could get the same level of care, how important is having a clinic in your neighborhood instead of traveling outside you neighborhood for a clinic? How difficult is it for you to travel to clinic? <i>(Probe for reasons)</i>	Proximity
13. How is your treatment paid for? <i>(Probe for own and family's)</i>	Reimbursement
14. Are you currently taking any medication for your HIV infection? Are you on a combination therapy? Do you know if the medication includes an antiviral or protease inhibitors?	Medication
15. IF HIV+ SPOUSE AND/OR CHILDREN Is your spouse [and child(ren)] currently taking any medication for their HIV infection? Do you know if the medication includes an antiviral or protease inhibitors?	Medication
16. How would you describe your current physical and emotional health? What symptoms or opportunistic infections related to your HIV infection have you had? What are your current symptoms? <i>(PROBE FOR BOTH PHYSICAL AND EMOTIONAL – SUCH AS DEPRESSION, BIPOLAR)</i>	R's physical and emotional health
17. IF HIV+ SPOUSE OR CHILDREN How would you describe your partner's [and children's] current physical and emotional health? What symptoms or opportunistic infections related to their HIV infection have they had? What are their current symptoms? <i>(PROBE FOR BOTH PHYSICAL AND EMOTIONAL – SUCH AS DEPRESSION, BIPOLAR)</i>	Family's physical and emotional health
18. Many people living with HIV/AIDS find it difficult to adhere to the schedule of taking drugs. Have you had any problem keeping your medication on schedule? Why? <i>(PROBE FOR REASONS, INCLUDING SIDE EFFECTS)</i>	Adherence & compliance
19. FOR THOSE WITH ADHERENCE PROBLEMS Why did you choose not to take your own medications on schedule? <i>(PROBE FOR DENIAL, KNOWLEDGE, FEAR, etc.)</i>	Barriers
20. IF HIV+ SPOUSE OR CHILDREN Have you had any problem maintaining your child's medication schedule? How about yourself, what is your experience with adhering to the schedule of medication? <i>(PROBE FOR REASONS)</i>	Family's adherence & compliance
21. Do you find there are times you can't get your medication [or medication for your family]? Why?	Barriers to getting medications
22. Who usually gives you instructions on how to take and refill the medications for you [and your child(ren)]?	Instructions
Medical Care: Delayed Care Seeker / Unconnected To Care	
23. How often do you think you should see a doctor? Do you go that often? Are there any problems in going to a doctor that often?	Delayed care seeker



QUESTIONS	CONCEPT/ INSTRUCTIONS
24. IF HIV+ CHILDREN How often do you think your child(ren) should see a doctor? Does he or she go that often? Are there any problems in taking your HIV positive kids to a doctor that often?	Family delayed care seeker
25. Since 1995, has there ever been a period of more than 6 months when <u>you</u> have not seen a doctor? Has there ever been a year of more when you haven't seen a doctor or gone to a clinic? Why? (<i>PROBE FOR INDIVIDUAL, ORG, STRUCTURAL REASON</i>)	Initial access to services Newly diagnosed
26. Has your <u>child</u> ever gone for more than 6 months without seeing a doctor or going to a clinic for their HIV infection? How long did it take you to start regular appointments after your child was diagnosed with HIV infection?	Family initial access to services
27. [IF DELAYED CARE] Why did you wait to take your child to see a doctor	Newly diagnosed

Health Insurance / Benefits

28. What insurance do you have for yourself and for your infected child? [PROBE FOR SCHIP (State Children's Health Insurance Program), COBRA, insurance through work, Medicare, Medi-Cal/Medic aid]?	Insurance
29. Do you think you should be getting [better] insurance? Does the insurance adequately pay for your child's HIV/AIDS health care?	
30. What type of benefits and supplementary income do you get, including Social Security Disability Insurance (SSDI), SSI, TANF, Emergency Assistance, Section 8 housing, etc? Are they sufficient to meet you [and your child's] need?	Benefits

Housing and Direct Financial Assistance

31. Do you have adequate housing? What are the barriers to finding good housing? (Pay particular attention to criminal justice history, difficulty obtaining a security deposit, and landlord discrimination, problems finding safe and acceptable housing for children.)	Housing barriers
32. Since being infected have you ever had to leave your housing? Why? What could have prevented it?	Housing loss
33. For you, has having stable housing been necessary before you could start scheduling and maintaining appointments with a doctor or a clinic for child regularly?	
34. Do you have any problems paying the electricity and other utility bills? Have you ever sought financial assistance to pay those bills? What was the outcome?	Financial assistance

HIV Services



QUESTIONS	CONCEPT/ INSTRUCTIONS
35. I am now going to read you a list of HIV services. [GO TO SERVICE QUESTION ON THE NEXT PAGE AND FILL IN QUESTIONS]	Need, Knowledge
36. Are there any other HIV or AIDS services that you feel you need but aren't available? Why do you think the service(s) aren't available?	Demand and unmet demand.
37. In general, how would you describe the quality of HIV care services that you receive? What services work well? What services work poorly?	Quality of services
38. In general, how would you describe the quality of HIV care services you receive for your child? What services work well? What services work poorly?	Family quality of service
39. Was there anything in particular that made getting services easier for you or your child(ren)?	Organizational facilitators
Additional Needs	
40. Is there anything else that you would like to tell us about your service needs or gaps in services, or barriers to care?	Considered open end



KEY INFORMANT INTERVIEW
PROVIDERS OF TITLE IV TARGET POPULATIONS
Los Angeles County
July 14, 2003

Provider:			
Informant:		Title:	
Contact Information:	Phone:	Phone2:	E-mail:
Interviewer:			
Date:			

We are conducting a needs assessment to determine the HIV and AIDS care needs of children, adolescents, and families. I am calling from _____, and while we have been hired by _____, your answers will never be linked with your name, and they will be reported in aggregate with other key informant interviews we are conducting. Thank you in advance for taking the time to answer a few questions.

1. First, can you tell me the services you provide to children, adolescents, women of childbearing age, and families? How they are funded or reimbursed? Now, about how much did you get from each funding source and what is the contract period for those funds?

POPULATION	Services (<i>PROBE</i> – see list)	Funding sources	About how much are you receiving from each of the funding sources for providing this service?	What is the contract period for the funding?
Children 0 -12				
Adolescents (13-19)				
Women of childbearing age				



POPULATION	Services (<i>PROBE</i> – see <i>list</i>)	Funding sources	About how much are you receiving from each of the funding sources for providing this service?	What is the contract period for the funding?
Families				

2. With your experience, list the top five services needed by each of these populations to improve or maintain their health status and quality of life? By “need” I mean need, regardless of whether they currently receive it or not. They can include services you don’t offer as well as the ones you noted above.

POPULATION	FIVE TOP SERVICE NEED
Children 0-12	1.
	2.
	3.
	4.
	5.
Adolescents (13-19)	1.
	2.
	3.
	4.
	5.
Women of childbearing age	1.
	2.
	3.
	4.
	5.
Families	1.
	2.
	3.
	4.
	5.

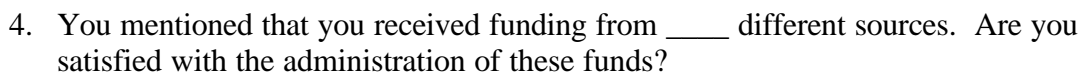
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3. Now, I would like you to think about gaps in services. From your perspective, what HIV/AIDS Care services do you feel are needed but are not adequately provided? Please tell us why you think it is not provided. (PROBE FOR BARRIERS).

POPULATION	SERVICES WITH LARGEST GAP	REASON(S) OR BARRIERS TO NOT OBTAINING SERVICE (<i>See List</i>)
Children 0-12	1.	
	2.	
	3.	
	4.	
Adolescents (13-19)	1.	
	2.	
	3.	
	4.	
Women of childbearing age	1.	
	2.	
	3.	
	4.	
Families	1.	
	2.	
	3.	
	4.	

Additional barrier comments:



5. What do you think that the different funding sources can do to streamline the processes for requesting and administering the funding for services to women, children, and families?

7. For all the services you provide to women, children, families, and youth, can you make any recommendations on how they could be provided better? Are there other models of service delivery that you think would work better?

8. Is there any other thing you would like to tell me about the needs of children, adolescents, women of childbearing age, and families?



Attachment 3 Service Assessment Grid

For each of the services below:

1. Under column A, note if you *needed* the service in the past year. Circle "1" for yes or "2" for no.
2. Under column B, note whether you *asked* for this service this past year.
3. Under column C, note if you *received* this service this past year.

At the end of each service group, please note the problems you faced in obtaining the services.

		A		B		C	
For each health care service below...		Did you <i>need</i> this service this past year?		Did you <i>ask</i> for this service this past year?		Did you <i>receive</i> this service this past year?	
		Yes	No	Yes	No	Yes	No
MEDICAL CARE							
1	Visits with a doctor, nurse, or assistant to take care of your on-going HIV treatment - Outpatient medical care.	1	2	1	2	1	2
2	Medical care by a specialist, including OB/GYN	1	2	1	2	1	2
3	Nutritional supplements, education, and counseling.	1	2	1	2	1	2
4	Dental care.	1	2	1	2	1	2
5	Home health care from a nurse or aide.	1	2	1	2	1	2
6	Hospice Services (In-home and residential)	1	2	1	2	1	2
7	Complementary care - includes acupuncture and traditional Chinese medicine.	1	2	1	2	1	2
8	Medication programs including ADAP that provides assistance obtaining and paying for HIV/AIDS related drugs.	1	2	1	2	1	2
9	Assistance paying health insurance premiums for those who have private health insurance.	1	2	1	2	1	2
When accessing medical services what problems do you have? (Write in)							

		Need it		Ask for it		Receive it	
		Yes	No	Yes	No	Yes	No
TRANSPORTATION							
10	Van transportation to HIV/AIDS services.	1	2	1	2	1	2
11	Taxi vouchers or bus tokens.	1	2	1	2	1	2
When accessing transportation services what problems do you have? (Write in)							



For each health care service below...		A		B		C	
		Did you <i>need</i> this service this past year?		Did you <i>ask</i> for this service this past year?		Did you <i>receive</i> this service this past year?	
MENTAL HEALTH & SUBSTANCE ABUSE SERVICES		Yes	No	Yes	No	Yes	No
12	Residential mental health services.	1	2	1	2	1	2
13	Individual or groups mental health therapy or counseling sessions	1	2	1	2	1	2
14	Peer counseling, support, or drop-in groups.	1	2	1	2	1	2
15	Outpatient substance abuse treatment or counseling.	1	2	1	2	1	2
16	24 hour-a-day residential substance abuse counseling.	1	2	1	2	1	2
17	Detox and / or methadone maintenance.	1	2	1	2	1	2
18	Prevention information and education on how to prevent the spread of HIV.	1	2	1	2	1	2
When accessing mental health and substance abuse services what problems do you have? (Write in)							

CASE MANAGEMENT		Need it		Ask for it		Receive it	
		Yes	No	Yes	No	Yes	No
19	Case management - someone to help you coordinate your HIV/AIDS care and help access benefits and provide referrals.	1	2	1	2	1	2
20	Medical case management and adherence support.	1	2	1	2	1	2
21	Case Manager (not a doctor or nurse) who helps you obtain treatment, medications, financial assistance, and benefits and assures coordinated access to care.	1	2	1	2	1	2
22	Employment Assistance - vocational counseling and training.	1	2	1	2	1	2
When accessing case management services what problems do you have? (Write in)							



For each health care service below...		A		B		C	
		Did you <i>need</i> this service this past year?		Did you <i>ask</i> for this service this past year?		Did you <i>receive</i> this service this past year?	
HOUSING		Yes	No	Yes	No	Yes	No
23	Housing information services - assistance in finding or getting housing.	1	2	1	2	1	2
24	Rental subsidy (NOT emergency financial assistance)	1	2	1	2	1	2
25	Housing that provides independent living with no on-site medical or case management	1	2	1	2	1	2
26	Residential housing or group home where there is 24-hour support such as case management or nursing.	1	2	1	2	1	2
27	Emergency of transitional housing for those who are homeless and in immediate need of housing.	1	2	1	2	1	2
When accessing housing services what problems do you have? (Write in)							

FOOD		Need it		Ask for it		Receive it	
		Yes	No	Yes	No	Yes	No
28	Food pantry or food banks (including nutritional supplements).	1	2	1	2	1	2
29	Food vouchers.	1	2	1	2	1	2
30	Home delivered meals.	1	2	1	2	1	2
When accessing food services what problems do you have? (Write in)							



For each health care service below...		A		B		C	
		Did you <i>need</i> this service this past year?		Did you ask for this service this past year?		Did you <i>receive</i> this service this past year?	
OTHER SERVICES		Yes	No	Yes	No	Yes	No
31	Emergency financial assistance, usually to pay rent, utilities, food, and clothing.	1	2	1	2	1	2
32	Legal services - preparing wills or estate planning; assistance with evictions and housing discrimination.	1	2	1	2	1	2
33	Adult day care, such as services provided at Continuum.	1	2	1	2	1	2
34	Day care for children during a caregiver's appointment for HIV/AIDS care.	1	2	1	2	1	2
35	Childcare	1	2	1	2	1	2
When accessing other services what problems do you have? (Write in)							



Attachment 4 Key Informant Report Guide
Coding Document for Key Informant Interviews with
Consumers of Ryan White Title IV Services, LA County

: Name			
Contact Information:			
Name of Interviewer:			
Date and time:	1:	2:	3:

1. Are you currently **(Circle number next to the answer)**

- HIV+ with disabling symptoms 1
HIV+ with no symptoms 2

2. Have you ever been told by your doctor, nurse, or other health care provider that you have AIDS?

- Yes 1
No 2

2a. IF DIAGNOSED WITH

AIDS, When were you
diagnosed with AIDS? Mo. Year

3. What do you consider your ethnic background?

- African American (Black) 1
Other non-Hispanic Black 2
Latino/Hispanic..... 3
Asian Pacific Islander (API)..... 4
Native American..... 5
White/Caucasian (non Hispanic) 6
Mixed Race **(Specify)** 7

Other **(Specify)** 8

4. Age..... Age

5. What is the most likely way you were infected by HIV? (Circle one)

- Having sex with a man 1
Having sex with a woman..... 2
Having sex with a transgender 9
Sharing needles 3
Blood products/Transfusion (blood or tissue recipient) 4
Hemophilia 5
Acquired at birth 6
Other
(specify) 7
Don't Know..... 8

6. How long have you known you've been HIV positive # Of Yrs

OPTIONAL			
6a. Has your T-Cell count?			
(Circle 1 for "Yes", 2 for "No" or 8 for "Don't Know")	Yes	No	Don't Know
Ever dropped below 500 cells/UL	1	2	8
Ever dropped below 350 cells/UL	1	2	8
Ever dropped below 200 cells/UL	1	2	8
Now dropped below 350 cells/UL	1	2	8
Now dropped below 200 cells/UL	1	2	8
6b. Has your viral load?			
(Circle 1 for "Yes", 2 for "No" or 8 for "Don't Know")	Yes	No	Don't Know
Ever rose above 30,000 copies	1	2	8
Ever rose above 10,000 copies	1	2	8
Currently above 10,000 copies	1	2	8

7. Do you ...			
	Yes	IF YES # HIV +	No
Live alone	1		2
Live with other adults (write how many)	—	—	2
Live with your children (write how many)	—	—	2

8. Where do you and your family go for HIV/AIDS medical care? (write provider's name)	How far is that from where you live? (in miles)
1.	
2.	
3.	
4.	
5.	

9. Would it be better if the entire family went to the same place for care?	
Yes	1
No	2
Advantages:	
Disadvantages:	



10. How important is having a clinic in your neighborhood?

Very Important	4
Somewhat important	3
Not very important.....	2
Not important at all	1

Reasons:

11. How is your (and your family's) HIV treatment paid for?

(Circle 1 for "Yes" or 2 for "No" for each item)	Yes	No
Insurance through work	1	2
COBRA or OBRA (insurance through my last employer)	1	2
Private insurance, not through work	1	2
Medicaid or MediCal	1	2
Medicare.....	1	2
SCHIP.....	1	2
Other (Specify)	1	2

INSURANCE

	Yes	No
Do you think you should be getting [better] insurance?	1	2
Does the insurance adequately pay for your child's HIV/AIDS health care?	1	2

12. Are you taking any medications?

(Circle 1 for "Yes", 2 for "No" or 8 for DK)	Yes	No	Don't Know
Combination therapy	1	2	8
Include antivirals or protease inhibitors	1	2	8
Antibiotics	1	2	8
Other medications	1	2	8

13. Is your HIV positive Spouse or Child[ren] taking any medications?

(Circle 1 for "Yes", 2 for "No" or 8 for DK)	Yes	No	Don't Know
Combination therapy	1	2	8
Include antivirals or protease inhibitors	1	2	8
Antibiotics	1	2	8
Other medications	1	2	8

14. In general, would you say that **today** your physical health is...

Excellent	4
Good	3
Fair	2
Poor.....	1

15. How would you rate your physical health now as compared to when you first sought treatment for your HIV infection?

Much better	5
A little better.....	4
About the same	3
A little worse	2
Much worse	1

16. In general, would you say that **today** your emotional health is...

Excellent	4
Good	3
Fair	2
Poor	1

17. How would you rate your emotional health now as compared to when you first sought treatment for your HIV infection?

Much better	5
A little better.....	4
About the same	3
A little worse	2
Much worse	1

18. At any time in the last two years have you been diagnosed with any of the following mental health problems?

(Circle 1 or "Yes" or 2 for "No" for each item)	Yes	No
Anxiety	1	2
Bipolar Disorder	1	2
Dementia	1	2
Depression.....	1	2
Other (specify)	1	2

19. In general, would you say that **today** your child or spouse's physical health is...

Excellent	4
Good	3
Fair	2
Poor	1

20. How would you rate your HIV+ child or spouse's physical health now as compared to when they first sought treatment for their HIV infection?

Much better	5
A little better.....	4
About the same	3
A little worse	2
Much worse	1



21. In general, would you say that today your child or spouse's emotional health is...

Excellent 4
 Good 3
 Fair 2
 Poor 1

22. How would you rate your HIV+ child or spouse's emotional health now as compared to when they first sought treatment for their HIV infection?

Much better 5
 A little better 4
 About the same 3
 A little worse 2
 Much worse 1

23. At any time in the last two years has your HIV+ child or spouse been diagnosed with any of the following mental health problems?

(Circle 1 for "Yes" or 2 for "No" for each item)	Yes	No
Anxiety	1	2
Bipolar Disorder	1	2
Dementia	1	2
Depression.....	1	2
Other (specify)	1	2

24. How often have you skipped taking your HIV/ AIDS medication as prescribed by your doctor?

Never / Have not skipped)..... 1
 Once or twice a month 2
 Once or twice a week 3
 More than twice a week 4
 I have stopped taking my medicine 5

25. If you've skipped or stopped taking your HIV/AIDS medication, why?

(Circle 1 for "Yes" or 2 for "No" for each item)	Yes	No
Side effects	1	2
Difficult schedule and requirements ...	1	2
Didn't want others to see the medications	1	2
Didn't understand the directions	1	2
Felt that medication didn't work.....	1	2
Could not afford medication	1	2
Forgot to take the medication	1	2
Ran out of medications	1	2
Hard to coordinate with food	1	2
Just did not want to take them.....	1	2
Homeless.....	1	2
Medication made me feel good so I felt I didn't need them anymore	1	2
My doctor advised me to stop taking my medications.....	1	2
Other (specify)	1	2

List some of their side effects:

26. How often have your children or spouse skipped taking HIV/ AIDS medication as prescribed by their doctor?

Never / Have not skipped 1
 Once or twice a month..... 2
 Once or twice a week 3
 More than twice a week 4
 Have stopped taking their medicine 5

27. If they have skipped or stopped taking their HIV/AIDS medication, why?

(Circle 1 for "Yes" or 2 for "No" for each item)	Yes	No
Side effects	1	2
Difficult schedule and requirements ...	1	2
Didn't want others to see the medications	1	2
Didn't understand the directions	1	2
Felt that medication didn't work	1	2
Could not afford medication	1	2
Forgot to take the medication	1	2
Ran out of medications	1	2
Hard to coordinate with food	1	2
Just did not want to take them	1	2
Homeless.....	1	2
Medication made them feel good so they felt they didn't need them anymore.....	1	2
Their doctor advised them to stop taking their medications	1	2
Other (specify)	1	2

List some side effects:

28. Do you find that there are times when you can't get your medication [or medication for your family)?

Yes 1
 No 2

Why?

29. Who usually gives you instructions on how to take and refill the medications for you (and your children)?



30. How often do you think you should see a doctor?	# of times a yr	
Do you go that often?	<u>Yes</u>	<u>No</u>
	1	2
Are there any problems in going to the doctor that often? What are they?		

31. How often do you think your HIV+ child or spouse should see a doctor?	# of times a yr	
Do they go that often?	<u>Yes</u>	<u>No</u>
	1	2
Are there any problems in going to the doctor that often? What are they?		

32. Since you found out you were HIV positive,		
(Circle 1 for "Yes" or 2 for "No" for each item)	<u>Yes</u>	<u>No</u>
Has there ever been a period of time of more than a year (12 months) when you didn't see a doctor or go to a clinic	1	2
Has there ever been a period of time of more than six months when you didn't see a doctor or go to a clinic?	1	2
Why?		

33. Has there ever been a period of time of more than six months when your child didn't see a doctor or go to a clinic for their HIV infection?	1	2
How long did it take you to start regular appointments after your child was born?	# of months	
If there was a delay in care, Why did you wait to take your child to see a doctor?		

34. Which of the following benefits do you receive?	(Circle 1 for "Yes", 2 for "No" or 8 for "Don't Know")		
	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
Food stamps	1	2	8
Long term disability	1	2	8
Short term disability	1	2	8
Supplemental Security Income (SSI)	1	2	8
Public Health Service, Bureau of Indian Affairs (BIA)	1	2	8
State Disability Insurance (SDI) ...	1	2	8
Social Security Disability Insurance (SSDI)	1	2	8
Veteran's benefits (VA)	1	2	8
CHAMPUS (VA Assistance for non-military personnel)	1	2	8
Worker's compensation	1	2	8
Annuity/Life insurance payments	1	2	8
Retirement	1	2	8
Rent supplement	1	2	8
Subsidized housing (HOPWA Subsidy, Section 8 certificate or Shelter Plus Care)	1	2	8
General Assistance (GA)	1	2	8
Emergency Financial Assistance	1	2	8
WIC	1	2	8
TANF/CalWORKS - formerly AFDC	1	2	8
Other (Specify)	1	2	8
Not eligible for benefits	1	2	8

35. Is the insurance sufficient to meet your [and your child's] need?	
Yes	1
No	2

36. Do you have adequate housing?	
Yes	1
No	2
What are the barriers to finding good housing?	

37. Is your living situation ...? (Circle 1 for "Yes" or 2 for "No" for each item)		
	<u>Yes</u>	<u>No</u>
Safe	1	2
Habitable (clean and livable)	1	2
Stable	1	2
Have you had to leave your housing?	1	2
Why?		
What could have prevented it?		



HOUSING	
38. For you, has stable housing been necessary for you to have before you could start scheduling and maintaining appointments with a doctor or a clinic for you or your child regularly?	
Yes	1
No	2
39. Do you have problems paying the electricity and other utility bills?	
Yes	1
No	2
40. Have you ever sought financial assistance to paying those bills?	
Yes	1
No	2
What was the outcome?	
(Complete end section of key informant interview outline)	
41. Are there any other HIV or AIDS services that you feel you need but are not available?	
42. In general, how would you describe the quality of the HIV care services you receive?	
43. What services work well?	
44. What services work poorly?	
45. In general, how would you describe the quality of the HIV care services your child receives? What works well? What doesn't work?	
46. Was there anything in particular that made getting services easier for you or you child[ren]?	
47. Is there anything else that you would like to tell us about your service needs or gaps in services, or barriers (problems) to care?	