

Rochester Area Task Force on AIDS, Inc.

Finger Lakes Health Systems Agency

1150 University Avenue

Rochester, NY 14607

Phone 585-461-3520 Fax 585-461-0997 TTY 585-461-4075

E-mail ratfa@flhsa.org

www.knowingisbetter.org

Services /Advocacy

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Minutes

Members Present: Roberto Burgos, Ramon Cintron, Gratia L'Esperance, Cherrie Hawkins, Catherine James, Gillian Justy, Matt Kaye, Annie Piazza, Isabel Rosa, Lela Seals, Ron Skwieralski, Bill Stevens, Patricia Terziani, Calvin Twoguns, Lynn Varricchio, Ann Williams.

Agency Updates: Lynn reported that plans for the AIDS Garden have taken root. The CAC has obtained a permit for a garden at the Bausch and Lomb Park on Upper Falls Blvd near St. Paul Street. Lynn provided additional details about the garden, where initial work will commence on May 2nd the United Way Day of Caring, with dedication and planting to be held on June 2nd at 10:00AM. There are three distinct gardens in the park, and planting will take place each fall for bulbs and in the spring for annuals. The garden was conceived of as a way to memorialize those who have died with affordable plants, in the part of the City that is accessible to the population. We hope that it will become a place of hope and healing.

CAC has planned nine months of trainings for all people living with HIV/AIDS. These will be from noon – 4PM and will include a meal, and training program. The courses needed were identified by CAC and resources are being paid by pharmaceutical companies. Fliers with all of the details will be sent to all of the AIDS provider agencies. The idea behind these is to help all people living with the virus get the most out of their medical care.

The AIDS Case Management Standards are now available. The Network needs the agencies that provide case management to review the standards, and using the standards define the type of case management your agency provides. We will use this information and some additional data to update our Case Management Plan.

Lynn advised the group that she had met with the Executive Directors of AIDS agencies, and together they have agreed on a system for developing an implementation plan for the priorities in the Service Development Plan. Lynn will be sending a list of the priorities to each agency and they will indicate which priorities they plan to address in their agency, and which they would be willing to partner with others on addressing. Where no resources are currently available we will have to explore whether they may be options from grants etc.

Lynn indicated that she had been in conversation with staff from NYSDOH and been advised that they have not been receiving referrals for partner contact and notification from some agencies that do testing. Lynn asked that representatives remind each of their agency that this is the role of local health departments and if new infections are to be prevented, partner notification is key. It may be that partners are identified after someone has been in care for a time, but referrals to county health departments still should be made.

Bill Stevens- no report from Catholic Charities Community Services

Ramon Cintron- on MWF Huther Doyle is now providing a support meeting for LGBT people in recovery. Michael Rosenberg is the contact.

Cherrie Hawkins- McCree McCuller Wellness Center's 1400 Portland Ave site, suite 31, offers free hepatitis A & B vaccine, at its hep B clinic, on Monday – Friday 8:30AM- 5 PM (except over the lunch hour 12-1 M,T, Th, F and 12-2 Wed.). The physician is on site on Monday and Thursday. Please call ahead for an appointment 368-4333.

Ron Skwieralski, of ACHC announced that he has been appointed Director of Community Services. The agency is seeking to hire a full time medical case manager and a ½ time case manager. At the present time one of their case managers is on maternity leave. The agency is planning its 3rd Pleasant Street picnic as part of National Testing Day events.

Calvin Twoguns of Liberty Research Group reported that he had an article published in the Native American Magazine. He is working on a report on Native American and Hawaiian Islander HIV/AIDS report for the National Health Board of Native American people.

Matt Kaye reported that he has recently completed cultural competence training at CHBT and he is interested in adapting DEBIs to various population groups. He has also completed all of the LTI trainings.

Catherine James reported that AFC's Project REACH is finalizing plans for a pastor's breakfast and conference on May 22nd in a location to be announced. Today at 1PM there will be a discussion on HIV/AIDS in the 50 and over population.

Patty Terziani reported that AFC held a retreat for women with HIV/AIDS at the Crowne Plaza. A second conference is being planned with PRYD for youth on the last Sat. of the month. This conference will include a talent show and education. Finally, ABC has given OHANA 1,000 in Wegman's cards to continue their nutrition, recreation, and peer support program that last year were funded by the MAC Foundation.

Ann Williams reported that VLSP now has a grant to help people with cancer, the deaf, as well as those with HIV make wills and guardianship plans for children. Ann distributed a flyer on the next Wills clinic that is planned.

Sr. Gratia told of a friend on disability and SSI who received notice of shut-off from RG&E. The paper work had been handed into the utility company before the shut off, but there was a problem with DSS getting the paperwork to RG&E. Her experience is that clients are helpless to get DSS to process paperwork, and RG&E is more interested in getting paid than getting DSS paperwork.

Gratia also reported that she is part of a justice group that is supporting workers at Crowne Plaza right to organize. While no hotel in town has a union, Crowne Plaza has actively resisted workers' right to organize. Gratia encouraged members to consider the workers' when deciding where to hold events.

Service System Problems/Concerns

It was reported that in addition to people losing Medicaid, some are losing food stamps. The question was raised whether the survey should also be picking up problems with food stamps.

Case managers recommended that others get the client to request in writing that DSS send information to the AIDS case manager, since DSS often send materials to out of date addresses, with the result that clients don't get the messages about appointments.

Another recommendation for communicating with DSS workers is to use email. It leaves a paper trail, and it overcomes telephone barriers. Releases are required from the client.

Another worker told of a woman who left prison, went to Bethany House to live, had 60 days of medications when she left prison, but ended up with a lapse in her medication coverage because of delays.

One of the case managers recommended that when trainings are planned for HIV/AIDS case managers we extend an invitation to DSS to have their case managers take the trainings so that they have a better understanding of HIV/AIDS, the importance of medications and adhering to the plan of care etc.

An issue arose whether single and childless couples without disability can be sanctioned for not complying with drug and alcohol treatment and lose their Medicaid. When the issue was brought up at the Executive Directors' meeting as a reason that CCCS and ARI have been losing Medicaid payment for case management, Bob Lebman indicated that it is unlawful for a substance abuser to lose Medicaid for not complying with substance abuse treatment.

From here the question was raised whether counties should be allowed to sanction people from Medicaid and food stamps, when people are living with serious illnesses that can be life threatening if they do not get medications and treatments which are indicated, because they fail to keep substance abuse appointments.

Trilby indicated that she would check the law on this matter. It was suggested that she confer with the county's attorney for Monroe and see if they concur. If so, perhaps a letter from the county attorney to DSS would help to insure the practice does not continue.

If a person is on disability and gets SSI, they should not be sanctioned. Anytime benefits are cut off, people should ask for a fair hearing and a continuation of benefits to retain benefits until a decision is adjudicated. Request emergency benefits if needed. LJ is an expert on disability hearings and Trilby will ask her to attend the next meeting.

Medicaid Churning

Catherine presented the form. The committee provided comments. Catherine and Trilby will make the recommended changes and distribute the forms to all of the agencies through RATFA. A letter with instructions should accompany the forms.

Cherri offered to collect and tabulate the data.

Cherri reviewed the proposed time line for accomplishing the task.

Members thanked Catherine, Cherri and Trilby for their work.

The next steps will be:

- to ask each agency to field test the data collection tool. ARI, Huther Doyle, and MMWC offered to have several staff complete the form;
- to train people from each agency on the use of the tool. They will then train their own staff, so that forms are completed consistently.
- Decide what we want the data reports to look like so that they will be as useful as possible for discussions with DSS and for lawyers to use if it comes to seeking relief from the courts.

Closing of Services Meeting:

The next meeting of the Services meeting will be on May 3rd at 8:30 AM. A joint meeting with Advocacy will follow at 9:00 AM. Advocacy will meet at 10:00 AM

Advocacy Meeting:

Members Present: Roberto Burgos, Sr. Gratia L'Esperance, Cherri Hawkins, Catherine James, Matt Kaye, Isabel Rosa, Mary Terziani, Calvin Twoguns, Lynn Varricchio

In-District Visits:

In-district visits were made to Susan John and David Koon's offices for purposes of encouraging/thanking them for sign on to the license plate legislation and prison health bills. A visit with Sen. Robach had to be postponed due to budget delays. Meetings need to be scheduled with other members of the local delegation.

- A. Koon welcomed the visit, and encouraged regular communication to keep him up to date on policy issues of concern. Susan John's staff person indicated that she was on-board with our concerns.
- B. Lynn indicated that she had used concerns regarding pandemic flu, as a means of encouraging lawmakers to get work on health dept. oversight of the quality of care in prisons now. If we wait until we have a pandemic flu for the state health department to really understand how prison health works it will be too late.
- C. It was recommended by one of the members that we set up meetings with the Executives of each of the counties to discuss with them the importance of connecting jail health to local

health care providers. As more and more counties contract jail health out to proprietary corporation, there is increased concern about the resources available for quality care in the jails. Since the jail population is predominantly young men of color, many of whom do not have a regular source of care jail presents an opportunity for connecting these high risk folks to health care.; It was suggested that the committee get a list of with whom counties in our region contract jail health services;

- D. Concern was then expressed about how health care is provided an overseen in youth detention facilities. Someone indicated that they thought it came under the NYS Office of Children and Family Services, but this needs to be confirmed. This is also a population with health risks.

Other:

Prior to the close of the meeting a comment was made about the increasing problem of providing transportation to get clients to services. The suggestion was made that an inter-agency shuttle service be developed. Lynn commented that she and a consumer who had previously worked in public transportation had discussed the idea of getting a fleet of a couple cars for the city and a couple vans for the counties that could be used as a medical motor pool for clients, with dispatch and livery provided by PLWH/A. If it could be run through an existing cab service it might work, if not, the liability could be very expensive. However, given the cost to Medicaid for current transportation... we need to consider options.

It was agreed that we would continue to hold just joint meetings until the Churning project no longer requires joint meetings.

When time allows, Pat should continue to set up in-district meetings with state legislators. Prior to sitting down with county executives, Advocacy Committee members need to come up with a list of issues of concern: (housing, safety, poverty, prevention.) We may also want to consider doing presentations for major county legislative bodies, and Mayor Duffy and key staff from the city and the Rochester City Council.