

Best Practices for Reaching and Engaging HIV-infected Youth in Care

FINAL REPORT APPENDICES

PREPARED FOR

HIV/AIDS BUREAU,

HEALTH RESOURCES AND SERVICES ADMINISTRATION

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Appendix A

Title IV Best Practices for Youth Project Telephone Consultation Protocol

The purpose of the telephone consultations is to identify effective and unique approaches to working with HIV-infected youth between the ages of 13 and 24. Please be honest and frank with your responses. All information gathered from this call will not be presented in any way as to link specific projects with specific responses. Feel free to ask any questions of me/us as we conduct this call.

1. Please describe the services your program provides to HIV-infected youth and settings in which those services are provided. How many HIV-infected youth do you serve?
2. Please describe your program's intake procedure, assessment strategies, and care plan approach used for HIV-infected youth.
3. What services does your program provide to affected families, and members of the support system of HIV-infected youth?
4. What types of compliance and treatment adherence services that are offered? Secondary prevention education and counseling?
5. What types of unique outreach, treatment, and/or support services has your program designed for specific subpopulations of HIV-infected youth such as transgender, MSM, African-Americans, Latinos, other racial/ethnic groups, or "down-low" youth?
6. How are services for HIV-infected youth organized in your program? Is specific staff assigned to youth? Clinic or program hours set aside specifically for youth? Materials developed that focus on youth?
7. What does your program do to engage and retain HIV-infected youth in care? What issues act as barriers or facilitators to engaging and retaining HIV-infected youth in care in your program? What strategies were tried and found to be unproductive in reducing or removing barriers?
8. What consent and confidentiality issues are encountered in working with HIV-infected youth? How are they addressed? What disclosure counseling and support services does your program provide to HIV-infected youth?
9. How is care coordinated with other agencies for HIV-infected youth? Other agencies include: (1) medical providers, (2) school/vocation education system, (3) lawyers, and (4) court system and juvenile justice/correctional system.
10. What types of cultural competence strategies has your program adopted to address HIV-infected youth?

11. Which funders support your services for HIV-infected youth? To what extent are current funds adequate for HIV-infected youth received by your program? If additional funds were available what other services would your program provide to HIV-infected youth?
12. In what ways are youth involved in the planning, delivery, and evaluation of services to HIV-infected youth in your program?
13. Which other youth-focused HIV care programs in the US do you consider models?
14. As the HRSA HIV/AIDS Bureau Title IV program develops its next youth initiative, what ideas should they incorporate in their request for proposals to promote and sustain innovative and effective HIV-infected youth initiatives?

Appendix B
Title IV Best Practices for Youth Project
Site Visit Protocol

Initial Meeting with Project Director, Staff, and Collaborating Agencies – Approx. 1 hour, 15 minutes

- a. What are the goals of your HIV youth project? What are the barriers to attaining these goals?
- b. How do you define your target populations? How is your HIV youth program marketed to your target populations?
- c. In our earlier telephone conversation we identified the following services as being provided by your HIV youth program: primary medical care, psychological counseling, case management, nutritional counseling, and outreach. Are there any other services that are being provided?
- d. What is the initial intake process for new clients served by your HIV youth program?
- e. What kind of informal client educational activities occur in facility waiting rooms or other space allocated to your program?
- f. In what ways does your program ensure that *new* clients keep their appointments with your program's staff? In what ways does your program ensure that *ongoing* clients keep their appointments? What barriers have been encountered in appointment keeping? How have these barriers been addressed?
- g. In what ways does your program work with *new* clients to initiate HIV treatment? What is the role of the client in development and changes to the client's care plan? In what ways does your program ensure that *ongoing* clients adhere to their HIV treatment plan? What is the role of outreach workers and/or peers in treatment education and adherence? What barriers have been encountered in treatment adherence? How have these barriers been addressed?
- h. How are clinical, psychosocial, and outreach activities coordinated by your program's staff? How are they coordinated with the staff of other programs that are involved with your clients? What barriers have been encountered in coordinating services? How have these barriers been addressed?
- i. How has your HIV youth program staff coordinated with other programs that are involved with your clients (e.g., collaborative care planning, case conferences, other regular meetings, collaboration regarding funding of joint projects)? What barriers have been encountered in coordinating services? How have these barriers been addressed?
- j. What sources of funds are used to support your program? To what extent has your program diversified funding for your program? What barriers and facilitators have you encountered in diversifying funding?

- k. To what extent has your agency provided financial support to your program (e.g., salary support, administrative costs, etc.)? In what way is the level of support likely to change in the future?
- l. What issues have your clients encountered in getting health insurance? What issues have been encountered in billing third party insurers for care provided to your clients (e.g., disclosure of HIV status, confidentiality, referral of clients to insurers' disease management programs, etc.)?
- m. What activities are undertaken to prepare clients that "age-out" of your program, including linkages with other programs to ensure a smooth transition to adult HIV care? What issues are encountered when your HIV youth program's clients "age-out" of your program? How have these issues been addressed by your staff?
- n. What approach has your HIV youth program taken to recruit outreach and/or peer workers? What approach has been taken to train outreach and/or peer workers?
- o. What staff burnout and retention issues has your program experienced? How has your program addressed these issues?
- p. How successful has your program been in organizing and presenting services to your target population? How have these successes been identified (e.g., through formal program evaluation, client surveys, etc.)?
- q. What do you see as strengths and weaknesses of your overall program? How have your program's weaknesses been addressed?
- r. What are your plans for maintaining funding during the next two to three years?
- s. What would you recommend as good practices for engaging and retaining your target populations in care?
- t. What tools and resources should other agencies develop and adopt to serve to meet better the needs of HIV-infected youth?

Simultaneous Meetings with Small Groups -- Approx. 1 hour, 15 minutes

A. Outreach Workers (Two site visitors)

- a. What is the role of outreach workers in recruiting HIV-infected youth into HIV counseling and testing? What activities has your program identified as being particularly helpful in recruiting youth? What barriers have been encountered? How have these barriers been addressed?

- b. What is the role of outreach workers in recruiting HIV-infected youth into care? What activities are undertaken to recruit youth? What activities has your program identified as being particularly helpful in recruiting youth? What barriers have been encountered? How have these barriers been addressed?
- c. What is the role of outreach workers and/or peers in assisting clients to keep their appointments with medical providers? What is the role of outreach workers and/or peers in assisting clients to keep their appointments with case managers? What barriers have been encountered? How have these barriers been addressed?
- d. What is the role of outreach workers and/or peers in HIV treatment education and adherence? What barriers have been encountered in working with HIV-infected youth regarding HIV treatment education and adherence? How have these barriers been addressed?
- e. What is the role of outreach workers and/or peers in primary and secondary prevention (i.e., prevention for positives)? What activities has your program identified as being particularly helpful in HIV prevention? What barriers have been encountered in working with HIV-infected youth regarding HIV treatment education and adherence? How have these barriers been addressed?
- f. What is the role of outreach workers and/or peers in assisting clients to obtain services at other agencies? What barriers have been encountered? How have these barriers been addressed?
- g. What is the role of outreach workers and/or peers in retaining youth in care? What activities are undertaken to recruit youth? What activities has your program identified as being particularly helpful in retaining youth? What barriers have been encountered? How have these barriers been addressed?
- h. What training have outreach workers and/or peers received from your program's staff to prepare you for your role? What additional types of training do you think would be helpful?
- i. What resources are the most helpful in carrying out your job as an outreach worker and/or peer? What additional resources do you think would be helpful?

B. Consumers (Two site visitors)

1. To start off, would you please briefly talk about your experiences with this HIV youth program? For example, how long have you gotten services here, what sorts of services have you gotten, which services been helpful to you, etc.
2. In your experience, what are the most useful ways to find HIV-infected youth that are not in care?
3. What kinds of outreach activities *are* helpful in finding groups of HIV-infected youth such as transgender, MSM, African-Americans, Latinos, other racial/ethnic groups, or “down-low” youth? What types of outreach activities *are not* helpful?

4. What types of outreach are the *most helpful* in reaching HIV-infected youth? What types of outreach are *not helpful*? Do you know positive youth not in care? What do you think is the reason they do not seek care? How should projects like this bring them in?
5. What things can an HIV youth program do that *work best* in getting and keeping HIV-infected youth in care? What things *do not* work in getting and keeping HIV-infected youth in care?
6. In what ways do doctors, case managers, and other people working at this HIV program learn about the medical and social support needs of individual HIV-infected youth? Are these approaches helpful in learning about the needs of youth? What approaches used by this HIV youth program *do not* work in learning about the needs of youth?
7. In your experience, what disclosure, consent, and confidentiality issues are faced by HIV-infected youth?
8. What are the *most useful* services offered by this program to youth? What are the *least useful* to youth?
9. In your experience, what types of services should be offered to HIV-infected youth by programs like this one?
10. What are the most helpful way services should be provided (e.g., one-stop shopping)?
11. What services should HIV youth programs offer to affected family members and members of youth support systems, such as lovers, friends, etc.?
12. In what ways are youth involved in this program in the planning and delivering services to HIV-infected youth?
13. In what ways do the people working at this program work with other agencies to get services needed by HIV-infected youth? Are these efforts useful? How can this HIV youth program work better with other agencies to get needed services?
14. What do you like *best* about this program? What do you like *least* about this program?
15. How can HIV youth programs become better educated about the needs of HIV-infected youth and how to work with them?

Tour of the HIV Youth Program Facilities – One-half hour

Appendix C
Title IV Best Practices for Youth Project
Supplemental Research Telephone Interview Protocol

The purpose of this telephone consultation is to identify effective and unique approaches to engaging special populations of HIV-infected youth between the ages of 13 and 24 into care. We're particularly interested in youth who are adjudicated or incarcerated, homeless, mentally ill, and/or in drug treatment. We will incorporate the information obtained today into a report to the HRSA's HIV/AIDS Bureau regarding strategies for reaching HIV-infected youth. We will not be identifying any specific agencies in that report.

1. Please describe the places in which your program provides services to the above described HIV-infected youth (e.g., clinical, case management, street outreach, drug treatment, etc.).
2. Please describe the program's outreach activities, intake procedures, assessment strategies, and care plan approach used for these HIV-infected youth.
3. What services does your program provide to such youth, their affected families, and members of their support system?
4. How are your services for such youth organized in your program? [Prompt regarding: specific staff assigned to youth, program hours set aside specifically for such youth, program activities specifically focused on youth, and any special materials]
5. What collaborations and partnerships have you established to reach these youth? How is care coordinated with these other agencies?
6. What consent and confidentiality issues are encountered in working with these youth? How are they addressed? What disclosure counseling and support services does your program provide to HIV-infected youth?
7. What types of cultural competence materials and/or strategies has your program adopted to reach and address these youth?
8. Which funders support your services for these youth? To what extent are current funds adequate for the program? If additional funds were available what other services would your program provide?
9. In what ways are the youth you serve involved in the planning, delivery, and evaluation of services to in your program?
10. Which other HIV care programs in the US do you consider models with regard to reaching the youth you serve?