



ATTACHMENT 1 Project Advisory Group Roster

Member	Affiliation
Michelle Bartz	AIDServe Indiana Inc.
Malinda Boehler	Wishard Health Services
Trevor D. Bradley	Indiana State Department of Health (ISDH)
Tim Brown	Consumer Advocate
Tracy Salsman	CAB At-Large Southern Region Rep.
Dr. Tom Brown	Ebenzer Foundation
Toney Calhoun Colis	
James Carr	
Josh Cazares	United Way of Monroe Co.
Carla Chance, RN	IN Primary Health Care Association, Inc.
Willis Coleman	Vice-Chair District #7 CAB
Bobbi Delon	Infectious Disease of IN
Jennifer Ford	
Tony Gillespie	Lake Co. Minority Health Division
Diana Gray	Damien Center, Inc.
Brad Gumbert	
Charles C. Hewitt	
Denise E. Ingram, M.D. - M.P.H.	Office of Medicaid Policy & Planning
Eileen Javurek, RN, BA	Wishard Health Services
Larry E. Jimison, Jr.	AIDServe Indiana Inc.
Kevin Johnson	ISDH
Bill Leisman	District 3 CAB Representative
Susan L. Keller, RN, MSN	Clarian Health Partners, Inc.
Kristen LaEace	AIDServe Indiana Inc.
Marlon Miller	
Lori Martin	ISDH
Lynn Nelson, RN, MSN	Area IV Agency on Aging and Community Action Prgms
Ron Purcell	IU AIDS Clinical Trials Unit
Juan E. Ramon	
George "Bud" Shipley, Jr.	District 12 Chairperson for IN HIV CAB
Debra M. Stanley	AIDS Ministries / AIDS Assist
Tony Teso	Vice-Chair – CHSPAC
Denise Travis, Ph.D.	Human Beginnings



INDIANA STATEWIDE NEEDS ASSESSMENT SURVEY OF PEOPLE LIVING WITH HIV AND AIDS

Sponsored by the Indiana HIV Planning Council and the Indiana State Department of Health

INTRODUCTION

Thank you for agreeing to participate in this important survey. Completing this survey gives you a voice in the planning of HIV and AIDS treatment services throughout the State of Indiana.

For each question below, circle or write in an answer. There are no right or wrong answers. Please take as much time as you need to answer each question based on your experiences. If you have any questions, please ask for assistance.

Your responses are completely confidential. Your name will never be linked to your answers. We ask some questions about your background because we need this information for analysis. However, this information will never be linked to your name.

Thank you in advance for completing this survey. Please go to the next page.

Confidential ID

We will be obtaining responses from many people living with HIV and AIDS over the next few weeks. In order to select a grand prize winner and to avoid duplication, please create a confidential identifier which you will place on the top of every page of your survey. This ID is unique to you, and will protect your confidentiality.

**What is the *first*
 initial of your
 first name**

**What is the *last*
 initial of your
 last name**

**What is the
 month of your
 birthday**

(For January
 through September
 use a leading "0"
 e.g. 01 for January)

**What is the day
 of your birthday**

(For days 1 - 9 use a
 leading "0" e.g. 01)

**What is the first
 letter of your
 mother's first
 name. (If don't
 know, the first
 letter of your
 father's first
 name)**

(01=Jan, 02=Feb, 03=Mar, 04=Apr, 05=May, 06=June, 07=July, 08=Aug, 09=Sept, 10=Oct, 11=Nov, 12=Dec)

Please copy the confidential identifier you have created to the top right of each page of the survey.

CIRCLE THE NUMBER CORRESPONDING TO THE ANSWER FOR EACH QUESTION

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

- HIV+ with symptoms 1
- HIV+ with no symptoms 2
- HIV negative..... 3
- Don't know HIV Status 4

Please see the interviewer.

Other (Specify)_____ 5

2. When were you born?..... / /
Mo. Yr.

3. Are you Hispanic/Latino(a)?
Yes 1
No 2

4. What best describes your race?
African American/Black 1
Asian 2
Native American/ Alaskan 3
Native Hawaiian or other Pacific Islander. 4
White/Caucasian 5
Multi-racial /Other(Specify) 6

5. Are you...
Male 1
Female 2
Transgender - Male identified..... 3
Transgender - Female identified..... 4

6. Do you consider yourself **(circle one)**
Heterosexual/Straight 1
Homosexual - Gay male 2
Homosexual - Lesbian..... 3
Bisexual..... 4

7. What language do you prefer to read and speak?
(Circle one)

	<u>Englis</u> <u>h</u>	<u>Spanish</u>	<u>Other</u>
Read.....	1	2	3
Speak.....	1	2	3

8. What is your highest level of education?
Grade school or some high school..... 1
Graduated high school/GED 2
Some college or technical/trade school ... 3
Completed college 4
Graduate school..... 5

9. Are you **(Circle one)**
Single (Never partnered/never married) .. 1
Partnered/Married..... 2
Divorced/Separated 3
Widowed/Surviving Partner 4

10. What is the zip code and County where you live?

_____ Zip _____ County

11. For each of the following, circle 1 (yes) or 2 (no).

	<u>Yes</u>	<u>No</u>
Are you currently homeless?.....	1	2
Do you feel safe in your current home?	1	2
Do you feel you will have to move soon?.....	1	2
Are you taking care of others who are HIV positive in your home? .	1	2
Is someone taking care of you at home?.....	1	2

12. How many.... **(Write the number in the box)**

Other adults are living with you?.....

Children and teens are living with you? ...

Write the ages of the children?_____

13. Is anyone else in your household HIV positive?

(Circle 1 for "yes", 2 for "no" or 8 for "Don't Know" for each item)

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
Partner/wife/husband.....	1	2	8
Adult family member or relative.....	1	2	8
Other adults	1	2	8
Children.....	1	2	8

(IF CHILDREN) Number of children HIV+ _____
(Write #)

14. Did anyone help you pay your mortgage/rent in the last year? **(Circle 1 for "Yes" or 2 for "No" for each item)**

	<u>Yes</u>	<u>No</u>
I pay for it myself, nobody helps.....	1	2
My family/spouse/partner helps.....	1	2
Friends help	1	2
Roommate helps.....	1	2
HOPWA/TBHA (rental assistance)....	1	2
Shelter Plus.....	1	2
Township Trustee	1	2
Section 8	1	2
AIDS Service Organization.....	1	2
Direct Emergency Financial Assistance (DEFA)	1	2
Other public or private agency helps	1	2

Which one(s)? **(list)**_____

CIRCLE THE NUMBER CORRESPONDING TO THE ANSWER FOR EACH QUESTION

15. What best describes your current work situation?
- Employed full-time 1
 - Employed part-time..... 2
 - Homemaker/Caregiver..... 3
 - Trial work period..... 4
 - Working part-time and on disability..... 5
 - Not working - on disability..... 6
 - Not working - applied for disability..... 7
 - Not working - looking for work 8
 - Not working - student 9
 - Other (Specify)..... 10

16. What is your household's estimated **yearly** income from all sources and before taxes?
- \$8,350 or less 1
 - \$8,351 - \$16,700..... 2
 - \$16,701 - \$25,050 3
 - \$25,051 - \$33,400 4
 - \$33,401 - \$41,750 5
 - \$41,751 - \$50,100 6
 - \$50,101 or more 7

GO TO Q. 17

GO TO Q. 16, TOP OF NEXT COLUMN

17. Over the last two (2) years, how long have you been...(Circle one answer for each of the items below)

	<u>Never</u>	<u>Less than a month</u>	<u>1-3 months</u>	<u>4 months to 1 yr.</u>	<u>More than 1 yr.</u>
In prison/jail	1	2	3	4	5
Homeless	1	2	3	4	5
Living in housing provided because you were homeless	1	2	3	4	5
Living in transitional, drug treatment, or half-way housing	1	2	3	4	5
On any housing or rental assistance waiting list	1	2	3	4	5
Living in subsidized housing	1	2	3	4	5

Next are a few questions about insurance.

18. Please tell us about your health insurance. Do you have ...(Circle 1 for "Yes" or 2 for "No")			18a. If insured, do you belong to an HMO?	
	<u>No</u>	<u>Yes</u>	<u>Yes, HMO</u>	<u>No, not a HMO</u>
Do you have any insurance (If no insurance, circle 2 and go to Q. 19.)	2	1	1	2
Private insurance through work	2	1	1	2
Private insurance - not through work.....	2	1	1	2
Insurance through my partner's/parent's plan at work.....	2	1	1	2
Insurance continuation from work through COBRA.....	2	1	1	2
Indiana Comprehensive Insurance Assoc. (ICHIA).....	2	1		
Health Insurance Assistance Program (HIAP)	2	1		
Early Intervention Program (EIP)	2	1		
EIP Limited - for vision and dental	2	1		
Ryan White Title III Benefits.....	2	1		
Medicaid	2	1	1	2
Medicare	2	1	1	2
Veteran Administration (V.A.).....	2	1	1	2
AIDS Substance Abuse Program (ASAP).....	2	1		
Hoosier Healthwise (Medicaid for those under 18 yrs. old)	2	1		
Other _____	2	1	1	2

CIRCLE THE NUMBER CORRESPONDING TO THE ANSWER FOR EACH QUESTION

19. Who pays for your insurance?
- | | <u>Yes</u> | <u>No</u> |
|---|------------|-----------|
| I pay for <i>all</i> of my own premium..... | 1 | 2 |
| I pay for <i>part</i> of my own premium..... | 1 | 2 |
| My employer pays for <i>all</i> of the premium..... | 1 | 2 |
| My employer pays <i>part</i> of the premium..... | 1 | 2 |
| Health Insurance Assistance Program (HIAP) | 1 | 2 |
| Don't know who pays..... | 1 | 2 |
| Other _____ | 1 | 2 |

20. Do you get insurance for your children through Hoosier Healthwise?
- | | |
|-----------------------------------|---|
| Yes..... | 1 |
| No..... | 2 |
| Not applicable - No children..... | 3 |

21. How much do you pay for insurance premiums out of your own pocket?
- | | |
|-----------------------------|---|
| Nothing/not applicable..... | 1 |
| Less than \$100/month..... | 2 |
| \$101 to \$200/month..... | 3 |
| \$201 - \$300/month..... | 4 |
| \$301 or more a month..... | 5 |

22. What is your insurance deductible (regardless of payor)?
- | | |
|-----------------------------|---|
| Nothing/not applicable..... | 1 |
| Less than \$500/year..... | 2 |
| \$501 to \$1000/year..... | 3 |
| \$1,001 - \$1,500/year..... | 4 |
| Over \$1,500 a year..... | 5 |

23. If you have Medicaid, what is your monthly Medicaid Spend Down Amount (Write amount in box)
- | |
|----|
| \$ |
|----|

24. Does your health insurance have... (Circle 1 for "Yes", 2 for "No" or 8 for "Don't Know")	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
Pre-existing conditions (won't pay for old medical problems).....	1	2	8
Limits on coverage that have stopped you from getting care.....	1	2	8

- 24a. How much do you pay for monthly drug copays?
- | | |
|------------------------------------|---|
| Nothing/not applicable..... | 1 |
| \$1 - \$2.99 per prescription..... | 2 |
| \$3 - \$9.99 per prescription..... | 3 |
| \$10 - \$25 per prescription..... | 4 |
| Over \$25 per prescription..... | 5 |
| Don't Know..... | 8 |

25. Over the past two years how long have you been without any insurance that covers treating HIV or AIDS treatment?
- | | |
|-------------------------|---|
| Never..... | 1 |
| Less than a month..... | 2 |
| 1 - 3 months..... | 3 |
| 4 months to a year..... | 4 |
| More than 1 year..... | 5 |

26. What program pays for your HIV/AIDS drugs? (Circle 1 for "Yes" or 2 for "No", or 8 for "Don't Know" for each item)	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
AIDS Drug Assistance Program (ADAP)	1	2	8
Indiana Comprehensive Health Insurance Association (ICHIA) / HIAP	1	2	8
Medicaid	1	2	8
V.A. Medical Assistance	1	2	8
Private Insurance or HMO	1	2	8
Patient Assistant Programs from drug companies	1	2	8
Clinical trials	1	2	8
Other (Specify) _____	1	2	8

27. Which of the following benefits did you receive in the past year? (Circle 1 for "Yes" or 2 for "No" for each item)	<u>Yes</u>	<u>No</u>
Food stamps	1	2
Long term disability (from work)	1	2
Social Security Disability Income (SSDI) - permanent disability	1	2
Supplemental Security Income (SSI)	1	2
VA Benefits	1	2
Rent supplement	1	2
Temporary Assistance for Needy Families (TANF) - formerly AFDC	1	2
Direct Emergency Financial Assistance (DEFA)	1	2

CIRCLE THE NUMBER CORRESPONDING TO THE ANSWER FOR EACH QUESTION

Add Service Question # 28 Here

CIRCLE THE NUMBER CORRESPONDING TO THE ANSWER FOR EACH QUESTION

29. BARRIERS TO SERVICES: Below is a list of barriers that can prevent people living with HIV and AIDS from obtaining treatment. For each item, circle the number indicating how big a barrier it is **for you:** a big barrier for you, a moderate barrier, a small barrier, or no barrier at all. A “big barrier” prevents you from obtaining services. A “moderate barrier” is one that causes concern and delays getting services. A “small barrier” causes minor concern and delay.

		Big Barrier	Moderate Barrier	Small Barrier	No Barrier	Not Applicable
1	Not knowing what treatment is available to me	4	3	2	1	0
2	The location of the organization providing services	4	3	2	1	0
3	Not knowing what services I need for treating my HIV infection	4	3	2	1	0
4	The level of expertise of the person providing the service	4	3	2	1	0
5	My state of mind or mental ability to deal with the services and treatments	4	3	2	1	0
6	The ability of the person providing services to speak to me in a language that I understand	4	3	2	1	0
7	My physical health	4	3	2	1	0
8	The lack of on-site child care when I go to get services and treatments	4	3	2	1	0
9	The quality of service	4	3	2	1	0
10	My thinking that I was not being affected by the infection (denial)	4	3	2	1	0
11	The amount of red tape and paperwork I had to fill out to get the service	4	3	2	1	0
12	My ability to talk and discuss my care with the service provider	4	3	2	1	0
13	The lack of sensitivity of the people providing the service to my issues and concerns	4	3	2	1	0
14	My concern that other people may see me when I go to get care or learn about my HIV infection (lack of confidentiality)	4	3	2	1	0
15	My ability to understand the instructions about services and treatment	4	3	2	1	0
16	My ability to find my way through the system	4	3	2	1	0
17	The agencies that provide service care will breach confidentiality.	4	3	2	1	0
18	The level of racial discrimination I felt from the people providing service	4	3	2	1	0
19	The organizations providing the service making me feel like a number	4	3	2	1	0
20	The amount of time I had to wait to get an appointment or see someone	4	3	2	1	0
21	Not having transportation	4	3	2	1	0
22	The cost of the service to me	4	3	2	1	0
23	Not having enough insurance coverage	4	3	2	1	0
24	The level of discrimination I felt from the people providing service because of my sexual orientation	4	3	2	1	0

CIRCLE THE NUMBER CORRESPONDING TO THE ANSWER FOR EACH QUESTION

		Big Barrier	Moderate Barrier	Small Barrier	No Barrier	Not Applicable
25	The ability to get the referrals to services I need	4	3	2	1	0
26	The level of discrimination I felt from the people providing service because of my HIV status or AIDS diagnosis	4	3	2	1	0
27	Not being eligible to obtain services because of rules and regulations	4	3	2	1	0
28	My concern that the services I need do not exist	4	3	2	1	0
29	The chance of being reported to the authorities	4	3	2	1	0
30	Adhering to or following the instructions for my medication	4	3	2	1	0
31	The lack of sensitivity of the service provider to my beliefs and spiritual concerns	4	3	2	1	0
32	Poor coordination among the organizations providing services	4	3	2	1	0
33	Not being able to get options about treatments from the people I go to for services	4	3	2	1	0
34	There is no single location where my HIV+ children and I can go for primary care	4	3	2	1	0
35	The lack of services for my family	4	3	2	1	0
36	My not having access to an HIV care treatment specialist	4	3	2	1	0
37	The lack of sensitivity of the service provider to my use of complementary treatment.	4	3	2	1	0
38	Other (specify) _____	4	3	2	1	0

CIRCLE THE NUMBER CORRESPONDING TO THE ANSWER FOR EACH QUESTION

30. Look back through the **list of 43 services** in Q. 28 (pages 4-7) and **check** the four services you need the most.

- Look below and in the box labeled "most important" write the numbers of the four most important services you checked from the 43 service items, for example if your most important service was "Visits to medical specialists such as skin, eye, intestinal tract, feet. (Not OB/GYN)", put 3 in the box and write a short description like "specialists".
- Then tell us if you feel these needs are being very well met, adequately met, poorly met or not met at all.
- As the final step, look back at the **list of barriers** in Q. 29, and list the biggest barrier to obtaining this service for you. For example, if you had listed "visiting medical specialists..." as your most important service and "the quality of service" was the biggest barrier to obtaining that service, write 9 in the box.

Please ask the interviewer for assistance with this question if you are unclear what to do.

a. Services needed by YOU	b. How well met? (Circle the number)				c. Write in the biggest Barrier for you from the list in Q 29. Use the Barrier NUMBER to identify them.
List top 4 services from the list in question 28 in order of their importance to you. Use the Service NUMBER to identify them.	<u>Very well</u>	<u>Ade- quately</u>	<u>Poorly</u>	<u>Not met at all</u>	
Most important:	4	3	2	1	Barrier
2 nd most important:	4	3	2	1	Barrier
3 rd most important:	4	3	2	1	Barrier
4 th most important:	4	3	2	1	Barrier

CIRCLE THE NUMBER CORRESPONDING TO THE ANSWER FOR EACH QUESTION

Next, a few questions about your HIV infection and health

31. How did you find out you were HIV positive?
- When you requested an HIV test through an HIV testing site or your physician 1
- When you went to your physician for treatment or physical exam (not specifically requesting HIV test).... 2
- When you went to the hospital for something else (not specifically requesting HIV test)..... 3
- As part of a physical exam for employment or the military 4
- FOR WOMEN:** As part of your care while pregnant 5
- Other (**Specify**)..... 6
32. What was the month and year that you first tested positive for HIV? Mo. Yr.
33. How many times have you been tested for HIV infection in each of the sites below?
(Write # of times tested for each site. Write "0" if never tested at the site or "DK" if you WERE tested at that site, but do not remember how many times.)
- | | |
|--|--|
| Counseling and Testing Center..... | |
| Community based clinic..... | |
| Health Department..... | |
| Hospital clinic or emergency room..... | |
| Hospital inpatient facility..... | |
| Private Physician's office..... | |
| VA Hospital..... | |
| Other (Please specify)..... | |
34. Have you been told by your doctor that your HIV infection has progressed to AIDS?
- Yes..... 1
- No..... 2
35. **If you have AIDS**, What was the month and year when you were first told that you had AIDS? Mo. Yr.
36. How long after you learned you were HIV positive, did you receive medical care from a physician or nurse related to your HIV infection? (**Circle one**)
- Have not received medical care..... 1
- Within a month 2
- Within 6 months 3
- Within a year..... 4
- After more than a year..... 5
- Don't remember 6
37. What is the most likely way you were infected with HIV? (**Circle one**)
- Same sex contact..... 1
- Opposite sex contact..... 2
- Sharing needles 3
- Born with HIV..... 4
- Blood transfusion or products/Hemophilia. 5
- Other (**Specify**) 6
- Don't know 8
38. What was your highest and most recent viral load? (**Write count, month & year; if don't know circle 9998**)
- | | | | | |
|---|-------|----|-----|-----|
| a. Highest viral load count | Count | In | Mo. | Yr. |
| b. Most recent viral load count | Count | In | Mo. | Yr. |
| Don't know (Circle) | 9998 | | | |
| Never had viral load test (Circle) | 9999 | | | |
39. What was your lowest and most recent T-cell count? (**Write count, month & year; if don't know circle 9998**)
- | | | | | |
|---|-------|----|-----|-----|
| a. Lowest T-cell count | Count | In | Mo. | Yr. |
| b. Most recent T-cell count | Count | In | Mo. | Yr. |
| Don't know (Circle) | 9998 | | | |
| Never had T-Cell count measured (Circle) | 9999 | | | |
40. At any time in this or last year, have you been diagnosed with any of the following diseases listed below? (**Circle 1 for "yes", 2 for "no" or 8 for "Don't Know"**)
- | | Yes | No | Don't Know |
|-----------------------|-----|----|------------|
| Hepatitis A or B..... | 1 | 2 | 8 |
| Hepatitis C..... | 1 | 2 | 8 |
| Syphilis..... | 1 | 2 | 8 |
| Herpes (genital)..... | 1 | 2 | 8 |
| Gonorrhea..... | 1 | 2 | 8 |
| Chlamydia..... | 1 | 2 | 8 |
| Genital warts..... | 1 | 2 | 8 |

CIRCLE THE NUMBER CORRESPONDING TO THE ANSWER FOR EACH QUESTION

41. Have you ever been diagnosed with active or inactive Tuberculosis (TB)?
- No 1
 Yes, have inactive TB..... 2
 Have active TB, in treatment..... 3
 Have active TB, not in treatment 4
 Don't know..... 8
42. In general, would you say that today your physical health is...
- Excellent 4
 Good 3
 Fair 2
 Poor 1
- 42a. 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
43. In general, would you say that today your emotional health is...
- Excellent 4
 Good..... 3
 Fair 2
 Poor 1

44. 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

45. At any time in this or last year 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 |
|--------------------------------|------------|-----------|
| Bipolar Disorder | 1 | 2 |
| Anxiety | 1 | 2 |
| Dementia..... | 1 | 2 |
| Depression | 1 | 2 |
| Other (Specify) _____ | 1 | 2 |

46. At any time in this or last year, have you received any of the following? (**Circle 1 "Yes" or 2 "No" for each item**)
- | | Yes | No |
|---|------------|-----------|
| Individual counseling/therapy..... | 1 | 2 |
| Group counseling/therapy | 1 | 2 |
| Medication for psychological or behavioral problems?..... | 1 | 2 |

47. The following questions are about the activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Limited a lot – need help	Limited a little – need some help	Not limited at all – don't need help
Vigorous activities (i.e. lifting heavy objects, participating in strenuous sports)	1	2	3
Moderate activities (i.e. moving a table, carrying groceries or bowling)	1	2	3
Ability to wash entire body (take a bath)	1	2	3
Ability to get to and from the toilet or bedside commode	1	2	3
Ability to move from bed to chair, on and off toilet, into and out of tub or shower, and ability to turn and position self in bed	1	2	3
Ability to safely walk, once in a standing position, or use a wheelchair, once in a seated position, on a variety of surfaces	1	2	3
Ability to feed yourself meals and snacks - does not include food preparation	1	2	3
Taking medications (ability to prepare and take all prescribed medications reliably and safely, including administration of the correct dosage at appropriate times)	1	2	3

47a. Recently, how much of the time (**Circle 1 for all of the time, 2 for most of the time, etc.**)

	All of the time	Most of the time	A good bit of time	Some of the time	A little of the time	None of the time
Have you had difficulty reasoning and solving problems (i.e. making plans, making decisions, learning new things)?	1	2	3	4	5	6
Do you forget things that happened recently (i.e. for example, where you put things and when you had appointments)?	1	2	3	4	5	6
Difficulty doing activities that involve concentration and thinking?	1	2	3	4	5	6

CIRCLE THE NUMBER CORRESPONDING TO THE ANSWER FOR EACH QUESTION

The following questions ask about medication and side effects

48. Have you ever taken any HIV medication?

- Yes..... 1 **GO TO NEXT QUESTION (Q. 48a)**
- No..... 2 **GO TO NEXT PAGE (Q. 54)**

48a. Are, or were you, on (Circle 1=Yes or 2=No for each item)

- | | <u>Yes</u> | <u>No</u> |
|---|------------|-----------|
| Combination Therapy (more than one antiretroviral and/or protease inhibitor)? | 1 | 2 |
| Early treatment with antiretrovirals (treatment before being diagnosed with AIDS) | 1 | 2 |

50. How often have you skipped taking your medication as prescribed by your doctor?

- Never / Have not skipped (Go to Q. 53)..... 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

49. What are, or were, the side effects of your medication(s)? (Circle Yes or No for each item)

- | | <u>Yes</u> | <u>No</u> |
|--|------------|-----------|
| Headaches | 1 | 2 |
| Stomach Pain..... | 1 | 2 |
| Neuropathy (tingling or pain in legs and feet) | 1 | 2 |
| Nausea and vomiting | 1 | 2 |
| Dizziness..... | 1 | 2 |
| Diarrhea..... | 1 | 2 |
| Fatigue..... | 1 | 2 |
| Weight loss | 1 | 2 |
| Other (Specify)..... | 1 | 2 |
| Other (Specify)..... | 1 | 2 |
| Other (Specify)..... | 1 | 2 |

51. IF SKIPPED OR STOPPED TAKING MEDICATION, How did you decide to skip or stop taking your medication?

- With the advice of your doctor..... 1
- Without the advice of your doctor 2

52. IF SKIPPED OR STOPPED TAKING MEDICATION, why? (Circle Yes or No for each)

- | | <u>Yes</u> | <u>No</u> |
|---|------------|-----------|
| 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 |
| Other (Specify) | 1 | 2 |

53. Are you taking any herbal supplements, vitamins, or dietary supplements? If yes, note if you are taking it with the advice of your doctor.

53a. IF YES, Are you taking it specifically to control your HIV infection or AIDS or side effects of that medication?

	<u>No</u>	<u>Yes, with my doctor's advice</u>	<u>Yes, without my doctor's advice</u>	<u>Yes</u>	<u>No</u>
Herbal supplements such as St. John's Wort, Kava Kava or Gingko?	2	1	3	1	2
Vitamins / antioxidants	2	1	3	1	2
Dietary Supplements	2	1	3	1	2
Other (Specify) _____	2	1	3	1	2

CIRCLE THE NUMBER CORRESPONDING TO THE ANSWER FOR EACH QUESTION

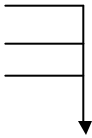
	Ever used		If used in last 12 months			
	No	Yes	Not used in last 12 months	Used less than once a month	Used at least once a month	Used once a week or more
Alcohol	2	1	1	2	3	4
Marijuana or hash	2	1	1	2	3	4
Crack	2	1	1	2	3	4
Heroin	2	1	1	2	3	4
Crystal Meth or Methamphetamines	2	1	1	2	3	4
Ecstasy	2	1	1	2	3	4
Speedball	2	1	1	2	3	4
Poppers	2	1	1	2	3	4
Pills not prescribed by my doctor (Specify) _____	2	1	1	2	3	4
Other substances (Specify) _____	2	1	1	2	3	4

54b. **IF YOU HAVE USED ANY SUBSTANCES**, Have you ever injected any substances not prescribed by a medical person?

- Yes 1
- No 2

55. Where were you born?

- a. The United States 1 **(CIRCLE ANSWER, GO TO 56)**
- b. Mexico 2
- c. Puerto Rico or other US Territories 3
- d. Other (Specify) _____ 4



55a. **IF NOT BORN IN US**, in what year did you first come to the US?

Yr.

55b. How would you describe your residency status in the United States?

- a. Citizen 1
- b. Have a visa (student, temp or permanent) 2
- c. Have legal refugee or on asylum status 3
- d. Undocumented 4
- e. Other _____ 5

CIRCLE THE NUMBER CORRESPONDING TO THE ANSWER FOR EACH QUESTION

56. In your own words, when you think of the next few years, what are the major challenges you expect to face in order to maintain and improve your quality of life **(Continue on the other side if necessary)**

57. Do you know anybody who is living with HIV or AIDS, and is not seeing a doctor or getting treatment services?

No 2

Yes 1

57a. **IF YES**, Would you give them a postcard saying where they can call us to complete a survey?

Yes 1

No 2

58. **IF YOU ARE A PARENT WITH CHILDREN LIVING AT HOME OR KNOW OF A PERSON CARING FOR AN HIV+ CHILD**, Would you be willing to be contacted again to provide more information about your needs as a parent or caregiver?

Yes 1

No 2

59. **(Optional)** Before we finish this survey, do you have any other comments about your satisfaction with the way you get HIV or AIDS related services, with the outcome of these services or other HIV and AIDS related services provided to you.? **If not enough space, please continue your comments on the other side.**

Thank You! Please return the survey to the assistant.

CIRCLE THE NUMBER CORRESPONDING TO THE ANSWER FOR EACH QUESTION

**FOR OFFICE USE
FIELD INTERVIEWER COMPLETE**

Mode of transmission

- MSM 1
- IDU 2
- Heterosexual Transmission 3
- MSM/IDU 4
- Adult Hemophiliac/blood products 5
- Don't Know (DK) 8

Race/Ethnicity (check all that apply)

- White 1
- African American 2
- Hispanic/Latino 3
- Asian/Pacific Islander 4
- Native American/Alaskan Native 5
- Mixed Race 6
- Don't Know (DK) 8

Gender

- Man 1
- Woman 2
- Transgender 3

Special Population

- None 0
- Undocumented 1
- Rural 2
- Over 55 3
- Women w/ children 4
- Adolescents 5
- Out of care 6

Source (FILL IN IF KNOWN)

- CCS 1
- ADAP/HIAP 2
- Surveillance 3
- Convenience 4

Interviewer #

Seq. Identifier

Location

Gary 1	Muncie 5	Richmond 9
South Bend 2	Peru 6	Bloomington 10
Ft. Wayne 3	Indianapolis 7	Jeffersonville 11
Lafayette 4	Terre Haute 8	Evansville 12



ATTACHMENT 3 Focus Group Outline

Focus groups will take place after consumers have completed a survey. The outline that follows is a guide for the facilitator and not a strict set of questions. In general, the topic areas will be opened with more general statements such as those found after each topic number. Additional probes (noted with bullet points) would be used if those subtopics don't come up as part of the conversation.

The overall length is just over an hour and half, but it requires excellent facilitation and moving through the list of items. The key sections are the services and barriers.

They require that the attachments be made up in large format and taped to the walls, with additional smaller version available for focus group participants to view on the table in front of them. Since the facilitator and assistant will write on them, there will be a set for each group.

The information and referral items are often brought up in the discussion of services and barriers, and often do not have to be asked. They are provided to be sure they are covered.



FOCUS GROUP OUTLINE FOR PEOPLE LIVING WITH HIV/AIDS

Prepared for the Indiana Statewide HIV/AIDS Needs Assessment

by The Partnership for Community Health

July 2000

QUESTION	CONCEPT - NOTES	TGT TIME
1. Set up ground rules: purpose, confidentiality, incentive, taping.	INTRO	5 min.
2. Please introduce yourself – first name only --and tell the others in the group a little about yourself, including: <ul style="list-style-type: none"> • How long you have known that you have been HIV positive • Have you had any symptoms or opportunistic infections related to your HIV infection? • Are you on any medication? (PROBE FOR ANTI RETROVIRAL AND PROPHYLAXIS, COMBINATION THERAPIES) • How long after you found out that you were infected with HIV did you seek services? 	Warm up Stage of infection Out-of-care Medication	10 min

These next question have to do with your need for services when you first found out were positive and your need for services now.

3. What are the HIV and AIDS care services you needed when you first found out you were HIV positive and what are the services you need now? Which ones are the most important to you? You can use the list we have put on the wall to help (ASSISTANT CHECKS OF ON LISTS, PROBE FOR INSURANCE NEEDS) <ul style="list-style-type: none"> • When you first found out, which services did you have the greatest need for? Did you get them? Were you offered options for referrals for medical care? • which do you have the greatest need for now? • Are there any on the list that you did not know about? Now that you know about them, are any of them important to you? (Among women probe for gynecological care). 	Initial and current needs and prioritizing service needs. Knowledge	20 min
4. What are the HIV and AIDS care services you anticipate needing in the future? Why?	Top of mind: future needs.	5 min
5. For (READ GREATEST NEED SERVICES), how would you describe the quality of the _____ services you receive? Are you satisfied with the services? Tell me why you are satisfied / unsatisfied -- what was good or bad about the service? (GET BOTH GOOD AND BAD EXPERIENCES)	Quality of service Satisfaction	5 min



Barriers

<p>6. What barrier did you in receiving (SPECIFIC SERVICES MENTIONED; GREATEST NEED). Now, look at the barrier lists on the wall and tell me if you had any of these barriers?</p> <ul style="list-style-type: none"> • First, Were there rules and regulations that kept you from seeking or obtaining care such eligibility for care.. • Next, were there personal issues that kept you from seeking or obtaining services such as language, fatigue or sickness, lack of awareness of the services, fear of confidentiality? • Do you feel that medical treatments are available and accessible to you? How informed are you about the new medications? Where do you get your information on medications? Have the benefits and side-effects been explained to you? • For those not on medication, did you know about them? Why did you choose not to take medication? What are some of the feelings that you had that kept you from seeking treatment? (PROBE FOR DENIAL, KNOWLEDGE, FEAR, etc.) • Now, were there any obstacles that kept you from going to any agency or provider of services such as their location or reputation? • Finally, once you were at the agency, was there anything that prevented you from getting the services you needed such as filling in papers or waiting for approval, waiting time for appointments, lack of sensitivity on the caregivers part, poor referral, or lack of sensitivity to your needs. What has been your experience with service providers? Please be specific -- you can name specific providers or care givers -- your comments are completely confidential. 	<p>Barriers - Top of mind.</p> <p>Rules and regulation barriers. Personal level barriers</p> <p>Knowledge & understanding</p> <p>Treatment barriers</p> <p>Organizational barriers</p> <p>Highlight knowledge and experience with providers. Probe for specificity.</p>	<p>15 min.</p>
<p>7. For those not on medication, did you know about them? Why did you choose not to take medication? What are some of the feelings that you had that kept you from seeking treatment? (PROBE FOR DENIAL, KNOWLEDGE, FEAR, etc.)</p>	<p>Barriers</p>	<p>5 min</p>

Information & referrals

<p>8. How did you learn about the organization(s) that you go to for services?</p>	<p>Information, referrals</p>	<p>5 min.</p>
<p>9. Are there any HIV or AIDS services you feel you need but cannot find?</p>	<p>Demand and unmet demand.</p>	<p>5 min.</p>
<p>10. Do you feel you know how to get through the system? Have you had good luck with referrals from one service to another? Do you need help? How many of you have a case manager? What has been your experience with case-managers? Do you want the same case manager to stay with you throughout your infection or would you like to access a different person for different problems? Does anyone other than your case manager advocate for your care?</p>	<p>Demand for case management and difference between client advocacy and case management.</p>	<p>5 min.</p>

Adherence

<p>11. Many people living with AIDS find it difficult to adhere to the schedule of taking drugs. What is your experience with adhering to the schedule of medication? (PROBE FOR SIDE EFFECTS)</p>	<p>Adherence & compliance</p>	<p>5 min</p>
--	-----------------------------------	--------------



Special Population Needs

12. What are the specific challenges or difficulties you face because you are -----?	Special population needs	5 min
13. Are there special needs of your community? What are they? Are they available?	Special population needs	5 min.

Information needs

14. (OPTIONAL IF TIME) Where do you usually get information about health issues? (PROBE FOR: friends, family, community members, health services, media).	Information	--
---	-------------	----

Recommendations

15. We all have the benefit of hindsight, that is knowing what you know now, what would you have done differently to treat your HIV infection?	Recommendation for initial service needs.	5 min.
16. Is there anything else you would like to tell us about your service needs or gaps in services, or barriers to care?	Considered open end	



ATTACHMENT 14 INDIANA Focus Group Coding Schema

INSTRUCTIONS

The attached coding sheet and codes are to be used in coding focus groups.

In the coding sheet the first two columns are for date and time of the focus group. These can be coded at the same time for each group.

The next two columns are for the risk group and ethnicity of the participant. Codes are in the “code” worksheet. If the focus group participants are the same ethnicity or risk factor these can be coded prior to or after the group.

The name should be the first name of the participant or a pseudonym. While you can type in the first name of the respondent while coding, be sure to change it before any distribution to protect the confidentiality of the participant.

The next column is for the actual quote.

Once the quote is typed in, then it has to be coded for the service and barrier. Use the codes in the “code” worksheet. If there is more than one applicable code, separate the code by a comma.

Once this is done, we can sort using EXCEL by any of the categories, or we can enter it into a database for analysis.



Focus Groups Services Codes

#	Services	Service Code
39	Adult day care	ADC
38	Adoption/foster care assistance	Adopt
20	An advocate to help resolve legal issues or access to care	Advocate
37	Baby-sitting or child care services	CC
19	Case management – someone to help you coordinate your HIV / AIDS health care	CM
18	Direct Emergency Financial Assistance (for utilities, drugs, etc...)	DEFA
22	Dental care	Dental
21	Drug reimbursement – assistance in paying for HIV / AIDS related drugs	Drug \$
28	Place to obtain food / food bank	Food Bank
11	Assistance obtaining health insurance	HlthIns
30	Home health care from nurse or professional home health agency	HHC
32	Hospice care where terminally ill PLWH/A live during the end stage of AIDS	Hospice
15	Assistance in locating or obtaining long term housing	Housing LT
14	Assistance in finding or getting emergency or transitional housing.	Trans
7	Information about treatments and care and health from peers or providers	Info
12	Assistance paying health insurance premiums	Ins
13	Assistance getting medical services or drugs that your health insurance does not cover.	Ins – add svc
4	Lab tests for infections such as viral loads or t-cell counts	Labs
23	Legal services	Legal
29	Home-delivered meals	Meals
25	Mental health therapy with a psychologist or social worker in individual or group sessions	MH
8	Newsletters, leaflets, booklets, or resource guide about HIV / AIDS treatment and care	Newsletter
6	Nutrition Education and Counseling	Nutrition
2	Appointments with OB/GYN specialist.	OB/GYN
42	Other care coordination services (such as Family Care and Prenatal Care Coordination)	Other care
1	Appts w/ a dr, nurse or their assistants in an office or clinic for a problem or to monitor your HIV infection	Out
3	Visits to medical specialists (ear, nose, throat, not OB/GYN)	Out – spec
26	Peer counseling, support groups, drop-in grps conducted by a nonlicensed counselor/social worker	Peer
9	Information about how to prevent infecting others with HIV	Prev
27	Referral to services	Ref
41	Rehabilitative services like physical therapy authorized by your doctor or medical provider	Rehab
17	Rent or mortgage assistance	Rent
10	Resource Guide that lists HIV/AIDS services	Resource
35	Home or community based assistance to provide relief to the caregiver (respite care)	Respite
33	Substance abuse treatment or counseling sessions (outpatient)	SAT
34	Substance abuse treatment in a 24-hour-a-day residential setting	SAT24
16	Translation or interpretation services	Translat
5	Transportation assistance to access physical or mental health care on regular /emergency basis	Trans
36	Employment assistance/vocational counseling and training	Voc
40	Volunteers/peers who assist w household/personal tasks & provide support (buddy/companions)	Vols
24	Holistic or complementary, including acupuncture, massage or chiropractic practitioner	Well
	Not in service	NIS
	Over 55	55



Focus Group Barrier Codes

#	BARRIER	BARRIER CODE
19	The organizations providing the service making me feel like a number	#
30	Adhering or following the instructions for my medication	Adhere
28	My concern that the services I need do not exist	Avail
8	The lack of on site child care when I go to get my treatments	CC
12	My ability to talk and discuss my care with the service provider	Com
33	Not being able to get options about treatments from the people I go to for services	Com – Treat
15	My ability to understand the instructions about treatment	Comprehension
14	My concern that other people may see me when I go to get care or learn about my HIV infection (lack of confidentiality)	Conf
17	The agencies that provide service care will breach confidentiality.	Breach
32	Poor coordination among the organizations providing services	Coord
22	The cost of the service to me	Cost
10	My thinking that I was being affected by the infection	Denial
26	The level of discrimination I felt from the people providing services because of my HIV status or AIDS diagnosis.	Disc- H/A
24	The level of discrimination I felt from the people providing service because of my sexual orientation.	Disc- Sex Orient
18	The level of racial discrimination I felt from the people providing services.	Racism
	Not eligible for services	Eligible
4	The level of expertise of the person providing the service	Expert
35	The lack of services for my family	Family
23	Not having enough insurance coverage	Ins
3	Not knowing what services I need for treating my HIV infection	Know – services
1	Not knowing what treatment is available to me	Know – treat
6	The ability of the person providing services to speak to me in a language that I understand	Language
2	The location of the organization providing services	Loc
34	There is no single location where my HIV+ children and I can go for primary care.	Loc – single
5	My state of mind or mental ability to deal with the treatment	MH
16	My ability to find my way through the system	Navigate
7	My physical health	PH
9	The quality of service	Quality
11	The amount of red tape and paperwork I had to fill out to get the service	Red
25	The ability to get the referrals to services I need	Ref
29	The chance of being reported to the authorities	Reported
27	Not being eligible to obtain services because of rules and regulations	Rules
31	The lack of sensitivity of the service provider to my beliefs and spiritual concerns	Sense – beliefs
37	The lack of sensitivity of the service provider to my use of complimentary treatment.	Sense – comp tx
13	The lack of sensitivity of the people providing the service to my issues and concerns	Sense – concerns
36	My not having access to an HIV care treatment specialist	Spec
	Discontinuation of Service	Stop
21	Not having transportation	Trans
20	The amount of time I had to wait to get an appointment or see someone	Wait
	Homeless	Homeless
	Jail	Jail
	Prevention	Prevention
	Quality of Life	Quality
	Rural	Rural
	Side effects	Side
	Comparison to other cities	Compare