The Study of Medicaid and Ryan White Program

Coordination:

Where Does the Responsibility Lie?

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Executive Summary

This paper seeks to identify specific strengths and weaknesses in the current interactions and collaborations between the Ryan White and Medicaid programs. Program overviews are provided to illustrate the various service delivery and financing models for HIV/AIDS care currently being employed by these programs.

A survey was administered to consumers, case managers, and nurse care managers in order to gain a practice-level perspective of the program and systems levels. Recommendations based on this research are then given for the Department of Health, the Agency for Health Care Administration, and the Ryan White grantees to address weaknesses found in HIV/AIDS service delivery, financing models, and for improving cross program and interagency coordination toward the development of a long-term, sustainable, and cost-effective system of care for persons living with HIV in Florida.
I. Methods of Payment for Services under Medicaid (The Agency for Health Care Administration-AHCA)

Florida Medicaid

Implemented on January 1, 1970, the Florida Medicaid program was set up to provide healthcare related services to low-income people. As it currently exists, low-income children and their families, the aged, blind, and the disabled are set as targeted, covered groups. In addition to belonging to these groups, income and asset limits must be met, which vary. The Florida Department of Children and Families (DCF) and the Social Security Administration determine eligibility. Medicaid is considered an entitlement program, which means that any eligible American citizen is guaranteed the right to service, and the government must ensure its funding each year. In addition, it is illegal to charge recipients for the services that they receive.

Depending on who is applying for enrollment, they will either enroll through the Florida Department of Children and Families or the Social Security Administration. To be eligible under DCF, the citizens must be have children under the age of 18 and meet certain criteria related to how many people live in the home, their ages, total household earnings, whether anyone pays rent or mortgage, and total assets held by the household members.

To be eligible for Social Security benefits, a citizen must be 65 years or older, blind or disabled. The definition of disabled from the Social Security Administration requires that "the disability must prevent any gainful activity (e.g. employment), last longer than 12 months, or be expected to result in death" (DCF, April 2003:7). In addition to the previous requirements, in Florida, the individual must also be: a United States Citizen (or qualified non-citizen), be a Florida resident, have a social security number (or file for one), file for any other benefits for which they might be entitled, and report any other third party liability (e.g. health insurance).

In addition to the previously mentioned requirements, the individual must also meet income and asset criteria that are based on the Federal Poverty Level (FPL) and an asset test that can include, but not be limited to bank accounts, property other than home, stocks or bonds, trusts and life insurance (DCF, April 2003:7). Income and asset criteria differ between programs.
**Medicaid Health Maintenance Organization (HMO)**

All Medicaid recipients eligible for managed care must enroll with a MediPass provider, a Medicaid HMO, a Provider Service Network (PSN), or the Children's Medical Services (CMS). With the exception of emergency, family planning, chiropractic, podiatric, some dermatology services and OB/GYN, services must be prior authorized.

Minimum services include: Child Health Check-up, community mental health and mental health targeted case management services within Escambia, Okaloosa, Santa Rosa Walton (Medicaid Area 1), Hardee, Highlands, Hillsborough, Manatee, and Polk counties (Medicaid Area 6), dialysis services in a freestanding center, durable medical equipment and medical supplies, family planning, hearing, home health, hospital (including inpatient, outpatient, and emergency services), laboratory (including independent laboratory), prescription drugs, physician, therapy, vision, and x-ray services.

Reimbursement for MediPass and PSN providers is on a fee-for-service basis (plus a monthly administrative fee), while the Medicaid HMO uses a capitated, fixed, per-member per-month rate according to the various eligibility categories (Diamond, 1999). Medicaid reimbursement rates are used for all services provided to CMS Network clients (CMS Physician’s Handbook, 2002).

**Project AIDS Care (PAC) Waiver Program**

Within Medicaid is the Project AIDS Care (PAC) Waiver program, implemented on November 1, 1989. The PAC waiver program was designed to assist those individuals suffering from the late stages of AIDS to live at home and stay out of hospice or hospital care. The program has evolved, as the disease has become more chronic than acute in nature. This program involves the use of a case manager to authorize the following services, which are not limited to: day health, education and support, home delivery of meals, personal care for foster children, skilled nursing, and special medical equipment and supplies to individuals with AIDS (Center for HIV Quality Care, 2003).

Eligibility for PAC includes: a medical diagnosis of AIDS, disability status according to Social Security Administration standards, being Medicaid eligible, being at risk of institutionalization in a hospital or nursing facility, and being able to safely reside in a home.
Currently, there are approximately 6,700 individuals being served by the PAC Waiver (Center for HIV Quality Care, 2003).

Reimbursement to service providers, which can be community based organizations, private corporations, and individual professionals, is termed fee-for-service. It is the lowest among the maximum Medicaid fee, the provider’s customary fee, or the individual care plan allowed amount. There is no bidding process under the PAC Waiver program. Service providers are paid a flat fee per service unit.

**Medicaid Provider Access System (MediPass)**

The MediPass primary care case management program, established in 1991, involves contracted primary care provider gatekeepers that either provide for or refer to other Medicaid providers for the following services: Child Health Check-Up, advanced registered nurse practitioner, ambulatory surgical center, chiropractic, county health department, durable medical equipment and medical supply, federally qualified health center, home health, hospital inpatient and outpatient, laboratory, licensed midwife, physician and physician assistant, podiatric, prescribed drug rural health clinic, therapy, and x-ray services.

The MediPass Disease Management Initiative was designed for MediPass members with certain chronic illnesses. Enrollees work with nurse care managers in a Disease Management Organization (DMO), whereby disease-specific education is given and treatment compliance is monitored.

Authorized by the state legislature to initiate programs for patients with the chronic illnesses asthma, diabetes, hemophilia, and HIV/AIDS, the Florida Agency for Healthcare Administration (AHCA) contracted directly with the DMO Positive Healthcare, a Florida-based subsidiary of the AIDS Healthcare Foundation in 1999. This program was the fourth to be started. In September 1999, about 700 Florida AIDS patients were enrolled. Medicaid AIDS patients are enrolled automatically in the disease management program unless they choose not to participate, or opt out (Neveleff 1999).

Eligibility for MediPass includes low-income families and children, children in foster or subsidized adoptions, and Supplemental Security Income (SSI) recipients not receiving Medicare. As of December 2002, 659,430 individuals (49% of Medicaid recipients) were enrolled in MediPass (Center for HIV Quality Care, 2003).
II. Methods of Payment for Services under the Ryan White CARE Act Programs
(Department of Health, Bureau of HIV/AIDS)

The Ryan White CARE Act

The Ryan White Comprehensive AIDS Resource Emergency (CARE) Act was initiated in 1990 to provide a safety network for people living with AIDS. This legislation was named after a youth named Ryan White was infected through transfusion and faced stigmatization in the schools and general society in the 1980's. Reauthorized in 1996 and 2000, the CARE Act is a federal funding program administered through the HIV/AIDS Bureau (HAB), within the Health Resources and Services Administration (HRSA), which falls under the aegis of the Department of Health and Human Services (DHHS). Overall funding is determined annually based on projections of the prevalence and incidence of HIV and AIDS in the United States. The Ryan White CARE Act currently serves over 500,000 people in the United States each year (Buchanan, 2002).

The Ryan White CARE Act grants are not meant to replace existing state or federal healthcare funding streams, but rather supplement them. The CARE Act is not an entitlement program. Considered a "discretionary" program, it is also not guaranteed to be refunded each year. In fact, federal law mandates that Ryan White funding be the payer of last resort. This means that HIV caseworkers must first try to get Persons Living with HIV/AIDS (PLWHAs) Medicaid assistance or other non-Ryan White public funding. There are, however, no federal regulations on eligibility for Ryan White funded services except that a recipient be either HIV positive or an immediate caregiver of an HIV positive person. Each state or designated area under the CARE Act is responsible for determining their own eligibility requirements. In a national survey conducted in 2000, researchers found that 20 out of the 51 recipients of a Title I grant (reaching Eligible Metropolitan Area (EMA) discussed below) did not have financial eligibility requirements. This is not the case with Medicaid programs (Buchanan, 2002). Additionally, all of the EMAs that charged anything for service did so on a sliding scale.

The CARE Act allocates funding through four "Titles" (I-IV) and one part, Part F. Each funding stream has a specific purpose and function through different, specific grantees. Funding is allocated by the federal government and administered through a contract management system at the Health Resources and Services Administration (HRSA).
**Title I-Eligible Metropolitan Area (EMA)**

Title I provides money to cities or city/county combinations disproportionately affected by HIV and AIDS, referred to as Eligible Metropolitan Areas. These areas contain over 500,000 people and at least 2,000 reported cumulative AIDS cases. Title I grants are generally administered to service providers through the county or city government entity which submitted the application to HRSA for Title I funds. The county or city government entity resides within the EMA encatchment area. These entities are considered "grantees." A grantee is required to establish a Health Services Planning Council to determine how the money will be distributed.

One study describes the specific duties of the Planning Council as including prioritizing service needs, developing a delivery plan that works with pre-existing services, and assessing service providers. The same study asserts that community based care must offer both medical and social support, including "ambulatory medical care, pharmaceuticals, mental health, home health care supported by drug treatment, housing assistance, hot meals, transportation, rehabilitation, and hospice services, as needed" (Rundall, Kwait, Marconi, 1999). Other complementary services are available, such as acupuncture and massage if the local council approves of their provision. No services, however, are redeemable for cash, and cash is never dispensed to a recipient. The EMAs of Florida are Tampa, Orlando, Jacksonville, West Palm, Miami/ Dade, and Broward County/ Ft. Lauderdale.

**Title II**

Title II funding is administered directly to state governments. Like Title I, local consortia (planning bodies) are used to make allocation recommendations for funding. Title II has some similarities with Title I, such as a focus on home and community-based health care. Title II grants fund a variety of services through county health departments and community based organizations. One of the major differences between the two Titles is that Title II includes the AIDS Drug Assistance Program, or ADAP. ADAP supplies pharmaceuticals to individuals that do not have the means to procure them, either because of insurance caps or lack of insurance altogether. Many people enroll while they await Medicaid eligibility, which can take up to 29 months. (Buchanan, 2002)
In order to enroll in ADAP a person must: have proof of being HIV positive; have less than $25,000 in assets, not including a house or car; have current CD4 and viral load tests; have prescriptions on the ADAP formulary; and have an income of less than 350% of the Federal Poverty Level (currently around $30,010 for one person). In addition to the asset and income restrictions, people in institutional care and persons with insurance covering drugs or Medicaid are also ineligible (Florida Department of Health, 2003).

In addition to ADAP, Title II also funds the AIDS Insurance Continuation Program, or AICP (AIDS Project Florida, 2003). AICP helps HIV positive Floridians who are in danger of losing their privately held health insurance. AICP provides insurance premium payments of up to $650 a month (for medical, dental, and vision coverage), including COBRA, an insurance plan that allows people who have lost their job to continue their job-based insurance programs for up to 14 months. AICP pays for group, family, and individuals policies. AICP also covers COBRA “conversion fee” payments, as well as any policy upgrade payments.

Eligibility for AICP requires an HIV positive diagnosis along with presentation of at least one identified symptom since diagnosis. Also, enrollment is contingent upon financial limitations, such as a gross income less than or at 300% of the Federal Poverty Level and cash assets of less than $4,500 for one person ($5,500 for more than one person). Current enrollment in a private health insurance is also required.

**Title III**

Ryan White Title III funding is concerned with primary healthcare for underserved populations and people of low socio-economic status. This funding is applied for directly to HRSA by health centers, health planning councils, and other community based groups. It is administered through grants management at HRSA directly to the applying organization. Generally, these clinics and centers are found in underserved rural areas and urban areas with little or no health infrastructure. Services include medical, educational, and psychological care. Grants are awarded directly to both public and non-profit organizations, such as local health departments, homeless programs and community, migrant health, hemophilia, and family planning centers.
Title IV

Like Title III, Title IV grants are dispensed to public and private entities, such as privatized health care and non-profit organizations directly from grants management at HRSA. Title IV’s target populations are women, youth, and children affected by and at risk for HIV; the services are comprehensive based care with a focus on family centered programs. Title IV also includes access to research of potential clinical benefit for women, children, and families.

Part F

Part F of the Ryan White CARE Act is funding for Special Projects of National Significance (SPNS). Awards for such projects are highly competitive and meant to emphasize innovation and target hard to reach populations, such as minorities and drug users. These grants are intended to assist the development of system wide solutions and impact overall availability of healthcare services.

In addition to the SPNS grants, part F also funds the AIDS Education and Training Center Program, or AETC. AETC programs are designed to educate health care providers on many levels regarding healthcare practices for people with HIV and AIDS. There are 15 AETCs nationwide, with the Florida-based location also serving the Caribbean.

III. Survey Methodology

So where does the "consumer," or HIV infected individual accessing the labynyth of services fit into this system? Anecdotally, many consumers lament the difficulties of accessing services from the multitude and multiplicity of programs available. When discussing concepts for improving coordination between programs and looking at payment methods and tracking utilization, it makes sense to take a look at who is utilizing the services (or why they may not be) and find out if they are having difficulties navigating systems. How can discussions concerning duplication of services take place without the input of those using the services? No one knows better what breakdowns or benefits in the system are occurring than those that depend on them for life saving and life improving services and products. We consider this population an indigenous population because of the daily nature of their experiences within these systems of care.
The second and third essential groups that logically fit into this framework are the individual case workers and frontline medical staff that have consistent and personal contact with consumers. These groups speak from a "systems" point of view and relate longitudinal and multi-case experiences within the systems of care described previously. Case managers and nurse care managers are also considered indigenous for the simple fact of their daily work attendance and experience in the systems of care.

Finally, because there is so little comprehensive public research on tracking utilization, specifically in the care systems that we are focusing on, it was decided that focusing on consumers and frontline social and medical case staff would provide information that was not readily available to Florida's Department of Health (DOH) or the Agency for Healthcare Administration (AHCA). Should these entities find it useful to look at other data that must be reported to them, concerning utilization from funded agencies and individuals, then an in-house analysis would be very informative. However, should they choose to engage an outside agency to gather and analyze these data, the objectivity and integrity of the outcomes would be much stronger than if they were to report them from an in-house analysis.

At this indigenous level, we identified the three key categories of participants as consumers, case managers, and nurse care managers. These groups were interviewed or surveyed to gather "ground level" data on how the programs are either functioning or not functioning. We wanted to look past simple satisfaction surveys to attempt to uncover specific issues relating to the different programs and the case coordination between them.

Of the three indigenous groups, the most important are the consumers. This group is defined as HIV/AIDS infected individuals and their caregivers. We limited the participation in this survey to consumers that have, at one time or another, been enrolled in both the Medicaid system and the Ryan White care system. In this manner, we asserted that the accuracy of the interactions between programs and program staff could be gauged. If a consumer had only experienced the Ryan White system, what could they tell us about Medicaid? At that point, we would merely be collecting satisfaction data on one program.

The second group considered indigenous in this study is the Project AIDS Care (PAC) case managers. These case managers are the representatives of the Medicaid system in this study. They were chosen specifically because of their high degree of familiarity with HIV/AIDS issues, their routine contact with the individuals, and because they are also experienced in overall
Medicaid systems and methodologies. Also, they have the most regular contact with other AIDS-specific care systems outside of the PAC program, such as Ryan White and Positive Healthcare's AIDS disease management program, unlike other Medicaid case managers which do not specifically deal with HIV/AIDS.

The third group considered indigenous in this study are the nurse care managers employed by Positive Healthcare and the AIDS Healthcare Foundation to create a more medicinal link for the consumer with regard to disease management and adherence issues. This group was chosen for its routine contact with consumers and other social case managers within the different systems, and especially for its fairly new introduction (less than five years) into the system of publicly funded AIDS care in Florida.

Survey Construction-Consumer Survey

Three separate surveys were constructed for the three different groups, which can be categorized into two designs. The consumer survey and the case/care manager provider survey all deal with the same issues and yet are constructed differently for very purposeful reasons. Each survey was self-administered to eliminate interviewer bias (Black, 1999).

The consumer survey was constructed very deliberately, gathering information from existing survey research modules, consumer advisors, academics, and Florida Department of Health, Bureau of HIV/AIDS staff. Many survey techniques are used in the survey such as open-ended questions, Likert scales, and popularity ratings. A variety of data gathering techniques was used to create an array of data to analyze and be able to cross match topics using differing methods. Altering methods are also intended to keep the survey more exciting for respondents (Bernard, 1995). Gathering a fairly large amount of data per respondent necessitates making the survey more engaging.

This survey was pre-tested with consumer advisors. Two groups of three were used independently to test for topic validity and question reliability. The survey was also reviewed and edited by knowledgeable Bureau of HIV/AIDS staff for content. The results of these pre-tests included suggested rewording, additions, and deletions. Examples include reading (literacy) level consideration and vernacular changes, such as “accessing” to include “getting” and “gotten,” “disenrolled” to include “kicked off” and “food bank” to “home delivered meals.” Additional examples of items were provided so that respondents would have a clearer idea as to
what was being asked and so that they were relevant to the services being questioned. A drawback of the study was that although an attempt was made to translate it, the survey was only in English format.

Although The AIDS Institute is affiliated with the University of South Florida, the organization is not under its aegis as an independent nonprofit. Therefore, approval from the USF Institutional Review Board (IRB) was not a requirement for this study. Three of the researchers involved with the survey’s construction and methods of dissemination, collection, and analysis, however, are graduate degree holders from USF and have had extensive experience with IRB criteria. Careful consideration was given to research involving the use of human subjects, examples included but not limited to privacy, minimal risk protocols, and protected groups.

Survey Dissemination—Consumer Survey

Careful consideration was put into how this survey was to be disseminated. Various dissemination methods were used, giving conscious regard to HIV-related confidentiality laws and the realities of HIV-related discrimination. Community gatekeepers were used to gain access to the community at large. Gatekeepers are defined as community activists (those community members that are involved in planning and action) that have "significant knowledge of the community and participate in situations that have potential for useful research activities" (Van Willigen, 1993:111).

Through our work in advocacy and community services over the years, The AIDS Institute has developed a good rapport with many gatekeepers throughout the state. This set of gatekeepers was contacted at the onset of the study to assist with reaching consumers that would participate. The gatekeepers were contacted electronically by email or through telephone conversations and were given many participation options. After agreeing to assist with the survey dissemination, each gatekeeper was either emailed, faxed, or mailed through the postal service a copy (or many copies) of the survey and an introductory letter. The introductory letter included a description of The AIDS Institute, the study and its intentions, funding sources, and response methods. The gatekeeper was also provided with requested materials or postage needs.

In the introductory letter, consumers were given the option to fax, mail, or email the survey back to The AIDS Institute research staff. In a situation such as a support group or
gathering, gatekeepers could also collect and mass mail them to the research staff. However, this technique was discussed with the gatekeeper, and they were explained the tenets of interviewer bias. They were discouraged to bias responses or disclose the identity of the respondent to research staff. This was intended to reduce bias inherent in having a community leader present when a respondent filled out the survey—and reduce the likelihood of respondents answering in a fashion that they thought would be "acceptable" to the gatekeeper.

Where possible, tenets of Dillman's Total Design for increased response rates were used. These include, but are not limited to: handwriting address labels, printing the surveys on colored paper (preferably green), keeping the survey less than 10 pages, and including an introductory letter (Bernard, 1995:277-281).

Additionally, the gatekeepers were given the option of having The AIDS Institute research staff participation. Research staff were available for minor travel to areas for support groups, gatherings, and/or meetings. In this instance, the research staff could fully explain the study and its intentions, while answering any questions that consumers had. However, the same limitations given to gatekeepers were advised for research staff in terms of reducing bias. Consumers in these situations were asked to place their finished surveys in a manila envelope and seal them before returning them to the research staff.

Oversampling, a phenomenon that occurs when certain groups or units are sampled with higher probabilities than others, may have occurred as responding consumers may have represented the consumers in the population that are more active concerning their follow-up and involvement with the Medicaid and Ryan White systems. Unknown factors or barriers such as time, transportation, organization, or mail delivery issues may have also affected the survey responses.

Survey Construction-Providers

While modeling, topically, after the consumer survey, the survey for the providers was constructed somewhat differently. To be able to compare data between the three groups, topics were held very similar. Topics such as coordination of care, eligibility, and enrollment were inherently included. However, the focus of the provider surveys was really coordination of care. Therefore, questions were focused directly on the interactions between the staff of the different programs and the experiences staff had interacting at different levels with staff from other
programs. Many of the ideas supporting the survey content were anecdotally driven directly from staff and consumers on interactions between professionals.

An open-ended question methodology was adopted for the surveys after these discussions. The purpose of using open-ended questions is to gather the widest range of response possibilities, although it allows for less quantitative data. It was the intention of the research staff to offer any and every opportunity for the respondents to think outside of their operations-level conceptual framework, or "think outside of the box." In this manner, it was asserted that we could gather information not yet collected with regard to the topic. Included are a few Likert scales to gauge range of opinion. The surveys for the PAC case managers and the Positive Healthcare nurse care managers are only slightly different in wording with respect to questions related to PAC/Positive Healthcare interactions.

The surveys were kept fairly short, totaling four pages in length, and were pre-tested by seven professionals. This pre-test number is consistent with percentages needed for reliability and validity tests as compared to total possible population sizes, according to research professionals (Bernard, 1995; Black, 1999; Van Willigen, 1993; Golden-Biddle and Locke, 1997; Grbich, 1999).

**Survey Dissemination-Provider Surveys**

The provider surveys were strictly disseminated through the postal service. For the PAC case managers, a mailing list of PAC funded agencies was obtained from PAC staff at the Agency for Healthcare Administration (AHCA). The packet was mailed to the "PAC Case Management Team," since multiple case managers may be located at each agency. In the introductory letter to the PAC case management teams, they were encouraged to make multiple copies of the survey for each of their case managers.

For the Positive Healthcare nurse care managers, administrators were contacted. The AIDS Institute research staff discussed with Positive Healthcare administrators the intentions of the study and the survey, and were given the opportunity to ask questions. Following these conversations, Positive Healthcare administrators provided research staff with mailing addresses for nurse care managers around the state. Introductory letters for nurse care managers also explained the study, its intentions, and instructions for responding.
Each packet mailed to both groups contained three pieces of material: an introductory letter, a copy of the survey, and a self-addressed, stamped envelope. In this manner, it was determined that respondents would not have to pass the survey through their supervisors and therefore, research staff could increase honesty reliability. The introductory letter introduced The AIDS Institute, explained the study and its intentions, and gave response instructions. Respondents were given the option of mailing the survey to research staff in self-addressed, stamped envelopes, or by faxing them directly. In both instances, anonymity was partially ensured, with the only possibility of identification being geographic postal markings or the fax number from the agency. Even considering these possibilities, a direct link to a specific individual would be extremely difficult.

IV. Survey Results

Survey Results-Consumers

Most (71.8%) respondents indicated having been a client of Medicaid services, while 89.7% of respondents indicated having been a client of Ryan White CARE Act services. Specifying services received through Medicaid, approximately half (53.8%) have received case management, nearly 2/3 for both medications (prescriptions) and physician visits (69.2% and 61.5%, respectively), about 1/3 for mental health services (35.9%), and significantly less (23.1%) for transportation, substance abuse services (7.7%) and other (7.7%). From the greatest to the lowest percentages indicating services received through the Ryan White CARE Act, 66.7% reported having received case management, 56.4% medications, 48.7% housing services, 38.5% meals, 35.9% transportation, 33.3% physicians visits, 28.2% mental health services, 12.8% AIDS Insurance Continuation Program (AICP), 12.8% other, and 10.3% substance abuse services.

Approximately half (51.3%) indicated having ever been concurrently enrolled in both programs (Medicaid and Ryan White CARE Act), while less than half (41%) indicated having received accessed services dually. Nearly 2/3 of respondents (66.7%) indicated not having ever had problems gaining (accessing) services from Medicaid, while about a quarter (25.6%) indicated that they have had problems accessing services. Response patterns were similar.
(69.2% and 30.8%, respectively) for the question pertaining to problems gaining (accessing) the Ryan White CARE Act system.

When asked how Medicaid services were referred and/or how it was found there was the possibility they may be eligible for Medicaid services, the majority of respondents indicated a Ryan White case manager (25.6%) or county health department (23.1%). Less frequent modes included hospital/benefits counselor and other (both 15.4%), physician or nurse (5.1%), family or friend (2.6%), and housing counsel (zero).

When asked to rate their migration from the Ryan White care system to the Medicaid system or vice versa, respondents’ data was scattered among “very difficult” (zero), “difficult” (12.8%), “a few problems” (23.1%), “easy” (12.8%), “no problems at all” (15.4%), and a purposeful skip (20.5%, indicating that the question was not applicable to these respondents).

The data was also scattered when asked what the most important services are that are received from Medicaid. Ordinal response options were one (1) through nine (9), with (1) representing “most important” and (9) representing “least important.”

Respondents indicated evenly distributed responses for case management. The majority of responses (36%) for physician visits, and 48.7% for medications were among the (1) through (3) side of the scale, weighing toward “most important.” Data for both transportation and other were indeterminate, while mental health, substance abuse, and meals were scattered around the mean (5), indicating semi-even distributions among “most important” and “least important.”

Most (69.2%) respondents indicated not having ever been denied enrollment to Medicaid. Similarly, most (79.5%) respondents indicated not having ever been kicked off (disenrolled from) Medicaid. Concerning Ryan White enrollment denials, most (89.7%) indicated that they had not ever been denied, while 87.2% indicated that they had not ever been “kicked off” (disenrolled from) Ryan White. For both Medicaid and Ryan White, the majority of those that indicated that they had been kicked off indicated that there had been someone available to help them reapply.

61.5% of respondents indicated they felt their lives are better because of Medicaid services, while a small number (5.1%) indicated “no,” 7.7% left the question blank, and nearly a quarter (25.6%) purposely skipped this question due to non-applicability. A large majority (79.5%) also indicated they felt their lives are better because of Ryan White services, while
12.8% indicated “no.” This is quite possibly the most encouraging question in the survey. It remains a very positive outcome that gives credit and credence to all service parties involved.

Nearly 2/3 (66.7%) indicated not having received services through Positive Healthcare, 12.8% indicated that they have, and the remaining 20.9% was comprised of unanswered or purposely skipped responses.

Of the few respondents that answered this question (15.4% combined), 5.1% indicated being “very unsatisfied” with their Positive Healthcare nurse, while 10.3% indicated being “very satisfied.” Similarly, of the same percentage (15.4) of those who answered the question regarding having been given enough information about what the respondents’ Positive Healthcare nurse was supposed to do, 5.1% indicated “no” and 10.3% indicated “yes.”

Of those that responded to the question regarding having received services through Project AIDS Care (PAC) Waiver through Medicaid, there was an even split (38% each) indicating “no” and “yes.”

Responses indicating satisfaction with their PAC case manager were skewed toward the satisfaction end of the scale, with 15.4% indicating “slightly satisfied” and 20.5% indicating “very satisfied.” Both “very unsatisfied” and “no opinion” received 5.1% of the responses, and slightly unsatisfied received zero. A majority (53.8%) purposely skipped this question, indicating non-applicability. When asked if they were given enough information about what their PAC case manager was supposed to do, 17.9% indicated “no,” and 25.6% indicated “yes.”

When asked if they had received services through PAC Waiver and Positive Healthcare concurrently, 1/3 (33.3%) of respondents indicated “no,” 12.8% indicated “yes,” and the remaining percentage (53.9) either left the question blank or purposely skipped it.

When asked how often they thought their PAC case manager and Positive Healthcare nurse communicate, respondents indicated “yes” for once a week 2.6%, 5.1% for once a month, and 2.6% for other. When asked how often they thought their PAC case manager and Positive Healthcare nurse should communicate, respondents indicated “yes” for other 5.1%, and once a day, once a month, and once every six months 2.6%.

Few respondents answered the question concerning whom they talk to more often—their PAC case manager or Positive Healthcare nurse. Although this may have been due to the question being near the end of the survey, where response rates in general tend to be the lowest, the final demographic questions that followed contained a very low percentage of blank
responses. 87.2% purposely skipped the question, while 7.7% indicated “PAC case manager” and 5.1% indicated “Positive Healthcare nurse.”

Low response rates were similar for the question regarding who respondents believed is more valuable—the PAC case manager or Positive Healthcare nurse. 87.2% purposely skipped the question, while 7.7% indicated “PAC Case manager” and 2.6% indicated “Positive Healthcare nurse.”

Data captured by the demographic question regarding gender showed that most (76.9%) of those surveyed were male. Concerning race, 61.5% identified themselves as being “white/caucasian,” 25.6% “black/African American,” 10.3% “Hispanic/Latino(a),” 2.6% “Native American,” and zero “Asian/Pacific Islander” or “Other.” A wide range of responses was given for age. Grouped into those in their teens, twenties, thirties, etc., with approximately 5% who left the question blank, 7.7% were teenagers, 2.6% were in their twenties, 33.4% were in their thirties, 35.9% were in their forties, 12.8% were in their fifties, and 2.6% were in their sixties.

**Survey Results-Providers-Positive Healthcare**

The nurses answering the survey had an average 12.4 years of experience in nursing, or a combined 235 years experience in nursing. On average, the nurses reported 2.17 years of experience with Positive Healthcare, or a combined 43.32 years. All areas of the state were represented in the survey except for Northeast Florida or the Jacksonville metropolitan area. However, there were a small percentage of respondents that did not identify an area of the state, and the location of these respondents cannot be assumed.

Respondents were asked to rate their interaction with the Medicaid MediPass program from “very difficult” to “very easy,” 76.2% of which cited "slightly difficult" to "very difficult." The nurses identified many problems that interfered with the ease of provision of services for their clients concurrently enrolled in the MediPass program. One very common complaint concerned the lack of communication regarding how, when and why clients were disenrolled from both Medicaid programs and Medicaid overall. The provision of timely contact information for clients so that the nurses may contact them to set up appointments was similarly identified as an issue. Nurses mentioned the lack of availability of providers and specialty providers for Medicaid services in their areas. Finally, the phone-in communication system of Medicaid is identified as a barrier to the efficient provision of services for the client.
Asked to suggest items for improvement to ease program coordination between MediPass workers and Positive Healthcare nurse care managers to better serve clients, the nurses suggested to: improve the communication lines between professional staff so that clients do not get confused in the middle; provide for more consistent client case information sharing between professional staff to cut down on duplicative efforts; provide additional training for Medicaid and Positive Healthcare staff on the respective programs and the scope of services available with each program so that professional staff have full knowledge of available services. The staff also suggested providing more training and time spent on review for loss of benefits from Medicaid staff for clients and Positive Healthcare staff so that all are fully informed. Finally, the staff at the Medicaid offices should provide more timely contact information documents for providers and specialty providers in each area.

One-third of all Positive Healthcare nurse care manager respondents reported having a "slightly difficult" interaction with the Project AIDS Care (PAC) program, administered through the Agency for Healthcare Administration (AHCA). Another 28% reported having "no opinion" concerning the interaction between Positive Healthcare and the PAC program, which can be interpreted as being neither difficult nor easy. Some of the problems identified by the nurse care managers were as follows (from most frequently mentioned to least frequently mentioned):

◆ Positive Healthcare staff (47% of respondents) identified problems with power struggles in the community with PAC staff regarding possible services provided for clients. These answers were closely linked with responses regarding duplication of services and waste. The tone of the answers was mostly one of frustration and not blame.
◆ Positive Healthcare staff also identified the lack of providers and specialty providers in many areas for PAC funded services.
◆ Funding was also mentioned as a barrier to the smooth provision of services to clients of the PAC program.

When asked to create solutions to problems with program articulation between the Positive Healthcare staff and PAC staff, nurse care managers recognized the following strategies: increase mandatory contact between Positive Healthcare and PAC staff to allow for more and clearer interactions; provide timely provider contact information sheets and listings to Positive
Healthcare nurse care managers and PAC staff; increased training and instruction for Positive Healthcare and PAC staff on the programs and services available through each program for updates and clarity.

Responses rating the interaction with the Ryan White Care system and the Positive Healthcare program were mixed, centering around a 42.9% majority of "no opinion," meaning that most respondents rated their interaction neither difficult nor easy. Overall, Positive Healthcare staff had positive comments for the Ryan White Care system, complimenting the work of the Ryan White staff many times. When surveyed about the specific problems that they have experienced, Positive Healthcare nurse care managers identified the following issues (from most frequent to least frequently mentioned):

♦ Funding irregularities in the system, which lead to inconsistent service provision.
♦ Case Management case loads were identified as being too high, and Positive Healthcare staff thought that this might lead to burn out, high turn over, and difficulty in efficiently providing services to clients.

When asked for suggestions for improving the Ryan White Care system to enhance the coordination of care for clients, nurse care managers responded with the following suggestions: Ryan White providers should provide timely listings of providers and specialty care providers; the Ryan White Care staff could look at providing more incentives to attract more providers, especially in rural areas; increase education efforts around service availability and other benefits for clients to make the process more transparent; investigate transportation sharing between the two programs to see if there can be an overlap in transportation efforts for both Ryan White and Positive Healthcare commitments.

Responses rating interaction with the Ryan White case management program were mixed, centering around a 42.9% majority of "no opinion," meaning that most respondents rated their interaction neither difficult nor easy. When surveyed regarding problems with the Ryan White case management system, Positive Healthcare nurse care managers identified the following issues:

♦ They believed that the case management caseloads were too high, which again impedes the provision of adequate services to clients and leads to high turnover rates.
 Positive Healthcare staff also alluded to a continued power struggle between themselves and the Ryan White case managers leading to strained relations, duplication of efforts on behalf of the client, and unclear responsibilities and accountability.

 Positive Healthcare staff recognized a need to continue client education regarding Ryan White service provision parameters and comprehensive rosters of service providers.

Positive Healthcare nurse care managers suggested increase training and education for the Ryan White case managers on service provision parameters under Ryan White, as well as through Positive Healthcare for client case coordination.

Respondents were also asked to identify other publicly funded assistance systems within which they interact. Housing Opportunities for People with AIDS (HOPWA), Children's Medical Services (CMS), and the Department of Children and Families (DCF) were a few of the agencies or programs identified. Problems cited for HOPWA were either lack of funding or long wait periods for enrollment. For both CMS and DCF, general program coordination problems were identified.

Survey Results-Providers-Project AIDS Care (PAC) Program

The case managers answering the surveys had an average 7.83 years of experience in case management, or a combined 219 years of case management experience. On average, the case managers reported 5.23 years of experience with Positive Healthcare, or a combined 146 years. All areas of the state were represented in the survey except for Northeast Florida or the Jacksonville metropolitan area.

While the majority (32.1%) of PAC case managers cited "no opinion" regarding their interaction with the MediPass system, the combined "slightly easy" and "very easy" categories/responses was nearly double (42.9% versus 21.4%) that of "slightly difficult" to "very difficult." When asked what specific problems they were having with the Medicaid MediPass program, PAC staff overwhelmingly identified the change or cancellation of program benefits for a client without their knowledge. Also identified were the lack of client education and knowledge concerning their benefits under Medicaid/MediPass and the ability to
read/comprehend paperwork provided to them. Also, PAC case managers found it very difficult to communicate with Medicaid staff due to the phone communications system and routing process.

When prompted for solutions to difficulties in dealing with the MediPass program, PAC staff provided the following insights:

♦ Increased education efforts for clients as to their benefits under the program providing for more informed choice.
♦ An increased effort to make written materials targeted to clients more readily understandable.
♦ Providing for more client choice within the programs for service providers and for Medicaid programs overall.

Responses rating interactions with the Positive Healthcare program from the Project AIDS Care case management perspective were mixed, centering around a single category, with "no opinion" being the majority. When the case managers were questioned as to any possible difficulties interacting with the Positive Healthcare program, they mostly commented on issues dealing with power struggles within the community that could stymie the efforts of both parties in trying to provide services for the client. Words like "pushy" or "no respect for clients" were used when describing the nurses. Many of these comments are closely tied to communication breakdowns and barriers. There were also positive comments made by a few individuals, mostly citing good collaboration to provide "the best client care."

When prompted for suggestions, PAC case managers identified improved communication between themselves and the Positive Healthcare nurse care managers to benefit the provision of services to the client best. Also, training and education regarding roles, responsibilities, and accountability from each professional area (PAC and Positive Healthcare) was suggested as a possibility for improving coordination of care for the client.

Responses rating the interaction with the Ryan White Care system were weighed toward the “slightly easy” to “very easy” side of the scale, with the fewest (10.7%) "no opinion" responses of all of the survey's rating scale questions. This denotes that this question incited the strongest participant responses. PAC staff identified the following conditions as problematic in the coordination of care within the Ryan White Care system: inconsistent funding levels; timely
notice of service/program changes; hefty paperwork requirements; and the availability of service providers and specialty providers. PAC case managers requested more timely notice of program changes, along with rosters of providers and possible services. Another possible solution to improved client case coordination between PAC and the Ryan White Care system was increased funding and increased availability of services. Some services that were specifically identified were housing, transportation, and meals.

A combined majority (67.8%) rated their interaction with the Ryan White case management program "slightly easy" to "very easy," with diminishing responses toward the difficult side of the scale. The PAC case managers, surveyed regarding program interaction between the PAC program and the Ryan White case management program, produced the following items as problematic: inconsistent funding for services; cumbersome intake paperwork; and overall communication and program coordination for the client. When queried for solutions, the case managers replied: limit case management case loads; provide for joint meetings and training for PAC and Ryan White case managers; and increase training efforts for Ryan White case managers regarding outside programs.

Finally, PAC case managers, when asked about other publicly funded assistance systems, identified Housing Opportunities for People with AIDS (HOPWA), the Department of Children and Families (DCF), Housing and Urban Development (HUD), and county health departments as problematic to deal with. Specifically, HOPWA received the most attention. Explicit problems included long wait periods on application lists as well as office visits, uncooperative staff, and communication (returned phone calls and un-replied letters).

V. Summary

Attempting to capture the way in which several different publicly funded health care systems articulate around consumers and the professionals that serve them remains abstruse and complex. The attempt to provide HIV/AIDS related services for those that otherwise could not afford them has created a system that, at times, becomes too complicated and laborious to be effective.
From a myriad of governmental sources such as the Health Resources and Services Administration and the Centers for Medicaid and Medicare Services, our elected officials, in cooperation with advocates and activists, pushed to create systems such as the Ryan White CARE Act and augment other systems such as Medicaid and Medicare. It was the intention of this analysis to shed some light on this complicated system from the perspective of those that have accessed it, as well as those employed by it. We turned to the "indigenous" populations of the Ryan White CARE program and the Medicaid system as they related to HIV/AIDS services to answer the fundamental questions: What would make accessing the services easier for you? and How could your job responding to the client be made easier?

In turn, the answers to these and other such questions should inform those individuals attempting to administer the programs with less and less funding and resources each year. The answers could serve to create a more efficient system from the perspective of both the client and the provider. A more efficient system is, of course, a more fiscally solvent program.

The following recommendations are derived directly from responses to the surveys from clients, case managers, and care managers. It is the hope of The AIDS Institute that these responses and recommendations serve to improve the quality and quantity of care provided to those infected and affected by HIV/AIDS—the intent of each program.

VI. Recommendations

The AIDS Institute highly recommends that the Florida Department of Health, Bureau of HIV/AIDS, work with and encourage the Agency for Healthcare Administration (AHCA), and Positive Healthcare to:

1. Encourage and create incentives for the local areas to pay more attention to keeping accurate information and distribute (or make available) to the community a listing of providers in all categories. The Bureau should facilitate the creation of a resource manual that can be easily updated by newsletter or announcement. This manual could hold a comprehensive listing of providers for Project AIDS Care, Ryan White, Medicaid/MediPass, as well as Positive Healthcare. The manual could also include other programs' guidelines and parameters. Other such programs could be: Children's Medical Services, HOPWA, HUD, and the Department of Children and Families.
2. Create and implement training modules for all professional staff in the different programs (Project AIDS Care, Ryan White Care Programs, and MediPass/Medicaid care systems) to include all roles, responsibilities, and restrictions. These modules will serve to create clarity and transparency in the service delivery system. In this sense, the staff will not be expected to go above and beyond what they are mandated to do, because everyone will have a better understanding of role parameters. This will decrease power struggle issues immensely and will improve the clients’ interactions with the improved system.

3. Create and implement training modules at varied locations for clients and their families and support systems in the different programs (Project AIDS Care, Ryan White Care Programs, and MediPass/Medicaid care systems) to include all roles, responsibilities, and restrictions. These modules will serve to create clarity and transparency in the service delivery system, and will provide a sense of responsibility and accountability for the clients. Again, the staff will not be expected to go above and beyond what they are mandated to do, because both clients and staff would have a better understanding of role parameters. Included in the role parameters should be the clients’ roles and responsibilities.

4. Continue to create client centered educational materials regarding program benefits and program parameters. Client centered materials must be cognizant of education levels and culturally sensitive lexicons. The development of these materials will necessitate client involvement in their design and implementation.

5. Create associated training materials for the changes in the Project AIDS Care (PAC) service delivery system relative to the new roles and responsibilities for each vested party.

6. Survey the Ryan White case management system with a similar survey or set of topics to gain a perspective on program integration and coordination.

7. Encourage a formalized committee and input process between the Florida Department of Health, Bureau of HIV/AIDS and the Agency for Health Care Administration as it pertains to HIV/AIDS. Attempts until now have been ad hoc and inconsistent at best. A formal HIV/AIDS advisory body, co-convened by the two entities, should be established to deal with issues pertinent to both entities. We, of course, recommend that this body include both HIV/AIDS infected individuals, their caregivers, and providers of services funded specifically for HIV/AIDS care.
REFERENCES


10. Florida Department of Children & Families (DCF) (April 2003). *SSI-Related Programs*
Fact Sheet.


