

June 22, 2010  
Priorities Committee Meeting  
Center for Applied Research and Evaluation Studies  
Southeast AIDS Training and Education Center

# **NEEDS ASSESSMENT FOCUS GROUPS: YOUTH, SELF-MANAGED, SUBSTANCE ABUSE & MENTAL HEALTH**

# PURPOSE

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- ✘ To identify the needs of client subpopulations of special interest as a supplement to the 2007-2008 Atlanta EMA HIV Consumer Survey and in support of the Council's priority setting process

# POPULATIONS OF FOCUS

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- ✘ Young people living with HIV/AIDS, ages 13-24
- ✘ Self-managed clients
- ✘ Mental Health and/or Substance Abuse clients

# METHODS

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- × Focus groups & Questionnaires (2 hours)
  - + 4 youth groups, 23 participants
  - + 2 self-managed groups, 20 participants
  - + 4 SA/MH groups, 36 participants
    - × Key informant interviews
- × Emory IRB non-research determination
- × Confidential
- × Conducted in English
- × Gift cards and lunch provided to participants

# RESULTS

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- × Participant demographics
- × Background
- × Key Findings
- × Recommendations

# PARTICIPANT DEMOGRAPHICS

	Youth	Self-Managed	Substance Abuse and Mental Health
Female	61%	35%	25%
Male	39%	65%	75%
Black	87%	95%	89%
White	0%	10%	6%
Hispanic	13%	0%	0%
Heterosexual	75%	70%	56%
Homosexual	25%	30%	44%

# PARTICIPANTS: SOCIOECONOMIC

	Youth	Self-Managed	Substance Abuse and Mental Health
Highest level of education	High school graduate/GED (35%)	High school graduate/GED (40%)	High school graduate/GED (47%)
Employment	Unemployed (48%)	Unemployed (45%)	Unemployed (44%)
Housing status	Living with family (65%)	Rent/own house/apt (70%)	Rent/own house/apt (61%)
Primary payer of health care	Medicaid (35%)	Medicaid (30%), Medicare (30%)	Medicare (28%) No insurance (28%)
Primary payer of medications	Medicaid (61%)	Medicaid (40%)	ADAP (31%)

# PARTICIPANTS: MEDICAL

	Youth	Self-managed	Substance Abuse and Mental Health
Currently Taking ART	48%	85%	78%
Diagnosed with HIV >5 years ago	52%	80%	72%
Diagnosed with HIV 0-4 years ago	35%	20%	12%
Overall health = very good	61%	60%	47%
≥2 medical visits in last 6 months	61%	65%	83%
CD4 ≥ 200	48%	70%	86%
Don't know CD4	48%	20%	0%
Viral load test in last 6 months	82%	80%	95%

## BACKGROUND: YOUTH

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- ✘ In U.S., 5% (23,524) of PLWHA are ages 13-24
- ✘ Increasing number of YPLWHA
  - + In 2007, 24% of newly diagnosed HIV cases in GA were aged 13-24
- ✘ In 2008, 6% (667) of EMA clients served were ages 13-24
- ✘ Developmental and clinical considerations

## KEY FINDINGS: YOUTH

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- ✘ Satisfaction with access to outpatient/ambulatory care and case management
- ✘ Current care setting is like family
- ✘ Worry about transitioning their HIV care to an adult setting, including fear of losing connection to current health care providers and lack of information
- ✘ Wait time as barrier to service
- ✘ Perceived stigma, disclosure of HIV status, and confidentiality
- ✘ Importance of peer support

## TRANSITION TO ADULT CARE

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- ✘ *“If I have to go down there, I’m leaving the clinic. Because they don’t look so happy, I mean they actually scare me. They’re like they’re [angry] at the world for what happened. It looks like they’re still dealing with it [HIV diagnosis].”*

# IMPORTANCE OF PEER SUPPORT

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- ✘ *“I mean it was a place where everybody that had the same thing, they were going through the same thing, and just go have fun and don’t got to worry about nobody talking about you or saying, oh my God, she got HIV, what she doing here?”*

# RECOMMENDATIONS: YOUTH

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- ✘ Develop case management standards, including an Individual Service Plan, specific to YPLWHA's transition to adult care
- ✘ Use peers to help YPLWHA navigate adult care setting
- ✘ Design and implement an orientation to adult care
- ✘ Incorporate a young adult clinic
- ✘ Reinvigorate and facilitate routine support group meetings

# BACKGROUND: SELF-MANAGED

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- ✘ In the Atlanta EMA, clients receive a self management designation based on the results of their intake assessment or upon successful completion of their ISP
- ✘ 2009 standards for self-managed clients developed by QM committee and CM task force
- ✘ Successful self management in HIV care is achieved through quality collaboration between consumers, providers, and healthcare systems
- ✘ Self management and self-care has been shown to result in better health status and increased quality of life for clients

# KEY FINDINGS: SELF-MANAGED

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- ✘ Stigma of restarting case management
- ✘ “Catch 22” barriers to services (income eligibility, employment)
- ✘ Housing instability
- ✘ Requirement of case manager’s signature or referral as barrier to accessing services
- ✘ Dissatisfaction with the case management system
- ✘ Self and peers as source of most accurate and reliable information
- ✘ Importance of self-advocacy

## STIGMA OF RESTARTING CASE MANAGEMENT

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- ✘ *“It’s really tough when you go out there and you’re trying to do good, and then you finally humble yourself to drag your[self] in there and ask a case manager for something. Because it takes everything in my power to go in there and ask them for something. So that’s the last house on the block for me. I’ve exhausted all other avenues before I made it to a case manager.”*

## CATCH 22'S

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- ✘ *“That’s another catch 22. You’re encouraging me to live a better life, become self reliant, an advocate for self, and I’m doing all these things, but I can’t keep that appointment because I can’t keep taking off work.”*

# HOUSING

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*“[It’s] extremely [important] as far as my housing is concerned that has to do with my health, having a roof over my head, having some stability and be able to lay down and provide my child some type of security.”*

# RECOMMENDATIONS: SELF-MANAGED

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- ✘ Develop standards for self-managed clients and programming to be assessed and evaluated at regular intervals
- ✘ Provide cultural competency and motivational interviewing training for case managers
- ✘ Increase outreach and education for PLWHA on the self management system and benefits of case management services should they need them
- ✘ Host regular brown bag sessions for self-managed clients to provide opportunities for networking, peer support, and non-HIV training topics
- ✘ Utilize peer counselors

## **BACKGROUND: SUBSTANCE ABUSE AND MENTAL HEALTH**

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- ✘ Untreated mental health issues, most commonly depression, is a barrier for consumers in need of HIV care
- ✘ Lack of mental health treatment can result in the development or perpetuation of substance abuse disorder
- ✘ Drug use is closely associated with lower adherence to antiretroviral therapy
- ✘ Symptoms of mental illness can be misinterpreted by clinicians as a normal part of HIV disease progression or side effects of treatment
- ✘ Racial and ethnic disparity in access to treatment

## **RESULTS: MENTAL HEALTH AND SUBSTANCE ABUSE**

- ✘ 56% reported triple diagnosis – HIV, mental health, substance abuse
- ✘ 58% prescribed medications for mental health condition in last year
- ✘ 19% had mental health-related hospitalization in last year
- ✘ 11% had drug/alcohol-related hospitalization in last year
- ✘ 70% have case manager

## KEY FINDINGS: SUBSTANCE ABUSE AND MENTAL HEALTH

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- × Housing instability
- × Triple diagnosis
- × Lack of coordination of services and medical history among providers and agencies
- × Importance of primary care
- × Communication with provider

# TRIPLE DIAGNOSIS

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*“She [the doctor] just said, ‘you might want to seek mental health because you say you’re angry all the time, go find out why you’re angry.’ I said, ‘I’m fine’ I just thought it was the dope.”*

## ADDITIONAL MEDICATIONS

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*“I was afraid of once the doctor told me I was bipolar, I’m thinking that all these many years I’ve been normal...So I was afraid of taking the meds and making me be another person, making me not be able to function.”*

# HOUSING

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*“But a lot of people with serious mental health issues that are also dealing with HIV/AIDS, they don’t have the capacity to look for themselves, that’s one of the reasons why they’re priorities. And like I’ve said, it’s also a big issue regarding having children because a lot of housing is geared towards, to be perfectly honest, single adults. They don’t even think about somebody with a child.”*

## CONTINUITY AND COORDINATION OF SERVICES

*“Sometimes when you’re in the middle of having some services needing to be accessed, you keep having to start over just because you keep changing case managers... [Having] my forms being turned in and completed by my case manager, and once they get to a point where we reach that area...they’re no longer with the agency.”*

## PROVIDER COMMUNICATION

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*“I can say regarding providers, some of them will ask you, some of them won’t. But one of the issues that’s come up, speaking with a lot of people in the HIV/AIDS community is they’re very hesitant about sometimes being open and frank and honest with the provider because they feel like that’s going to be a way to spring them out of services.”*

## RECOMMENDATIONS: SUBSTANCE ABUSE AND MENTAL HEALTH

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- ✘ Increase services that address mental health and substance abuse dually
- ✘ Provide cultural competency and motivational interviewing training for case managers
- ✘ Utilize peer counselors
- ✘ Develop and implement standards for post-treatment and crisis care
- ✘ Collaborate with non-Ryan White mental health and substance abuse programs to improve continuity of care

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