


Draft Results: Indiana Consumer Survey

A Component of the 2009 HIV Services Needs Assessment

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Background

- Even though advances in HIV/AIDS care over the last decade have led to dramatic decreases in HIV related morbidity and mortality, many of the afflicted continue to go undiagnosed, experience difficulty adhering to HIV medications, and have trouble getting health care. Hence, many continue to experience poor health outcomes.
- These disparities have been a major concern for HIV affected communities served by programs funded through the Indiana State Department of Health, HIV/AIDS division (ISDH).
- ISDH turned the development and administration of their 2009 health needs assessment of the HIV-infected population to the Comprehensive HIV Services and Planning Council (CHSPAC).

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HIV Needs Assessment

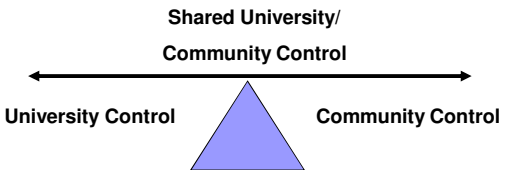
- Collaborators:
 - ISDH, CHSPAC, IUPUI (Sociology, IRSI [Institute for Research on Social Issues], Indiana Compact and Center for Service and Learning), Walgreens Pharmacy
- Purpose:
 - Examine the care and support-services utilization experiences of the Indiana HIV-infected population
 - With particular attention directed to uncovering any critical gaps in the provisions of the state's HIV related services.

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Methods

- **Community based participatory research model** (involves the HIV affected community at nearly every stage of the research process)

Shared University/
Community Control



University Control Community Control

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Methods

- Primary Data from Three Sources
 - Consumer self administered mail survey (data collection completed June 2009, report pending)
 - Provider self administered on-line survey (data collection completed June 2009, report pending)
 - Consumer focus groups (postponed until 2010; needs more extensive planning)

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Consumer Sample

- 746 Care Coordination Clients
- 8% of Indiana HIV/AIDS population
- 25% of CC Clients
- All CC regions represented
- 80% Male, 19% Women 1% Transgender
- 21% Black, 69% White, 7% Hispanic, 3% other
- 89% Living at 225% of the 2009 federal poverty level
- 18% Have children in the home
- 30% were in poor-fair health, the rest were doing good-excellent
- Most in CC greater than 12 months (85%)

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Provider Sample

- 103 HIV Care Providers
- All regions represented
- Who are they?
 - 17% Program Managers (mostly CC)
 - 45% Care Coordinators
 - 19% Clinical Care Providers
 - 4% HIV Prevention and Testing
 - 4% Pharmacist
 - 11% Other
- See handout in packet for quick provider results.

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HIV Primary Care

- **In the past 12 months,**
 - 17% had difficulties getting an appt.
 - 8% had not sought HIV care
 - 10% >than 6 months since having HIV labs
 - 14% sought HIV-related care in an ER because they were unable to get an HIV care appointment
- **Comments**
 - Lack of infectious disease providers and patient choice
 - Difficulties getting appointments
 - Provider insensitivity

There is only one Dr. for HIV here. I usually had to wait more than 30 days for an appointment or go to an ER or walk in clinic which sucks! (Region 10)

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HIV Medications

- **Of those on medications (341), in the past year**
 - 59% had difficulties getting their medication because of lack of health insurance
 - 67% had difficulties getting their medication because of difficulties with co-pays
- **Comments**
 - Most center on difficulty affording

*"I have not been on HIV meds for over 4 months cause I can't afford them (Region 6) *I have Medicaid but have a 1200 month spend-down so cannot see a doctor or get my meds (Region 7) *Bioscript sends one month at a time. Due date is April 21. They send a supply on the 21 fed x blue. So there are times the HIV meds stop for 3 days. It would be better to send the meds a week early (Region 7)*

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HIV Case Management

- **In the past year...**
 - 18% had difficulty getting care coordination services at least once, a quarter of these had trouble four or more times.
 - 15% never feels comfortable sharing their problems with their care coordinator
 - an additional 17% only sometimes feel comfortable.
- **Comments**
 - Uninformed CC
 - Lack bilingual CC
 - Lack of CC in area
 - Difficulties reaching CC
 - Difficulties getting appts
 - CC Turn-over issues

**When I first went on Medicare at 65, my CC at the time was not aware of MDAP (Region 10) *it hurt my feelings that the Damien Center no longer cares about its older clients to even return a phone call (Region 9) *Stop changing them every 6 months to a year. I don't like to get close then you lose hem. I feel that is wrong (Region 1)*

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Case Management Works!

	N	1-12 Months	> 12 Months	Change	P
Been homeless or living in unstable housing at least once in the last 30 days.	711	14%	8%	-6%	<.05
Missed work at least once in the last 30 days due to homelessness or unstable housing.	720	14%	6%	-8%	<.01
Had trouble getting HIV medications (lack insurance).	334	80%	54%	-26%	<.001
Had trouble getting HIV medications (difficulty paying).	348	78%	66%	-12%	<.05
Did not seek any dental care in the last 12 months.	702	37%	27%	-10%	<.05
Had trouble getting mental health care in last 12 months.	367	35%	17%	-18%	<.01
Had trouble getting HIV medical care appointments in the last 12 months.	656	25%	15%	-10%	<.05
Did not seek any HIV medical care in the last 12 months.	710	17%	6%	-11%	<.001

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Oral Care

- **In the past year**
 - 28% did not seek dental care
 - 47% of those who sought had trouble
 - 43% said dental care ranks as their most needed non-HIV service
- **Comments (over 100 clients)**
 - Lack coverage, ability to pay
 - HIV meds cause teeth decay
 - HIV exacerbates oral problems
 - Dental residency restrictions
 - Discrimination and stigma

** Provide dental. Twenty years of medications has done a lot of damage to my teeth (Region 12).*

** Can't afford out of pocket but need teeth removed because of recurring infections due to HIV status. Therefore my health is always poor. (Region 4).*

** Dentists are afraid to provide services to HIV patients (Region 6).*

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Mental Health and Substance Abuse Care

■ Top non-HIV related service

- 12% Mental Health Services
- 2% Alcohol and Substance Abuse Services
- 15% Had missed work, school, or a doctor's appointment due to mental distress at least four times in the last 30 days.
- 20% of people who sought MH services had difficulty accessing
- 6% of those who sought drug and alcohol services had difficulties obtaining such services.

■ Comments

- Need more MHSA Services
- Being unhappy with MH options
- High prevalence of in HIV pop

**Dealing with the stigma of HIV in society makes so many of us unstable mentally or turn to drugs/alcohol to deal (Region 7). * Places that provide mental health along with HIV treatment (Region 7).*

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Housing

- 9% had experienced homelessness or unstable housing at some time within the previous year
- 7% had missed work, school, or a doctor's appointment at least once in the last 30 days because of unstable housing
- 15% had been notified of possible eviction from their home
- 25% identified housing assistance as their most needed support service

■ Comments

- Lengthier housing assistance
- Emergency financial
- Help for homeowners
- Housing location services

** I think the housing help \$ was great but it needs to be longer than 9 months (Region Not Listed). * We have a mortgage. If I were renting I would be eligible for housing assistance. This seems unfair and causes me a lot of stress. Wells Fargo threatens foreclosure monthly (Region 12).*

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Transportation

- 10% had missed work, school, or a doctor's appointment at least four times in the last 30 days because of difficulties with transportation.
- Of those who need support services (e.g., housing assistance, childcare, transportation), 7% listed transportation as their most important need

■ Comments

- Missed appointments
- Gas and vehicle repair help for long-distance appointments
- Need for in-home services, one stop shop approach

**I live in Grant Co. My doctors are at I.U. 70 miles one way. When the price of gas is high gas cards would be great (Region 5).*

** It would also be a major help if the different HIV/AIDS agencies had an outreach program for those with transportation difficulties. I.e., at home appointments (Region 7)*

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Select Disparities in Services

■ Significant differences (at least $p < .05$)

□ Gender

- Women (42%) were more likely than men (28%) to have been notified of a possible utility disconnection in the past year.

□ Race: Racial group differences exist for poverty indicators. For each, Whites tended to fare better overall than either Blacks or Hispanics. For example,

- Hispanics (38%) were more likely than either Blacks (26%) or Whites (23%) to have been hungry in the last 30 days.
- Being homeless or living in unstable housing within the last thirty days was also more likely for Hispanics (23%) than for other groups; the disparity between Whites (6%) and Blacks (13%) for this poverty indicator was also pronounced.
- Blacks had a higher likelihood of having problems (housing, transportation, substance abuse) that interfered with work than did Whites or Hispanics.
- Black clients (77%) had the most trouble getting medications because of a lack of insurance in contrast to 70% of the Hispanic and only 50% of the White clients.
- Lacking money for medication interfered with Hispanic's (86%) ability to receive medication slightly more than it did for Blacks (83%), and substantially more than it did for Whites (59%)

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Select Disparities in Services

- **Households with Children:** When comparing those living in households with children and without children, there are significant differences in poverty indicators, experiencing problems that interfere with ability to work, attend doctors appointments and experiencing HIV status discrimination. Households with children fare consistently worse.

- Individuals in households with children (34%) are more likely than those who live without children to go hungry in the last 30 days.
- Homelessness and unstable housing affects those in households with children (14%) more often than those without children (8%).
- Clients living with children (44%) are far more likely than those without children (28%) in the household to be notified of possible utility disconnection as well.
- Discrimination in the form of being denied services is more common among those with children (31%) than those without children (20%).

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Other Service concerns

- Financial Assistance
 - past year, 32% had been notified of possible eviction at least once
 - 33% ranked this and food as their most important support service
- Food and Food Banks
 - last 30 days, 25% had been hungry and unable to get food at least once
- Linguistic Services
 - 2% ranked as most important support service
- Employment Services
- Specialty Care
 - 24% ranked as most important non-HIV related care service
- Vision Care
 - 8% ranked as most important non-HIV related care service
- Client Support Services

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Central Issues Across Service Categories

- Gaps in health insurance coverage
 - 4% uninsured, 59% single plan, 37% multiple plans
- AIDS Stigma
 - 22% felt that services had been withheld from them at least once in the past year because of their HIV status
- Education, Information and Communication
- System linkages and Interactions
- Self Reliance and Consumer Involvement
- Recommendations
- Appreciating Services

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■ Appreciating the state

- *I have 100% trust and confidence in the services for HIV + people. Thank you! (Region 11).*
- *The greatest service for me is the HIAP/ICHIA program. That's why I'm still here. Thanks to all who are working so hard to help me! (Region 7).*
- *This July I will have survived HIV for 22 years! I would not be alive without the help I receive from the state of Indiana. Thank you very much! (Region 6)*

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■ Appreciating Doctors

- *Dr. Robert Baker is always very helpful, knowledgeable, courteous and quite professional. (Region 6).*
- *I am lucky to receive assistance and support from my Dr. (Region 10).*
- *Also, my doctor at Wishard Special Medicine, Helen Rominger is super awesome, she gets on me and makes sure I am taking my medicine correctly. Also, she always asks me how am I feeling not body wise, but mentally. I love that she cares about me (Region 7).*

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■ Appreciating Care Sites

- *I am very thankful to have the Fort Wayne Task Force. They have made living with HIV easier (Region 3).*
- *The Aliveness Project of Northwest Indiana is a true godsend organization they showed me how to believe in a life with HIV (Region 1)*
- *I have been blessed with the case management. I've received from the folks of Positive link Bloomington, Thank You! (Region Not Listed).*

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■ Appreciating Care Coordinators

- *I would give my care coordinator an A (Region 11).*
- *I am also thankful for the help from my care coordinator (Region 7).*
- *My care coordinator does a great job (Region 12).*
- *Katie Bennett is a very special person (Region 6).*
- *I am lucky to receive support from my care coordinator (Region 10).*
- *My Care Coordinator is the BEST! (Region 7).*
- *My care coordinator Mrs Paulette Majors is awesome (Region 7).*
- *Gina is a God sent and an asset to any organization (Region 7).*

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■ What do we do now?

- **Time for the CHSPAC planning committee to get involved...**



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