NEW JERSEY
PART B
COMPREHENSIVE PLAN
2009-2014
NEW JERSEY

STATEWIDE COMPREHENSIVE PLAN

AS REQUIRED BY THE RYAN WHITE TREATMENT MODERNIZATION ACT

SUBMITTED TO:

Health Resources and Services Administration
HIV/AIDS Bureau

SUBMITTED BY:

New Jersey Department of Health and Senior Services
Division of HIV/AIDS Services

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Introduction
Introduction

The Part B Comprehensive Plan builds on the foundation of the 2009 New Jersey Statewide Coordinated Statement of Need (SCSN) in its recognition of the unique dimensions of the epidemic and the array of care and treatment services that exist within the State of New Jersey. The Plan was developed using information from existing Ryan White planning documents and grant applications.

The Comprehensive Plan also includes the expertise of, and information obtained from, policy analysts representing corrections, prevention, education, substance use, mental health and housing. Information from the four Part B regions, six Part A planning councils, Part D Family Centered Care Network participants and the HIV Prevention Community Planning Group (CPG) was also reviewed and incorporated into the Plan. In addition, input from people living with HIV disease was sought.

The Comprehensive Plan describes the organization and delivery of HIV health care and support services to be funded by the Ryan White CARE Act. However, the Plan is a working document that is revisited and revised as warranted by the epidemic, needs of people living with HIV disease and/or program changes.

Development Process

The SCSN Planning Task Force was a planning body convened by The New Jersey Department of Health and Senior Services, Division of HIV/AIDS Services. The Task Force, consisting of 33 elected members and community participants, met monthly to complete the following tasks: (1) development of the SCSN document; (2) development of the Part B Comprehensive Plan and (3) planning of the New Jersey All Titles Conference.

Task Force members and community participants represented the people living with HIV/AIDS community, Part F, the six Part A TGA/EMA in New Jersey (Bergen-Passaic, Vineland-Millville-Bridgeton, Jersey City, Middlesex-Somerset-Hunterdon, Newark and Philadelphia), the Part B regions (Atlantic-Cape May, Mercer, Monmouth-Ocean, and Burlington, Camden, Gloucester and Salem counties which comprise the South Jersey portion of the Philadelphia EMA), Part C, Part D, prevention services, corrections, and other public and private agencies providing services to the PLWH/A community. In addition, the members and community representatives of the SCSN Task Force represented all planning regions in the state and had experience and expertise in evaluation, needs assessments, and policy and planning.

Background: In January 2005, the Comprehensive Plan Committee of the Task Force (Committee) was assigned to develop the Part B Comprehensive Plan for submission to Division of HIV/AIDS Services in December 2005. The Committee developed a process (approved by the full Task Force) to create the Comprehensive Plan. The process included the following components: (1) data collection and review; (2) development of discrete goals and objectives; (3) review and consistency with the SCSN Document, Epidemiologic Profile and New Jersey HIV/AIDS Strategic Plan; and (4) approval of final Comprehensive Plan by the SCSN Planning Task Force.

Part B Comprehensive Plan: The Comprehensive Plan Committee reviewed the current and previous SCSN documents (particularly the recommendations) to use in
the development of the initial goals and objectives for the 2009 Part B Comprehensive Plan. In collaboration with the SCSN Document Committee, it was determined that the requirements for both documents could be combined with the State of New Jersey Epidemiologic Profile so that each complemented, completed, and supported the others. The members of the Committee also reviewed previous Comprehensive Plans, the HIV Prevention Comprehensive Plan and the New Jersey Strategic Plan.

**Development of 2009 Comprehensive Plan Goals and Objectives:** Using the process developed for the SCSN document and 2006 Comprehensive Plan, community representatives reviewed and compiled recommendations. The completed goals and objectives were submitted to DHAS for approval and implementation.
Section 1
Where are we now?
What is our current system of care?
Description of the State

Socio-Demographics: A detailed socio-demographic description of the State of New Jersey is contained in sections of the 2006 Epidemiologic Profile and the 2009 SCSN Document.

New Jersey is the most densely populated state in the country and contains or borders 12% of the 100 most populous counties in the country. In addition, it is highly developed with an ethnically and economically diverse population.

Race/Ethnicity: New Jersey is one of the most religiously and ethnically diverse states in the country. Black, non-Hispanics and Hispanics comprise 16% and 17% of New Jersey’s population respectively.

New Jersey recently experienced an increase in “outmigration.” The number of people leaving the state exceeded the number of people moving into the state. This demographic change was predominately due to White, non-Hispanics moving out. New Jersey’s White, majority population has been declining for years, but the pace of decline has accelerated, totaling over 5% since 2000. This outmigration is most pronounced in the northeastern corridor of the state.

Nativity: It ranks 3rd among all states in the proportion of the population that is foreign-born (20%) and 5th in the proportion of households in which a language other than English is spoken (28%). Of those who speak a language other then English at home, 43% indicate that they speak English “less than well.” Over 7% of New Jersey households are linguistically isolated (no household member over 14 years old speaks English or speaks a non-English language and speaks English “very well”). This includes: 31% of Spanish-speaking households; 19% of other Indo-European languages; 23% of Asian/Pacific Island languages; and 17% of other languages.

Over 19% of New Jersey’s immigrant population relies on some form of public assistance, compared with an average of 13.5% of New Jersey residents. Although 86% of New Jersey residents graduated from high school, over 35% of New Jersey’s immigrants lack a high school diploma.

Although New Jersey’s high cost of living is a drain on all residents, the economic climate is even worse for immigrants, particularly when it comes to the skyrocketing housing costs. Many immigrants crowd into houses or apartments. (Called “stacking:” a large number of people crowd into a single dwelling). The average Mexican household in New Jersey has at least four residents (the most in the US).

In general, many new immigrants from the Spanish-speaking world are far less affluent than the general population. The more recent immigrant groups include: Mexican, 164,000; Dominican, 159,000; Columbian, 87,000; Cuban, 77,000; and Ecuadorean, 74,000. On average, for every dollar earned by the average New Jerseyan: Colombians earn 60 cents; Ecuadoreans earn 54 cents; and Mexicans earn 41 cents (the widest income disparity that Mexicans face in any state). Typically, Mexicans live in rental housing and pay 17% more than the state average for apartments. More than 60% of Mexicans in New Jersey are undocumented. The number of illegal immigrants raised an average of 6% each year between 2000 and 2006.
New Jersey also ranks 8th in the proportion of all births that are to immigrant mothers. In addition, 52% of those immigrant mothers had not graduated from high school. It is estimated that the undocumented account for 31% of all immigrant births in New Jersey.

**Poverty Rates:** Income data reveal significant disparities based on geography. Six townships have poverty rates more than double the statewide rate, including Camden City and Passaic City where poverty rates are well over three times the statewide average. The same six townships have severe poverty rates (50% of Federal Poverty Level) well over twice the statewide rate and the share of their residents living on incomes below 200% of FPL (true poverty) ranged from 48-66%.

There is a persistence of historically disproportionate representation of the same vulnerable populations in New Jersey among the poverty population. There is a significant disparity in poverty rates between racial and ethnic groups (17% African Americans and 16% Latinos/Hispanics). However, analyzing income adequacy using the self-sufficiency income as the primary measure reveals a much larger percentage of people with insufficient income among Latinos (42%) and African Americans (34%).

The experience of poverty for Hispanics and African Americans is three times the rate experienced by Whites. People of color are disproportionately clustered in townships with the highest poverty rates. More than 50% of residents of Newark and Camden City are African American and more than 50% of the residents of Passaic City and Paterson are Latino/Hispanic. These same cities had close to 25% of their residents living below FPL and close to 50% living on incomes below 200% of FPL.

Nearly 19% of the residents of Cumberland County are below the FPL. Three other counties (Hudson, Passaic and Essex) have official poverty rates close to 14%. The true poverty rate (200% of FPL) is: 35% in Cumberland County, 35% in Hudson County, 30% in Essex County and 30% in Passaic County. Almost 21% of all New Jerseyans live on less than 200% of FPL.

**Other Sources of Funding:** New Jersey has the highest imbalance between what it gives to the federal government and what it receives of any other state in the U.S. In fiscal year 2005, NJ taxpayers gave the federal government $77 billion dollars but only received $55 billion dollars back. This difference is higher than any other state and means that for every $1.00 New Jersey taxpayers sent to Washington, the state gets a return of $.61 dollars. (This calculation is after making the federal government deficit neutral because sometimes it spends more than it takes in.) As of 2005, New Jersey has not ranked above 48th for per capita spending (with a rank of 50th for the majority of that time) since 1982 while ranking 2nd or 3rd in per capita federal taxes paid to Washington.

As a result, New Jersey runs into deficits frequently and has one of the highest tax burdens in the nation. Factors for this include the large federal liability which is not adjusted for New Jersey’s higher cost of living and Medicaid funding formulas.

Since 2005, New Jersey’s share of Ryan White funds has decreased almost $4 million (a reduction of nearly 5%). This decrease represents a reduction in funds in Parts A, B, C, and D and F. The only increases occurred in Community-Based Dental Partnership, Housing Opportunities for Persons with AIDS (HOPWA) and Special
Projects of National Significance (SPSN). The largest decrease occurred in the planning regions covered by Part A, representing over 85% of New Jersey’s population that is living with HIV/AIDS. New Jersey also experienced a reduction of almost $1.6 million in Part B funds, the majority of which came from the AIDS Drug Assistance Program (ADAP) appropriation. The reduction in Part A funds was ameliorated through the infusion of state funds to the Part A planning regions.

**State Funds:** New Jersey has perennially provided more state funds than the federally mandated contribution requires. However, New Jersey’s emerging fiscal crisis may see a reduction of state funds from those typically earmarked for AIDS Drug Distribution Program (ADDP).

The State of New Jersey is facing a deficit in excess of $1.5 billion this fiscal year with a higher projected deficit next year. This may require the State of New Jersey to redirect funds from non-medical, support services to core medical care services to ensure its availability to those who need it.

**Economic Factors:** New Jersey appears to rank among the wealthiest of all 50 states in the country. It ranks 2nd in per capita income, 1st in median household income, and 48th in the proportion of the population living in poverty using the Federal Poverty Level (FPL) as the measure. However, there are alarming areas of economic stagnation and growing problems in New Jersey. The severely strained resources of the current economic crisis pose new and dangerous challenges to the well-being of the most disadvantaged in New Jersey, including the vulnerable HIV/AIDS population.

Data used for demonstrated need are based on information gathered in 2007, before the current economic crisis began to gain momentum. The most current data points, including information on unemployment rates, job losses and the foreclosure crisis present a more consistently negative picture suggesting that the more time-lagged data may actually understate the severity of conditions now. Once the spiraling effect of the current economic crisis is felt, any gains made against poverty and the continuum of care for people living with HIV/AIDS in NJ may be wiped out.

While median household income rose nationwide for 3 straight years, income levels in New Jersey remained essentially flat. Median household income in Cumberland County was lower than the national average by $2,800 and lower than the New Jersey average by $19,100. The city of Passaic was the nation’s 10th poorest city with a median income of $17,691. The city of Camden was the nation’s third poorest city with a median income of $25,389.

New Jersey is among the most expensive states in the nation according to a variety of state-to-state comparison measures, making the use of a nationwide standard particularly problematic for measuring true need in New Jersey.

Although, incomes tend to be higher in New Jersey, the higher salaries are negated by the high property, state/local income taxes, the high cost of living, the highest medical care costs in the US, and the low rate of return by the federal government.

**Income Disparity:** The story of wealth and poverty in NJ presents a disturbing dichotomy that is often concealed by statistical averages showing the state’s relative affluence. New Jersey is home to both rich and poor with a wide gap separating the
Income inequality is the 15th worst. The shared aggregate income held by low-and middle-income populations continued to decrease in 2007. The share of all income in the state decreased for the bottom 4/5th of the population, while the share of the wealthiest 20% increased.

One measure of the worsening inequality in NJ is the Gini Index (a commonly used statistical measure that calculates the degree of income inequality within a population group (a coefficient of 0 indicates perfect equality and a coefficient of 1 signifies all the wealth is held by one person)). New Jersey’s Gini index is .458, 15th worst in the nation and the rising inequality occurred at a faster rate in New Jersey than in other areas of the nation.

Poverty Level: Overall, nearly 9% of NJ residents lived in poverty in 2007, which is lower than the national poverty rate; however, given NJ’s large population, the state’s relatively low poverty rate translates to a large number of people (estimated at about 729,211). Particular susceptibility to poverty increases twofold for those with disabilities compared to those without any disability. Eleven percent of New Jersey’s residents report a disability.

Newark and Camden are two of the poorest cities in America, but New Jersey as a whole has the highest median household income among the states. Twenty-eight percent of the residents of the city of Camden live below the Federal Poverty Level. The proportion of residents in the counties of Cumberland, Essex, Hudson and Passaic living below the Federal Poverty Level is higher than the national average.

The FPL which does not take regional differences into account fails to capture what it takes to make ends meet in a high-cost state such as New Jersey. A more meaningful measure of income adequacy (self-sufficiency income) indicates that in all 21 NJ counties, the real income required to be self-sufficient is between 2.5 and 4 times higher than the FPL.

The ability of families to meet their most basic needs is a measure of economic stability and well-being. Poverty thresholds measure the extent of serious economic deprivation, whereas “family budget” is the income necessary to secure safe and decent, yet moderate living standards in a community in which the family resides. Family budget provides a broader measure of economic welfare. Using family budget as a measure, 20% of New Jersey’s working families do not have sufficient incomes to support themselves. New Jersey ranks 16th in the proportion of the population in families with incomes less than family budgets (23.3%) and 7th in the number of people in families with incomes less than family budgets (383,000).

Housing Affordability: The average income of New Jerseyans is 33% higher than the national average, but that advantage is negated by housing costs, including the highest average property taxes in the U.S. (52% higher than the national average). New Jersey now leads the nation in homeownership costs, and the number of residents devoting more than 30% of their income to mortgages, property taxes and insurance is growing. Five years ago, less than 1/3 of homeowners spent over 30% of their income on housing. In 2005, almost 40% spent in excess of 30%, with nearly 25% reportedly paying in excess of 40% of their income on housing costs. The percent of cost-burdened renters in NJ increased to 51% in 2007.
In order to keep housing costs below 30%, for the average renter in New Jersey a salary of $44,112 per year (on average) is required. A minimum wage worker would have to work 119 hours (almost 3 full-time jobs each week) to afford a modest 2-bedroom apartment in New Jersey.

New Jersey is 1st in median housing costs for mortgaged homeowners ($1,938), with 1 in 6 homeowners paying more than $3,000 a month for housing. In 2001, 1 in 14 homeowners in New Jersey paid more than $3,000 for housing each month. One in 6 home-owning households spends at least 50% of their income on housing costs. New Jersey homeowners pay almost 50% more on housing than the national average.

Foreclosure filings in New Jersey jumped 95% during the third quarter of 2008 from the same period last year. Nationally, the number of foreclosure filings climbed 71% in the third quarter. In the Newark metropolitan area (including Essex, Hunterdon, Morris, Sussex and Union counties), foreclosure filings increased 90% in the third quarter to 5,056. The Edison metropolitan area (including Middlesex, Monmouth, Ocean and Somerset Counties) had an almost 86% increase in foreclosure filing during the same period to 4,486. The Camden area had the biggest quarterly jump at 254% to 2,837.

New Jersey’s foreclosure rate was the 8th highest in the nation in October 2008 with one in every 410 household units in foreclosure, exceeding the national average of 1 out of every 452 households.

**Tax Burden:** New Jersey boosted its per capita taxes by more than any other state between 2002 and 2007. New Jersey (along with Tennessee, Mississippi and Rhode Island has the highest state sales tax. The state has the highest cigarette tax in the country, the highest average property taxes and the 7th highest income tax rate.

**Unemployment:** NJ’s unemployment rate has been steadily increasing and recently hit 6%, the highest rate in 5 years. Over the first six months of 2008, New Jersey employment fell by 21,000 jobs (.52%) and declined by another 3,900 jobs in September. Employment fell and unemployment rose throughout 2008. Although the current job losses mirror the national trend, NJ lagged behind the rest of the country in job growth by more than a percentage point.

Economists are predicting more difficult times ahead with workers bracing for even more major layoffs and growing unemployment amidst a slowing economy. Uncertainty in the national economic climate is expected to impact NJ’s unemployment significantly in the near future and developments in New York City’s financial sector will likely influence New Jersey’s employment trends.

**Income Assistance Programs:** Welfare recipients have not received an increase in assistance since 1987. Maximum welfare grant levels are now well below the severe poverty income thresholds, so the buying power of people who depend on this assistance has been steadily eroding.

**Health and Planning Indicators:** Detailed information on health and planning indicators for the state is described in the Epidemiologic Profile and the SCSN Document.
Cost and Complexity of Health Care Delivery: Complicating the provision of health care in New Jersey is the population and geographic diversity of the state. Although it is the most densely populated state in the country, there are many rural areas without public transportation and where a large portion of the population does not have access to a private automobile. There are other areas where there is sufficient public transportation and more automobiles than people.

Just as labor markets, health systems and economic circumstances vary from one state to another, the impact caused by rising health care costs and stagnant earnings differs considerably among the 50 states. Although the economy in the state has weakened, the cost of health care has continued to rise making it an even greater burden on New Jerseyans.

New Jersey has a reputation for “taking care of its own” as demonstrated by the state’s dollar for dollar match of federal Medicaid funds and providing 63% of per enrollee Medicaid spending. New Jersey has 1,207,767 uninsured residents (13% of the population). Thirteen percent qualify for and receive Medicaid coverage, 97,063 (1% of the population) qualify for and receive other public health coverage (such as Charity Care and PAAD). Twelve percent of the population of New Jersey reports a disability.

The hourly wages for New Jersey health care practitioners in New Jersey is the highest in the US, meaning New Jersey residents pay among the highest amount for health care in the country. The state ranks 12th in per capita health care spending and 10th in health spending as a percentage of the Gross State Product. New Jersey’s per capita spending for the 601,646 residents enrolled in Medicaid is $5,957, with $3,722 of those funds being provided by New Jersey general funds.

Between 2000 and 2007, health care costs have skyrocketed, even as wages have remained stagnant. While numerous other factors have also threatened economic well-being, such as rising gasoline prices and the crisis in the housing market, the confluence of stagnant wages and rising health care costs has become a significant strain on family budgets. New Jersey has the highest mean annual health care wages in the United States.

In New Jersey between 2000 and 2007: health insurance premiums for family insurance increased by 71%; the employer’s portion of the annual premium increased 64%; the employee’s portion of the annual premium increased 99%. Health insurance premiums for individual coverage increased by 63%; the employer’s portion of the annual premium increased 56%; the employee’s portion of the annual premium increased 97%. While the median earnings of New Jerseyans increased 15%, the growth in insurance premiums was 4.7 times the growth of wages in New Jersey.

New Jersey is falling behind in ensuring adequate health care as rates of health insurance coverage for adults (and children) are worsening. National un-insurance rates declined, the average rate in New Jersey increased. The uninsured living in severe poverty grew by 10% to more than 50% between 2006 and 2007. At the national level, 36% of those in severe poverty were uninsured. The number of New Jersey residents without health insurance has risen by 76% since 1990.

In health care expenditures, the measure of spending for all privately and publically funded personal health care services and products, New Jersey ranks 9th in total
health spending, 13th in spending per capita; and 9th in annual percentage of growth in health care spending.

New Jersey ranks 9th in personal health care expenditures, 19th in the average annual percent of growth in personal health care expenditures, 5th in the average price of retail prescriptions filled, 6th in state health care expenditures, and 7th in state mental health expenditures.

New Jersey ranks 20th in the proportion of the population without health insurance coverage, but the proportion of residents who do not have health insurance increased by 20% in 2003. In addition, the residents of only 12 other states lost a larger number of employee-sponsored insurance programs (88,552 (13%)). The proportion of Hispanics in New Jersey without health insurance is 30% (ranks 9th), the proportion of Black, non-Hispanics without health insurance is 19% (ranks 15th) and the proportion of residents of “other” race/ethnicities is 7% (ranks 16th).

New Jersey ranks 9th in state Medicaid funding and has 171,000 people eligible for both Medicaid and Medicare. In addition, New Jersey has a total of 47,081 individuals who receive income from both SSDI and SSI. In 2005, New Jersey legislators made provisions to reimburse the cost of the Medicare “wrap around” for those who are eligible for both Medicare and Medicaid from the state’s Medicaid funds.

**Co-Morbid and Co-Occurring Conditions:** The teen birth rate in New Jersey has risen almost 5% in 2006, as did some key sexually transmitted infections including syphilis, gonorrhea and Chlamydia. Over 3% of New Jersey’s HIV/AIDS population is homeless, according to the point in time survey conducted in January 2007. Almost 6% of the AIDS population was diagnosed with AIDS as a result of infection with tuberculosis and 5% of all HIV-related hospitalizations included individuals also infected with Hepatitis C. Over 66% of tuberculosis cases in New Jersey occurred in foreign-born persons. The proportion of tuberculosis cases in New Jersey by race/ethnicity in 2005 were: White-14.8%, Black-25.4%, Hispanic-29.7%, Asian-30.1%

Mental disorders are common in the United States, with an estimated 26% of the population over age 18 having a diagnosable mental disorder in any given year. The proportion of the population (6%) that suffers from severe mental illness constitutes the main illness burden, however. It is reasonable to assume that the proportion of people living with HIV/AIDS (PLWHA) with severe mental illness is much greater than in the general population. That proportion is concentrated in about 6 percent of the population. The New Jersey Association of Mental Health Agencies reports the third highest mental health expenditures ($1,160,000,000) in the United States and eighth highest per capita spending for mental health ($133.43). However, New Jersey receives no funds from (Substance Abuse and Mental Health Services Administration (SAMHSA) for mental health treatment of people with HIV/AIDS.

Overall, New Jersey ranks second nationally in the proportion of people infected with HIV through injection drug use (IDU), however, it ranks 10th in SAMHSA funding for substance abuse treatment of people with HIV/AIDS and 27th in funding for substance abuse prevention in people with or at risk for HIV/AIDS.
**Current Epidemic:** Detailed information on the current HIV/AIDS epidemic in the State of New Jersey is described in the Epidemiologic Profile and the SCSN Document.

HIV/AIDS remains heavily concentrated in the poorer, more urban areas of the state. The highest concentrations of HIV/AIDS are along the New York City to Philadelphia corridor (Bergen, Passaic, Hudson, Union, Essex, Middlesex, Monmouth and Ocean counties) and the Philadelphia to Atlantic City corridor (Camden and Atlantic counties).

HIV/AIDS disproportionately affects minority residents such as Black, non-Hispanics (16% of the general population, 55% of people living with HIV/AIDS) and Hispanics (17% of the general population, 22% of those living with HIV/AIDS). Furthermore, New Jersey ranks second in the proportion of women living with HIV/AIDS (36%).

Since the beginning of the epidemic in New Jersey, HIV/AIDS has been primarily associated with (IDU) and heterosexual transmission.

**Future Trends:** Detailed information on the anticipated trends in the HIV/AIDS epidemic in New Jersey is described in sections of the Epidemiologic Profile and the SCSN Document.

Although the number of infections with HIV has generally decreased, it is anticipated that the epidemic will continue to affect minorities disproportionately. Recent changes in the patterns of exposure indicate that while IDU will continue to represent a significant proportion of those living with HIV/AIDS, it is increasingly becoming a sexually transmitted epidemic and will remain predominately a disease of adults in their most productive years (25-64 years of age).

**History of Response to the Epidemic:** Detailed information on New Jersey’s response to the HIV/AIDS epidemic is described in the Epidemiologic Profile and the SCSN Document.

Overall, diagnosed cases and deaths due to HIV disease in New Jersey have declined in the last few years; however, the number of people living with the disease has increased steadily.

New Jersey’s response to the epidemic is demonstrated by the continuum of care and the HIV/AIDS Prevention Plan’s prioritized populations and interventions. In general, New Jersey has concentrated its prevention efforts and care services in the epi-centers of the epidemic, while still acknowledging and responding to increasing needs and challenges in the areas with fewer numbers of people with HIV disease.

**Assessment of Need:** Detailed information on the various needs assessment venues and findings is described in sections of the Epidemiologic Profile and the SCSN Document.

New Jersey provides a number of venues in which to assess the current and changing needs of people living with HIV disease throughout the state. In particular, the 2008 information was solicited through events targeting both consumers and providers. The Grantee engaged two methods to solicit input from the community regarding services: consumer surveys and focus groups. Consumer groups were surveyed to assess knowledge of the service system and challenges and/or barriers
in accessing services. Providers participated in facilitated discussion regarding challenges/barriers in collecting data.

The events included:

1. Women of Color and HIV conference-Consumer focus groups
2. Family Centered HIV Care Network Needs Assessment Survey
3. The Community Planning Infected/Affected Committee – Consumer surveys
4. The All Parts Grantee Meeting - Medical provider focus groups

Both the Women of Color Conference and the Family Centered HIV Care Network survey drew a historically underserved population. The needs assessment survey focused on the barriers that HIV positive women encounter when trying to access gynecological care.

**Unmet Need Estimate:** Detailed information on the estimate of unmet need is described in the Epidemiologic Profile and the SCSN Document.

At least annually, the surveillance unit of the Division of HIV/AIDS Services provides data to the Care and Treatment Unit and all TGA/EMA grantees on the HIV/AIDS epidemic. One important component of this reporting includes unmet need. Unmet need refers to the population of HIV-infected individuals who are aware of their HIV status who are not receiving minimally adequate HIV-related services, defined as receiving at least one viral load (VL), CD4 count/percent or HAART within a one-year period.

Because mandatory laboratory reporting of HIV-related tests was implemented in New Jersey several years ago, New Jersey is able to provide up-to-date, population-based assessments of unmet need, including a description of people who have unmet need.

The statewide analysis indicated that of the 30,916 people living with HIV/AIDS in New Jersey as of 12/31/07, 48% (36% of AIDS cases and 65% of HIV cases) have unmet need. Those with unmet need differ by gender, diagnosis, race/ethnicity, mode of transmission and date of diagnosis. Unmet need is higher for males than females; higher for Hispanics than for Black, non-Hispanics and higher for Black, non-Hispanics than for White, non-Hispanics; higher for men who have sex with men (MSM) and IDU than for heterosexuals, higher for those aged 30-39 and aged 20-29 than for those under age 13 or aged 13-19 and higher for those diagnosed in 1995 and earlier than those diagnosed more recently.

While New Jersey’s unmet need estimates may seem high, these results are comparable to those of other states. Mosaica, an organization that contracts with HRSA to provide technical assistance for unmet needs assessments, reports that the median estimates of unmet need among all Part B grantees is 52% for HIV cases, 38% for AIDS cases and 43% for HIV/AIDS. Although methodologies vary from jurisdiction to jurisdiction, making comparisons problematic, these data imply New Jersey’s estimates are comparable to other areas.

New Jersey is constantly striving to increase the accuracy and completeness of its assessment of unmet need. This includes more aggressive follow-up for potential cases as well as linkages to other databases. In particular, it is anticipated that the analysis could be improved with access to client level data from the EMA/TGA,
including privately funded anti-retroviral therapy, CD4 and viral load tests. While there are limitations to the estimates, New Jersey is working to reduce them as much as possible through a comparison of the HIV/AIDS Reporting System (HARS) with the Social Security Death Registry, Routine Interstate Duplicate Review (RIDR) and the EMA/TGA data.

**Gaps in Care:** Detailed information on gaps in care is provided in the SCSN Document.

While a formal gap analysis was not undertaken, New Jersey believes the strength of its response to the epidemic is its continuum of care, which is tailored to the regional and local needs and gaps in services throughout the state. However, an ongoing issue with the continuum of care revolves around the availability of transportation, particularly in the more rural areas of the southern part of the state, Hunterdon County, and the northwest portion of the Newark EMA.

**Prevention Needs:** Detailed information on prevention services is described in the New Jersey Comprehensive HIV Prevention Plan, the Epidemiologic Profile and SCSN Document.

The State of New Jersey presents unique HIV prevention challenges because of the diversity and density of the population. The state includes many “corridors” of HIV infection that reflect commuting patterns, illicit drug distribution patterns, farm laborer migration, the undocumented, as well as, numerous cultures, dialects and languages.

**Description of the Current Continuum of Care:** Detailed information on the current continuum of care is described in sections of the SCSN Document and is graphically represented in Attachment C.

**Profile of RWCA Funded Providers by Service Category:** A complete listing of all resources available in New Jersey (both RWCA funded and others) is included in the Resource Directory accessible online at the Community Prevention Strategic Development Initiative (CPSDI) website. Although developed and maintained by funding from the Prevention and Education Unit of the Division of HIV/AIDS Services (DHAS), this directory includes Care and Treatment services as well as Prevention Services.

In order to ensure the Resource Directory is as up-to-date as possible, it is maintained by CPSDI staff on their website. DHAS requires each grantee periodically review and update its listing. Many of the Part A grantees also require their service providers complete periodic reviews and updates.

In addition, the DHAS website includes a directory of all Part B and prevention funded service providers, as do the websites of the Bergen-Passaic TGA and the Newark EMA. Other Part A funded providers are included in resource directories available throughout the TGA/EMA.

**Barriers to Care:** Detailed information on identified barriers to care is described in sections of the SCSN Document and the Epidemiologic Profile.

New Jersey represents a service, prevention and planning challenge because of the diversity and density of its population. Although all 21 counties are designated as
metropolitan by the U.S. Census Bureau, there are large areas that remain rural. In these regions, access to medical services can be difficult due to the size of the area and scarcity of public transportation. As stated by one New Jersey consumer, “there may be an available bus every eight minutes on a corner in Newark, but in my neighborhood, there is only one every eight hours.”

**Medicaid/Medicare Programs:** Detailed information on Medicaid and Medicare is described in the SCSN Document.

New Jersey is ranked 9th in state Medicaid spending. There are 172,605 residents eligible for SSI (ranked 14th nationally) and 3% of the population is eligible for SSDI (ranked 37th nationally). The “wrap around” portion for pharmaceutical coverage for those dually eligible for Medicare and Medicaid will be reimbursed from state Medicaid funds.
Section 2
Where Do We Need To Go?
What System Of Care
Do We Want?

Section 3
How Will We Get There: How
Does Our System Need To Change
To Assure Availability Of And
Accessibility To Core Services?
Continuum of Care for High Quality Core Services: The operational definition of the New Jersey Continuum of Care and the core services is provided in the SCSN Document. In addition, a graphic representation, describing the continuum of care is provided in Attachment C.

Shared Vision for System Change: The vision for system change in New Jersey is provided in sections of the Epidemiologic Profile and the SCSN Document.

Needs Assessments: As the Part B grantee, DHAS is required to participate in statewide planning efforts. Of the 21 counties in New Jersey, 15 are in Part A planning regions and only six receive Part B funds only. The Part A planning regions include the epicenters of Newark, Paterson, Jersey City, New Brunswick and Camden. DHAS has a voting seat on each planning council. Each of the planning councils has conducted a wide range of planning and data collection activities to which the Part B grantee has access.

The Part B Grantee recently contracted with a major university to facilitate planning activities. It is likely that a gap analysis in Part B Regions will be done in 2009. There will be additional needs assessment activities to follow.

The 2008 information was solicited through events targeting both consumers and providers. The Grantee engaged two methods to solicit input from the community regarding services: consumer surveys and focus groups. Consumer groups were surveyed to assess knowledge of the service system and challenges and/or barriers in accessing services. Providers participated in facilitated discussion regarding challenges/barriers in collecting data.

The events included:

1. Women of Color and HIV conference – Consumer focus groups
2. Family Centered HIV Care Network Needs Assessment Survey
3. The Community Planning Infected/Affected Committee – Consumer surveys
4. The All Parts Grantee Meeting - Medical provider focus groups

Both the Women of Color Conference and the Family Centered HIV Care Network survey drew a historically underserved population. The needs assessment survey focused on the barriers that HIV positive women encounter when trying to access gynecological care.

As it has been in previous years, the Grantee recognizes comprehensive medical services, medications, in-home health care and health insurance continuation as priority services needed by all PLWHA. A mix of federal and state funding is used to ensure that the demand for services is met and that no one who seeks treatment is turned away. Services, including substance abuse treatment, mental health, transportation and case management, support medical adherence and are ranked as priorities by both consumers and providers.

A creative mix of service delivery models, like evening and weekend clinic hours, neighborhood medi-vans, and co-location of services, have ranked high in previous needs assessments and have been implemented to retain clients in care. The demand for safe and affordable housing is everywhere in New Jersey. Even with a mix of available funding sources, there are insufficient funds to meet the housing need. Transportation issues continue to rank high in terms of need. Consumers
residing in the suburban communities surrounding the state’s epicenters need a range of transportation providers, from vans to bus tickets, to access services.

Each of the Part A, Part C and Part D grantees has also undertaken various needs assessment and gaps analysis activities during the current fiscal year. However, many of the needs assessment reports are not completed and/or are in draft form. When the final reports are issued, each of the grantees will provide DHAS with a copy for use in future planning and coordination activities.

**Recommendations:** The recommendations of the SCSN Task Force in 2006 were provided in the 2006 SCSN Document. These recommendations were formed after a careful review of the data in the SCSN Document, the Public Hearing report, the All Titles Conferences reports, and the concerns expressed during the Public Forums at the monthly SCSN Task Force meetings.

The recommendations from the SCSN Documents helped to provide a substantive portion of the goals, objectives and activities for the 2006 Part B Comprehensive Plan, those goals represent a statewide perspective on the system of care desired and the changes required to achieve that system. Those recommendations have continued to form a substantive portion of the goals, objectives and activities of the 2009 Part B Comprehensive Plan. The conclusions section of the SCSN document helped provide an expanded framework to determine additional goals and objectives.

**Long-Term Goals And Objectives: Short-Term Activities To Achieve The Goals**

**Goal 1.** Maintain the most current, accessible medical care, medications, treatment, support services and prevention interventions for all persons living with HIV/AIDS in New Jersey.

- **Objective A.** Demonstrate that all support services link and maintain clients in medical care.
  
  i. Ensure that the priority for case management is linkage to medical care and medications.
  
  ii. Use case managers as “gatekeepers” for access to all services (i.e. case managers to serve as sole entity for referring and linking HIV positive individuals to any and all needed services).
  
  iii. Require case managers document adherence to medical care before referral for any service (except primary medical care).

- **Objective B.** Eliminate barriers to care.
  
  i. Annually review the location of clinics and infectious disease specialists to ensure a sufficient number and equitable distribution across the state.
  
  ii. Ensure that community-based providers of comprehensive care services are easily accessible throughout the state.
1. Ensure that all populations, especially low-income, under-insured, and homeless individuals, those with mental illness and/or substance abuse issues, and those in the correctional system can access and receive care.

   a. Provide suitable transportation to and from medical appointments (including mental health, substance abuse treatment, dental).

   b. Ensure that all funded programs provide culturally appropriate services for all populations.

   • **Objective C.** Ensure the availability of a wide range of HIV medications, those used to address side effects, and those aimed at improving the quality of life of those living with HIV (e.g., psychotropics, insulin, methadone, nutritional supplements).

   • **Objective D.** Establish statewide standards of care, using community input such as that used to develop the Culturally and Linguistically Appropriate Services (CLAS) Standards.

   • **Objective E.** Develop and maintain an up-to-date, statewide directory of available counseling, testing, prevention, care and treatment services (preferably on-line to ensure it can be kept current).

   • **Objective F.** Ensure HIV infected clients are enrolled in, or have completed, the most current Prevention for Positives intervention.

      i. If appropriate, HIV positive individuals will be referred to Comprehensive Risk Counseling and Services (CRCS) and all will have provided Partner Counseling Referral Service (PCRS).

**Goal 2.** Increase the percentage of HIV positive individuals who are enrolled in, and adhere to, comprehensive care services.

   • **Objective A.** Identify those who are HIV infected via the wide availability of counseling and testing services, the utilization of “rapid” testing procedures, and innovative outreach strategies.

   • **Objective B.** Educate the general public about HIV/AIDS as a means of encouraging people to get tested so they will know their status.

   • **Objective C.** Ensure referral and linkage to medical care and case management within 24 hours of the notification of a positive test result at state-funded counseling and testing venues. (Extended follow-up may be necessary to ensure/maintain the linkage to care and case management).

   • **Objective D.** Reduce the proportion of unmet need (i.e., people who know that they are infected with HIV but have not had reported CD4/viral load testing or have accessed prescribed ART within a year).
a. Ensure the availability of case managers to assist clients in accessing needed services, especially medical care, medications, shelter, food, mental health and substance abuse treatments, in a timely manner. Case management assistance will include:

   i. Arranging client transportation;
   ii. Regularly monitoring client attendance at medical appointments;
      1. Making referrals for “lost to care” outreach for clients who have missed medical appointments.
      2. Making referrals to peer mentors who can accompany clients to medical appointments/other needed services.
   iii. Helping clients obtain ADDP (if eligible) and all other entitlements/benefits (such as Medicaid/Medicare, SSI, SSDI);
      1. Referring clients to legal services to determine eligibility for benefits or to assist in obtaining benefits as necessary.
   iv. Assessing client’s adherence to medication regimens and referring to treatment adherence specialists, as needed;
   v. Ensuring access to safe, affordable, permanent housing;
   vi. Enrolling clients in mental health/substance abuse treatment as needed; and
   vii. Annually assessing each client’s service needs to ensure an accurate and up-to-date service care plan. If the planning region’s Case Management Standards of Care require more frequent assessments, those Standards should take precedence.

**Goal 3.** Provide training on the most recent advances in HIV care and treatment as well as prevention.

- **Objective A.** Offer training for providers in client needs assessment, recent advances in treatment, the importance of medical care and treatment adherence as well as other pertinent topics.

- **Objective B.** Ensure that individuals are trained to provide ongoing education to communities across the state on HIV prevention, testing and treatment.

**Goal 4.** Facilitate and aggressively promote collaboration and coordination in planning and service delivery across all funding streams including all RWCA Titles, prevention, counseling and testing, federal, state, local, and regional agencies.
Objective A. Increase information sharing and communication between all pertinent state departments and agencies on the availability and accessibility of resources.

Objective B. Develop standardized statewide needs assessments and solicit the cooperation of all RWCA Parts in design, implementation, and funding.

Objective C. Establish a statewide database to reduce duplication of services and unmet need, as well as to provide for the continuity and coordination of care.

Objective D. Reduce the number of planning bodies by combining the planning and needs assessment activities of care and treatment and prevention.

Goal 5. Ensure that prevention interventions (including Prevention with Positives and preventing vertical transmission) are a mandated component of HIV/AIDS care and treatment services.

Objective A. Ensure the availability of Comprehensive Risk Counseling and Services (CRCS) (including Health Education/Risk Reduction), particularly at medical facilities, substance abuse treatment programs, psychiatric hospitals, correctional facilities and community-based organizations/drop-in centers.

i. Educate agencies and communities about the availability and benefits of CRCS.

ii. Increase communication and collaboration with the Department of Corrections to ensure that HIV Prevention Education and CRCS are available prior to discharge of the incarcerated.

Objective B. Increase creative outreach, harm reduction and education strategies.

i. Increase community education and awareness of HIV risk to identified high risk and emerging high-risk populations.

ii. Continue to support Syringe Exchange Programs.

iii. Increase the use of the HIV positive community to assist in the development and implementation of outreach, harm reduction, and education strategies.

Objective C. Continue partner notification and access to medications.

i. Continue access to medications for women to reduce vertical transmission.

ii. Include updates on risk behavior and possible partner notification with each visit.
**Goal 6.** Monitor and evaluate the effectiveness of current methods of communicating with HIV positive individuals to ensure that consumers are informed and able to provide feedback to the Division of HIV/AIDS Services in a timely manner.

- **Objective A.** Identify barriers to the provision of information to consumers.
  
  i. Ensure that consumers are informed of opportunities to provide feedback in a timely and consistent manner. This includes giving notice of public hearings at least 2 weeks prior to the event.
  
  ii. Establish a system for following up on concerns identified by consumers including informing them of any changes or actions to be made.
  
  iii. Provide a means to communicate updated HIV-related information to consumers (e.g., quarterly consumer education forums, newsletters, websites).

- **Objective B.** Include in contractual agreements with each funded agency that it annually review and update (as needed) the agency’s information in a statewide resource directory (Goal 1, Objective E) as a means of reducing service information barriers and maintaining a current resource directory.

**Goal 7.** Evaluate and respond to changes and emerging trends in the epidemiology of HIV infection among various populations (e.g. women, youth, those with mental illness, etc.).

- **Objective A.** Continue to track trends to ensure a responsive prevention and care and treatment system.

  i. Continue to produce and utilize a comprehensive statewide Epidemiologic Profile.

  ii. Produce separate Epidemiologic Profiles for each Planning Region.

  iii. Continue to produce separate sections of the SCSN for each planning region to facilitate the planning for each region.

**Goal 8.** Annually review the Comprehensive Plan in order to measure progress in meeting stated goals and objectives.

- **Objective A.** Report the results of the review to the statewide planning body that incorporates both prevention and care and treatment representatives.
Section 4
How Will We Monitor Our Progress In Meeting Our Short-And Long-Term Goals?
**Implementation, monitoring and evaluation plans:** The Division of HIV/AIDS Services will provide a progress report on the implementation of the goals and objectives of this plan periodically. In addition, Division of HIV/AIDS Services will continue to use the evaluation and monitoring techniques it has always used to ensure compliance with the conditions of award, SCSN Document and previous Comprehensive Plans. These include:

- Monitoring of the funded agencies by the Program Management Officers to ensure agencies attain the service units mandated by contracts and as specified in the Implementation Plan in the 2009 Part B RW Treatment Modernization Act Grant Application.
- Monitoring of Division of HIV/AIDS Services attainment of performance goals.
- Continued participation in quality management activities that evaluate the quality of care and assess the extent to which HIV health services are consistent with PHS guidelines.