CENTRAL NEW YORK HIV CARE NETWORK
SERVICE CONTINUUM CONCERNS: 2007

SYSTEMIC OBSERVATIONS

DISINTEGRATION OF SEAMLESS CLIENT SERVICES. In 2007 a disturbing coming together of financial, bureaucratic, and epidemiological factors is progressively eroding the fabric of a comprehensive continuum of services for persons living with HIV/AIDS. Examples are provided below.

COMPLEX CLIENT NEEDS. Many persons living with HIV/AIDS (1) are co-infected with HCV, (2) have additional – and often multiple – diagnoses (Mental Illness, Substance Use/Abuse), and (3) struggle with the consequences of profound social development deficits (limited education, spotty/absent employment history, domestic violence, to name a few). For these individuals, consistent and on-going assistance in dealing with life's complexities often makes the difference between success and failure in medical treatment. Case Management would seem to be the logical mechanism for pulling these multiple threads together – but it appears to be less, rather than more, available over time, and increasingly limited in scope. On-going resources for PWA mentoring, life-coaching, trouble-shooting, and reality-checking are seldom available. Also missing is consistent support – including travel assistance – for peer interactions and support programs that may be effective in promoting and reinforcing individual and group initiative, information-sharing and problem-solving regarding the challenges of living with HIV/AIDS.

COMMITMENT & FUNDING. The long-overdue conclusion in late 2006 of the cyclical re-authorization of the Ryan White CARE Act -- the federal program that funds HIV/AIDS care and support services not directly covered by Medicaid -- demonstrated the consequences of chronic under-funding for an advancing epidemic. Protracted wrangling between advocates for jurisdictions with emerging epidemic impact (the Southern Coalition) and defenders of jurisdictions heavily-impacted by HIV/AIDS and with well-established response mechanisms (including New York and four other states that continue to comprise over fifty percent of the historic and living epidemic in the U.S.) was a sad commentary on the failure of national, state and local commitment to develop and sustain a response capable of keeping pace with the impact of the HIV/AIDS epidemic. Instead of working forcefully for adequate funding, the re-authorization process became highly politicized and deteriorated into re-cutting the slices of the same size pie and pitting one portion of the country against the other.

UNDERMINING PROVIDER COLLABORATION. Continuing restrictions in funding, consequent narrowing of focus for specific funded programs, long term survival of persons living with HIV/AIDS, and continuing increases in patient enrollment for clinical services and client enrollment for non-clinical, community-based services all contribute to the disintegration of collaborative effort among providers and fragmentation of services of patients and clients.

MEDICALIZATION. While the increasing concentration of medical aspects of HIV/AIDS response affords new opportunities for getting PWAs into care and for developing PWA skills for effective partnering with clinical providers to maximize medical outcomes, it has raised significant obstacles for responding to the social networking aspects of support that can contribute enormously to the overall outcome for Persons Living with HIV/AIDS. With declining and less comprehensive community-based services, many clients have difficulty navigating complex pathways to care and support.

LAST RESORT FUNDING. While no one advocates funding of duplicative services, the increasing focus on ensuring that all alternative resources have been ruled out before a program can respond to PWA needs is having an unfortunate impact, requiring significantly increased – and unfunded – staff time to explore and document client ineligibility at alternative programs. Instead of appearing to clients as a source of assistance, some programs are beginning to appear to clients as barriers to service when clients and applicants fail to meet increasingly restrictive eligibility requirements.

SERVICE-RELATED ISSUES

Case Management

- Practice suggests a programmatic assumption that client needs, once identified and referred, have been addressed and met, despite the obvious on-going need for assistance
- Premature closing of cases leaves clients unsupported when problems recur
- Rising caseloads and time-consuming intake procedures make crisis response increasingly impossible
- Prohibitions on accompanying clients to clinical or DSS appointments are counter-productive when those venues often afford the best opportunity for case collaboration and reducing the need for subsequent follow-up or remediation
- Prohibition on transporting clients, even when access is difficult and follow-up is unreliable
- Prohibition on following up with hospitalized or incarcerated clients means clients may drop off the collective radar, possibly jeopardizing other services , such as housing and Medicaid
- Unresolved conflicting guidance regarding the extent of Case Manager involvement in documenting client need and completing referrals to programs addressing identified needs

Mental Health

- There are persistent access barriers, including very limited resources in the community
- Limiting PWAs to one unit of Medicaid service per day, requires repeat visits, with increased Medicaid transportation expenses, even when services are co-located (e.g., one visit for individual counseling, another for clinical evaluation and medication, and another for group therapy)
- Requiring repeat visits increases barriers to care, increases transportation expenses, and reduces likely follow-through

Housing Services

- With two HOPWA programs providing long-term rental assistance subsidies in Central New York there are about 100 persons enrolled and 80 on the waiting list
- Moving to the top of the HOPWA waiting list takes more than a year
- Section 8 programs in the region's larger municipalities no longer place applicants on a wait list, since the wait would exceed four years
- HOPWA assistance, intended to stabilize PWA's until they qualify for Section 8, has essentially become a dead-end option
- HOPWA programs, inadequately funded to meet existing housing assistance need, cannot absorb the cost of adding housing Case Management without seriously reducing funds available for client assistance
- Developing a parallel Case Management structure for housing would result in duplication of effort when clients already have a community-based Case management relationship
- The complexity of cases in which rental assistance clients fail to comply with HOPWA certification requirements (and may therefore seek assistance from extremely limited legal assistance channels) provides clear indication of client need for on-going involvement in Case Management

HIV Testing

- Community Awareness outreach efforts have been strengthened by collaborative public HIV testing events, e.g., around National HIV Testing Day (6/27)
- Reduction in CTS funding has reduced the number of CTS personnel in the region and the number of test kits that can be obtained
- Target population restrictions undermine community testing events – even when community events demonstrably attract targeted populations – despite increasing community interest in hosting testing events as part of prevention education and outreach
- Difficulty in securing clinical oversight for community-based CTS staff has severely restricted the expansion of HIV CTS resources in the region

Latest Update: 6/20/07

Hi Steve -- clients at ARISE might be trying to juggle (1) sessions with a therapist for one-on-one counseling, (2) psychiatric visits with the MD/psychiatrist for medication evaluation and management, and (3) group therapy -- we have anger management groups, healthy relationships group and others.