

Providing Age-appropriate HIV Service to Adolescents

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This article chronicles some of the lessons learned from the DAYAM Project, a SPNS-funded program developed by the Department of Pediatrics at the University of Medicine and Dentistry of New Jersey (UMDNJ). The information is based on interim findings from the first three years of a four-year demonstration project.

Introduction

The Newark, New Jersey-based DAYAM Adolescent HIV/AIDS Project is a comprehensive, multidisciplinary and developmentally-sensitive HIV/AIDS program designed to decrease the occurrence of initial HIV infections in youth between the ages of 13 and 25 and to overcome barriers to the early diagnosis and treatment of those who are HIV positive. In order to accomplish these goals, the program intervenes in the lives of both at-risk youth and those who are infected and in need of care. The project model is consistently youth-focused, the result of extensive work with both HIV-positive and HIV-negative youth in community and clinic settings.

The DAYAM model represents an ongoing mediation between ever-changing adolescent cultures and developments in the treatment of HIV/AIDS. While the project reflects the learning derived from extensive work with youth, fundamental challenges remain, such as the difficulty of identifying infected adolescents who are either unaware of their serostatus or are aware but not in treatment. With the development of highly active anti-retroviral treatments (HAART), new challenges have emerged. Ensuring adherence to the complex regimen and resolving the many life issues that characterize the lives of youth living with HIV/AIDS.

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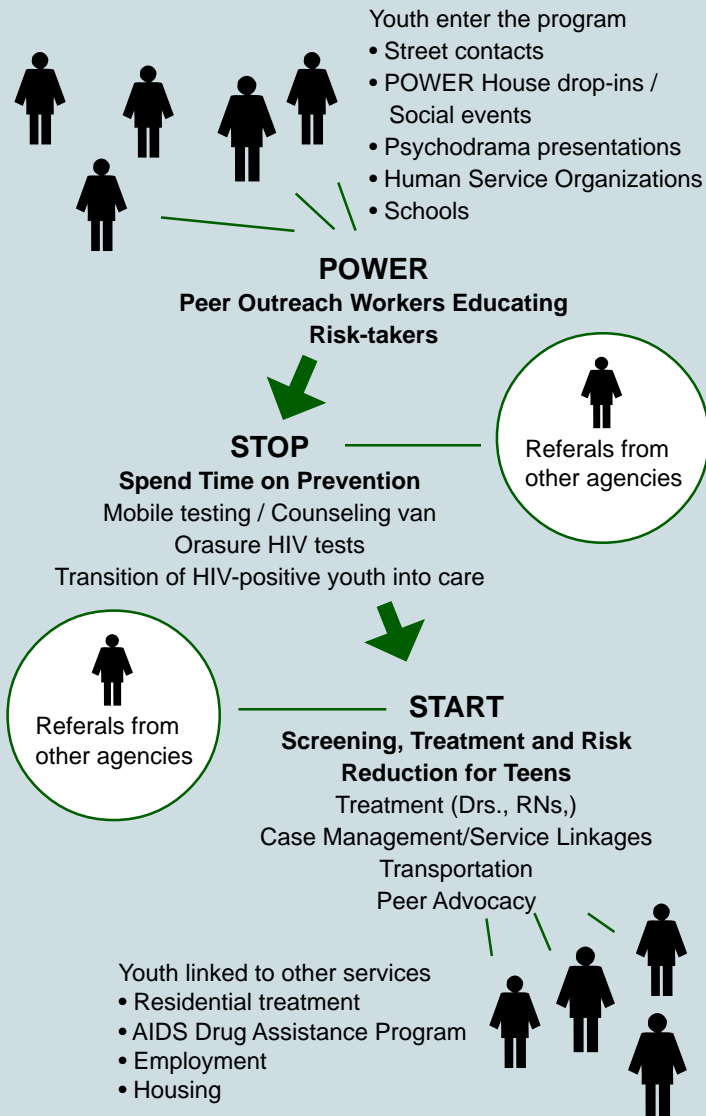
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DAYAM model for continuum of care



The following piece documents lessons learned by the DAYAM staff as a result of their case-finding efforts and their experience of the impact of anti-retrovirals on the lives of the HIV-positive youth involved in the program.

The DAYAM Project Model of Care and Services

Location

The service area for this project includes the four largest municipalities in the Ryan White-designated Newark eligible metropolitan area. Together, these municipalities constitute the urban center of Essex County, the second most populous in New Jersey. The majority of the almost half a million people in the project's service area are African American (66 percent). Whites and Hispanics/Latinos account for 24 percent and 9 percent respectively.

The project is located at the UMDNJ University Hospital in the city of Newark. A city with a rich history, Newark has been troubled in recent decades by overwhelming economic difficulties and widespread social

ills. Multiple generations of city residents have lived and continue to live in poverty. Crime rates are well above the national average and drug use is widespread. Newark and Essex County now add to that list, the distinction of being the epicenter of the AIDS epidemic in New Jersey.

Although Newark is home to only four percent of New Jersey's general population, it represents 19 percent of the state's cumulative cases of AIDS and 22 percent of the HIV infection reports. And while Essex County accounts for less than 10 percent of New Jersey's population under 20 years of age, it accounts for 32 percent of reported AIDS cases and 34 percent of HIV infections reported among New Jersey youth between 13-19 years of age. Given the latency period of HIV, it is likely that a significant number of those between 20-29 years of age who are reported to have HIV/AIDS were infected during their adolescent years.

Program Model and Services

The DAYAM program is designed to provide services that span the adolescent HIV/AIDS continuum, including prevention, access to counseling and testing, transition to clinic-based care, and state-of-the-art medical and supportive services using case management, counseling, and peer advocacy to transition youth across the continuum of care. The program model consists of three major components:

1. **POWER (Peer Outreach Workers Educating Risk-takers)** A peer outreach program which employs high-risk peers to provide street contacts, social events and psychodrama presentations to thousands of adolescents each year, in addition to handing out educational materials and condoms. Between January 1998 and December 1999, more than 3,500 adolescents were reached during street contacts alone.
2. **STOP (Spend Time on Prevention)** A mobile van provides HIV testing, including pre- and post-test counseling. POWER workers often accompany the van to provide outreach in areas popular with high risk groups. In 1998 and 1999, 881 adolescents were tested.
3. **START (Screening, Treatment and Risk Reduction for Teens)** HIV-positive youth are transitioned by a STOP counselor and a START case manager into treatment at START. Since the initiation of SPNS funding in October 1996, a total of 33 new HIV-positive youth have entered the START program. Before the SPNS enhancements were funded, the START program consisted of medical staff only; the program did not have case managers or peer advocates.

Provider Teams

The teams assembled across the three project components are made up of both adult professionals and youth peer workers. Medical care is provided by pediatricians and licensed nurses with other specialist medical care available through UMDNJ's University Hospital. Experienced case managers assist with the management of care and help access ancillary services. Outreach workers and peer leaders guide a large cohort of peer educators. Peer advocates are also specifically trained to work with youth who are HIV positive or living with AIDS. Administrative staff are as much a part of the team as anyone else, providing crucial assistance managing this multicomponent project. The integration of all levels of staff into strongly bonded provider teams increases the effectiveness of the model overall. Equally important, are the close relationships between professional staff and peer workers which ensure a youth friendly tone for the project while also constantly enhancing the knowledge and skills of the youth.

Lessons Learned

POWER, the outreach component of the DAYAM Project, has developed highly effective methods for reaching large numbers of youth engaged in high-risk behaviors and providing them with crucial information and resources for preventing HIV infection. In conjunction with the STOP team and the outreach van, many of the youth approached in the community

have accepted HIV testing and have participated in pre and post-test counseling which further reinforces the risk-reduction information shared by the outreach workers. The success of the program is due in large part to the way in which the project works with peer workers. The introduction of the Orasure HIV test led to an increase in testing rates. The lower than expected identification of infected youth has raised questions about the prevalence of HIV in the community and prompted an expansion of outreach activities.

Lesson #1: Challenge youth to reduce risk.

Simply being from the targeted communities is insufficient for youth to qualify as peer outreach workers in the program. The POWER outreach activities are built on the foundations laid by an intensive intervention into the lives of at-risk youth who become peer outreach workers. That is, peer workers are challenged to reduce or resist risk behaviors prior to going out into the community and urging others to do the same.

Before working with others in the community, the youth selected for the POWER program are involved in a program of activities intended to impact critical behavioral and psychological issues that increase the likelihood of their engaging in high-risk activities. These include low self-esteem, family stress, poverty, racism, and peer pressure to become sexually active, smoke and use drugs. Through the program, youth are integrated into a social support network that reinforces the risk-reduction messages of the program. The POWER staff, young adults from the community and alumni of the program offer positive role models and a mechanism for linking youth in crisis with supportive services. Youth involved in the POWER program experience psychosocial and developmental gains from their participation in the program. They learn to value school and work and as they transition to other employment or academic activities they increasingly rely on the POWER staff for guidance and assistance.

While the POWER training shapes the peer workers, the youth, in turn, have shaped and strengthened the program. Reflecting on their experiences, the POWER youth have underscored the efficacy of peer street outreach. As representatives of a number of adolescent subpopulations and cultures (e.g. pregnant youth, youth with histories of STDs), they have been able to target other members from these groups. In the field they work as a team, ensuring that members of the team are matched with youth encountered in the community. Peers from subpopulations or subcultures are more familiar with the sites of youth congregation and operate more comfortably and easily in these settings. Finally, they are also familiar with the idioms and in-group language of these subpopulations.

Lesson #2: Establish a presence.

To back the peers, the POWER and STOP teams ensure that the presence of the DAYAM Project is reinforced in other ways. To build an on-the-street profile, the outreach van is distinctively marked and regularly returns to the same location. The distribution of risk reduction kits, tee shirts and other items that identify the POWER team increases acceptance of the project and ensures that the message lingers after the peer outreach workers and the van have departed.

Peers from targeted populations are familiar with sites where youth congregate, integrate easily and use the in-group language and idioms.

Through these multiple messages, members of the community are also informed of the DAYAM Project's other services. Those contacted on the street often enquire about ways of accessing DAYAM services not immediately available in the field. Many of the youth request a telephone number to anonymously access information and testing. Future POWER team members are also recruited through these street contacts. As a result of the street encounters, the project staff learned that it often takes several contacts with an individual to establish the trust and comfort required for the individual to engage in a detailed conversation about risk factors and to accept the offer of an HIV test. The consistent presence of the van and the project message is important to building individual and community acceptance and trust.

Once a young person has accepted the offer of an HIV test, steps are taken to ease the testing process. Counseling sessions before and after testing are youth oriented, focusing specifically on adolescent psychosocial issues associated with

HIV. A case aide establishes a method to confidentially contact the young person in the event she/he does not return for the test results. These include recording telephone numbers, addresses and favorite sites for congregation, trusted friends and relatives.

STOP staff found that one of the greatest barriers to testing was fear of the needle. The advent of the Orasure test was the most effective solution to this barrier. As word of this alternate testing method spread among the youth, there was a noticeable increase in the willingness to be tested. The success of the Orasure method demonstrated unequivocally that this is a viable, if not superior, method for testing members of the at-risk youth population.

Lesson #3: Outreach stretches beyond targeted populations.

Despite contacting thousands of youth and testing hundreds, the number of new cases identified was surprisingly low. One adolescent was identified through testing compared to 38 infected adults tested during the same period. Staff on the STOP van were, however, consulted by five youth who had either known they were HIV-positive and had never sought treatment or had been in treatment but dropped out of programs. A number of HIV-positive youth were referred to the START treatment program by local churches, human service organizations and other hospitals or they heard of the program by word-of-mouth.

Two lessons were derived from these outcomes. The first is that when conducting street outreach, information about the program reaches beyond the target population. As a result of the outreach van's high visibility, community-based organizations and city and state institutions learned of the program and referred clients into the program. This inadvertent institutional outreach proved very beneficial for the project and has been made a component of the outreach effort.

The second lesson is that the initial outreach plan was not accessing groups in which HIV infections are concentrated. As the director of the DAYAM project has observed, in order for infection to occur, it is necessary that both risk behaviors and the HIV virus be present. Surveys of youth reached during outreach clearly indicate that they are a

high-risk group in need of prevention programming. Fortunately, the virus does not appear to have been introduced to these groups.

How do the Youth Identify?

Of the 38 HIV-positive youth in the clinic between 1993-1998:

- 19 gay or lesbian
- 3 transgender
- 1 pregnant
- 11 parenting
- 4 in commercial sex work
- 90% African American
- 10% Latino/a



Infections are not uniformly distributed across a population but follow routes determined by social and behavioral networks. The infected youth in care with the START team provide a profile of what these networks and subpopulations are. The project initiated a number of activities to increase access to these networks by developing outreach for specific subpopulations, including young women who are or had been pregnant, youth with histories of STDs, LGBT youth, sex workers, and Latino/a youth.

To enhance access, two strategies were adopted. The first was to partner with other agencies that target specific subpopulations. Part of the counseling and testing outreach is now conducted in collaboration with Covenant House which serves runaway youth and youth involved in sex work/survival sex. Project Fire, serving gay and transgender youth, has been approached to develop a similar collaboration as have community youth programs that have significant Latino/a populations.

The second strategy has been to conduct outreach in new areas and at late night hours. This is specifically targeted to youth who are involved in commercial sex work, are homeless and are drug users. For these populations, the visibility of the van may be a barrier and outreach workers are using different tactics to develop a presence on the street that will not draw attention to the youth.

Lesson #4: Develop and maintain adherence.

The START treatment team helped the youth in their care achieve an 85 percent compliance rate with appointment keeping and a 70 percent compliance rate with medications. These successes may be attributed to changes in the medications and the structure of the program.

Changing medications

The majority of problems with medication adherence resulted from the therapies themselves. The number of pills required in each dose and the frequency of dosing was a

burden on the youth and interfered with daily routines (school, work, etc.). The youth also feared that their HIV status would be revealed if others became aware of what medications they were taking. Consequently, they chose not to take the medications when at school or at work.

Mental health issues, family problems, difficulties obtaining childcare, social issues such as peer pressure, and problems with public transportation were greater contributors to medication and appointment compliance than anticipated.

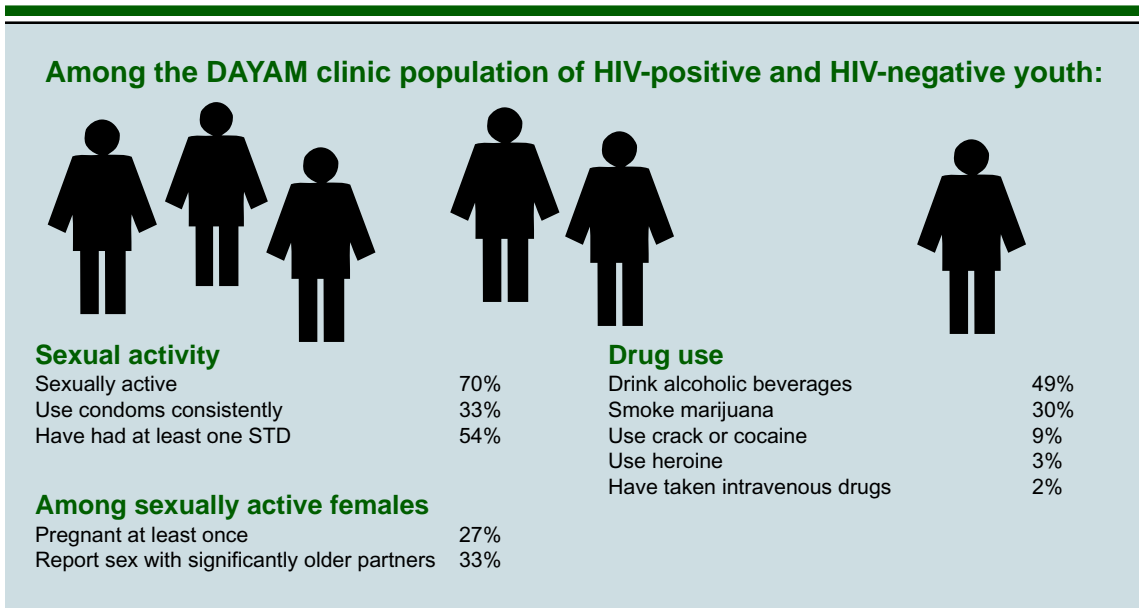
The introduction of combination nucleoside reverse transcriptase inhibitors (Combivir) decreased the number of pills per dose while the reduction in the periodicity of dosing for an additional protease inhibitor (Viracept) significantly improved the quality of living of many clients. The frequency of clinic visits decreased, there were fewer admissions and fewer visits to hospitals for emergency care.

Psychosocial barriers to adherence

Mental health issues, family problems, difficulties obtaining childcare, social issues such as peer pressure, and problems with public transportation were greater contributors to medication and appointment compliance than anticipated. A number of the youth were diagnosed with depression and experienced overwhelming stress because of family conflicts. Young mothers were reluctant to bring their children to clinic with them and had difficulty arranging childcare when needed. The youth also experienced their HIV-status as a barrier to their full participation in the activities of their social groups which are made up predominantly of non-infected youth. Taking medications only reinforced this sense of difference and exclusion. Finally, the public transportation system in the city is inconvenient, particularly for youth who are ill. Many lack the finances to pay the expense of transportation.

Each barrier had to be addressed by project staff. Through counseling and support from fellow patients, youth have been able to reduce the negative impact of mental health and family issues. Issues of shame and difference have also been addressed through counseling and peer support. Case managers have helped alleviate problems with transportation by providing vouchers and rides with UMDNJ vehicles. Childcare linkages have been made with relatives and public programs.

One of the most useful changes to the project was an expansion of the one-stop shopping model to mean not only that most if not all services are available in one place, but that they are available at the same time. Noting that appointment-keeping compliance is inversely related to the number of appointments, the entire START team is available during clinic hours. This reduces the need to make multiple appointments and reduces the disruption of school and employment schedules.



Peer advocates and support groups

The DAYAM project has developed into a significant social support network for HIV-infected youth through the increasing use of peer workers in the treatment environment. As with the use of peers in the POWER and STOP components of the program, this benefits both the youth selected as peer workers and those they serve.

Three years ago an HIV-positive client in the program was hired as a peer advocate to assist the case managers escort and link youth to needed services and to remind them to take their medications. As a result of the success of this first peer advocate, three more were hired with the assistance of Title I funding. In addition, a case aide position was established as a career advancement for the most effective peer advocate. These positions helped build the self-esteem of the youth who were selected to fill them while also giving the youth a greater input into the running of the program. The result was a marked increase in involvement, trust and self acceptance. For example, a number of the youth who had been clients in the program for some time came out as gay. They had originally presented themselves as heterosexual because they feared being ostracized by others in the program.

The peer advocates also revitalized the program’s attempts to convene support groups. The advocates invite fellow patients to attend the groups, they plan agendas, enlist speakers, and advertise the programs. There is now one active group that averages at least 10 attendees. The peer advocates have also helped to create a peer culture within START that supports adherence to medications and keeping medical appointments.

Lesson #5: Support normal life activities.

The use of anti-retroviral therapies has significantly improved the quality of living of many of the youth in the START program. Their medical needs have been reduced as evidenced in fewer visits to the clinic and fewer hospital admissions. Yet the youth are making more frequent and longer visits to the nursing and case management staff for assistance with their ancillary service needs, the needs associated with surviving HIV infection and being more involved in normal life activities such as school and employment.

Emerging needs

The youth are requesting a range of services that go beyond the scope of direct medical intervention. Aware that sustained good health requires a holistic approach to the youth, START staff are working to meet these needs which include: mental health services for clients and family, academic remediation, job training and job placement, transportation, nutrition counseling and access to alternate therapies, and childcare.

The need for mental health services has greatly increased. As both the infected individual and the family adjust their understanding of HIV as something that youth can live with rather than as a death sentence, existing personal and family stresses emerge more strongly. Clients have presented with depression. Behavioral problems such as impulsive and aggressive behavior have also needed to be addressed. To accomplish this, mental health professionals are being integrated into the START team.

Case management

Case management services are being used more extensively by more of the youth. Case managers assess each adolescent's individualized needs in all areas of daily living, including housing, financial assistance, family and partner relationships, school and employment, substance abuse, mental health, parenting and child care. The case managers, assisted by the peer advocates, are the glue that holds the system together for START patients. Transportation and food vouchers are often provided. Concrete survival needs such as stable living arrangements and food are addressed first, so that they are not barriers to medical care and medication and appointment adherence. For other service needs, such as housing and employment-related services, START patients are linked to community resources.

Scheduling appointments

As medical treatment takes up less of their time and they become more involved in life activities, the youth have requested the opportunity to receive services at times that do not interfere with either school or work activities. This means there is a greater demand for evening and weekend clinic hours. Evening and Saturday hours are now available.

DAYAM Project Chronology

October 1996

- Advertise three new budgeted positions: a nurse practitioner, case manager and program assistant. The case managers tracks HIV-positive youth identified through testing and eases their transition into treatment. The nurse practitioner augments clinical services.

December 1996

- Outreach to Newark schools for in-class program; no responses.
- Focus groups held to review and make suggestions regarding outreach methods to enhance and encourage HIV testing.
- Latina program assistant added.

January 1997

- Institute regular monthly meetings for all DAYAM's HIV programs to facilitate inter-program communication and continuity of care. Discuss successes, problem-solve, share information on client needs, multi-site collaboration, new initiatives, and grant opportunities. POWER outreach slowed by winter weather; focus more on presentations and school-based work. Staff all take case management training.

May 1997

- Begin Orasure (saliva testing) on STOP van. State Department of Health supplies STOP with 50 Orasure tests per month.

June 1997

- Case aide is hired to assist with case management functions; caseload consists of clients with less complex needs. Housing and food are paramount to clients.
- Combivir (AZT and Epivir) prescribed to START patients. Enables clients to take combination therapy in less doses, with fewer pills, thereby facilitating treatment adherence.
- Decision made to hire nurse coordinator rather than nurse practitioner. Search for candidate begins.

September 1997

- POWER plans "Let's Talk Month" at a local high school; involve teachers with buttons, manuals, etc. in educating students about risk behaviors, STDs, HIV. Local middle school efforts going well; POWER co-facilitates four health classes one day a week.
- Efforts continue to collaborations to increase testing/identification of homeless youth; STOP to do HIV testing on-site.
- Still receiving 50 Orasure tests from the State DOH per month; need approximately 250 per month.
- Still trying to negotiate a collaborative agreement with Project Fire (sponsor of houses for transgendered and MSM youth) as well as with Integrity House (substance abuse program).

November 1997

- Nurse hired to function as patient care coordinator to track patients' lab tests, follow-up, specialty referrals, etc. Full interdisciplinary team now in place.

December 1997

- START averaging two new patients per month mostly referred by other agencies. "Shout outs" for medication adherence and appointment compliance started every Thursday.

January 1998

- Emergency cash assistance identified by case managers as essential for clothes, bridge fund for medications, personal hygiene products, etc. Apply for funding through Title I application.

February 1998

- Caseload assignments for case managers now at 24 active clients each.
- Patient's family is assisted/linked to services as needed. Title I award includes additional medical care dollars, as well as case management, and direct emergency services (including dollars for prescriptions and transportation).

May 1998

- Program expands START team to include bilingual medical assistant.
- First peer advocate hired.
- One hundred-fifty more youth than last year at this time, are tested—largely due to Orasure.
- Counseling group has five clients. Previously had problems getting youth to attend because of privacy/disclosure issues.

June 1998

- Emphasize need for late hour HIV outreach/testing and counseling, particularly for sex workers, transgendered, homeless teens, and Latinos.

August 1998

- Case managers, peer advocates, medical assistant, RN, data coordinator and others now colocated, facilitating communication regarding clients.

May 1999

- The program gets so many requests to do presentations statewide that street outreach is suffering.
- Decision made to divide peers into two teams; one will focus on street outreach; the other will do psychodrama presentations.

August 1999

- Title I funding enables expansion of peer advocate positions to four slots. Three new peers hired, two males and one female.

September 1999

- As clients feel better, doctor visits decreased while visits to other team members (nurses/case managers) increased significantly. The program definition of “appointment compliance” is modified to reflect this.

November 1999

- Ongoing efforts to recruit more Latinos in coordinator and/or outreach positions in effort to change community image of program as being African American-focused.
- Video on DAYAM's HIV programs completed. To be used for marketing to community, to potential funding sources, etc.

December 1999

- Continue to receive funding from Ryan White Title I to maintain expanded peer advocate

component with three additional male and female peers and will promote one peer advocate to case aide position as a career ladder move.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by the DAYAM Project, you are welcome to contact the project director and request technical assistance:

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