# *National Evaluation of the Medicaid Demonstration Waiver Home- and Community-Based Alternatives to Psychiatric Residential Treatment Facilities*

***Contract Number:***

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# Final Evaluation Report

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**Prepared By:**

Oswaldo Urdapilleta, Ph.D.
Geena Kim, Ph.D., Ying Wang, Ph.D.,
Jennifer Howard, M.S.W, M.P.P., Rekha Varghese, Ph.D.,
Genevieve Waterman, M.S., Sirisha Busam, Carrie Palmisano

IMPAQ INTERNATIONAL

***Submitted to:***

Effie George, Ph.D.
Ronald R.J. Hendler, M.P.A
Disabled and Elderly Health Programs Group
Centers for Medicare and Medicaid Services

***Submitted by*:**

IMPAQ International, LLC
10420 Little Patuxent Parkway
Suite 300
Columbia, MD 21044
www.impaqint.com

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# EXECUTIVE SUMMARY

In July 2003, the New Freedom Commission on Mental Health released *Achieving the Promise: Transforming Mental HealthCare in America*. This report outlined significant barriers to providing home- and community-based services (HCBS) for children and youth with mental illness or Serious Emotional Disturbances (SED) as an alternative to placing them in psychiatric residential treatment facilities (PRTFs). To address these barriers, the Commission recommended that the Centers for Medicare & Medicaid Services (CMS) conduct a Medicaid waiver Demonstration waiver program to test alternative approaches to providing HCBS for this population.

The Home- and Community-Based Alternatives to PRTFs Medicaid Demonstration waiver program was created by section 6063 of the Deficit Reduction Act of 2005 (P.L. 109-171). This Demonstration waiver program allowed up to ten State grantees to compare effective ways of providing care for children enrolled in the State's Medicaid grant program in the form of HCBS vs. care in PRTFs. For purposes of the waiver, PRTFs are deemed facilities specified in section 1915(c) of the Social Security Act. The waiver program targets children/youth who might not otherwise be eligible for Medicaid-funded, intensive community-based services and supports.

CMS awarded ten States grants between $15 million and $50 million each over the grant period, for a total funding of $217 million. One, Florida, did not continue in the Demonstration waiver after the Year 1. The nine fully participating State grantees are Alaska, Georgia, Indiana, Kansas, Maryland, Mississippi, Montana, South Carolina, and Virginia. Participating States are required to provide State matching funds.

## A. The Demonstration Waiver Program

The Demonstration waiver program enabled States, for the first time, to use Medicaid reimbursement to serve a population of children/youth with mental illness or serious emotional disturbances in their homes and communities. The goal of this evaluation of the Demonstration waiver program is to address Congress's statutory requirement for the Demonstration waiver "to test the effectiveness in improving or maintaining a child's functional level and cost effectiveness of providing coverage of home- and community-based alternatives to psychiatric residential treatment for children enrolled in the Medicaid program under title XIX of such Act."[1]

## B. Evaluation Approach

This final evaluation report provides responses to the two questions raised in the statute, updating the information presented in the fourth year evaluation report as well as providing

[1] Sect 6063. PUBLIC LAW 109–171—FEB. 8, 2006.

additional analyses to help identify successful strategies and the children and youth for which those strategies are most effective.

The primary evaluation strategy used in our analysis was a pre-post methodology, in which outcomes before program implementation are compared to outcomes for the same group after implementation.

The evaluation assessed changes in the functional level of the children/youth in the Demonstration waiver using two types of measures: 1) Demonstration waiver-specific outcomes that are common across grantees and 2) outcomes that are defined through well known functional assessment instruments. All the outcome measures reflect changes over a 6-month period: school functioning (e.g., number of absences from school, and school absence severity), substance abuse (e.g., severity of substance abuse), juvenile justice (e.g., number of arrests and any involvement with law enforcement), as well as others (including involvement with child protective services). Using these common outcomes provided a sample of more than 2,000 records.

Demonstration waiver States used one of three functional assessment instruments to gather data from children/youth enrolled in the Demonstration waiver. In most cases, the instrument developers provided guidance to the grantee States on their use. The *Child and Adolescent Needs and Strengths* (CANS) was used in *Indiana, Maryland, Mississippi* and *Virginia*, which together cover the largest number of children in the Demonstration waiver. *Alaska, Georgia*, and *Kansas* used the *Child & Adolescent Functional Assessment Scale (CAFAS). Kansas, Montana*, and *South Carolina* used the *Child Behavioral Checklist* (CBCL). The key research questions and approaches are common to all our analyses, although we did not use all items from each instrument, due to instrument (versions, State-specific elements) and data collection variations across States. States measured participants' functional assessments at baseline, 6-month intervals, and disenrollment

Our relatively large sample sizes and the subpopulation analyses we developed enabled us to identify and examine possible correlations between subpopulations of children and youth and outcomes and patterns across different State grantees. Taken together, the evaluation strategies we used substantially increase the confidence we can place in our findings.

## C. Summary of Findings

The evidence available to date yielded the following answers to the statutory questions raised by Congress.

*Question#1*: Did the Demonstration waiver services result in the maintenance of, or improvement in, a child/youth's functional status?

*Finding:* Overall, the Demonstration waiver has consistently enabled children/youth to maintain their functional status while in the waiver program. In many instances, program participants had improved level of functioning in several areas. Furthermore, outcomes appear to be improving over time.

Of particular importance to CMS and the States was to determine *which* children and youth do better in *which* setting: community or institutional. Rather than an overall assessment of PRTFs vs. HCBS, the intention was to enable States and the Federal government to better understand the contextual elements that enable individual children to be successful. The evaluation took into consideration that the participating States had different PRTF level of care criteria, resulting in every State having populations with different needs and different baseline functional scores. Nonetheless, it is clear that two populations had the most benefits from participating in the Demonstration waiver: (1) children with higher and an intermediate Level of Needs (LON) across different functioning domains and (2) children and youth that were transitioned from PRTFs verses those that were diverted from the inpatient facility. Prior to the Demonstration waiver, "few effective alternative treatment options available for children with serious emotional disturbances"… and "more and more youth were admitted to residential treatment".[2] It is important to note that these findings controlled for children's demographic characteristics, diagnosis, baseline functioning impairments and source of enrollment/admission status (diversion vs. transition).

*Question #2*: Was it cost-effective to provide coverage of home- and community-based services for children in the Demonstration waiver?

*Finding:* Over the three waiver years, Demonstration waiver treatment costs totaled no more on *average* than anticipated aggregate PRTF expenditures in the absence of the Demonstration waiver.

Indeed, there is strong evidence that the Demonstration waiver costs substantially less than the institutional alternatives. Over the first 3 waiver years[3] across all states, waiver costs were more no more than 31 percent of the average per capita total Medicaid costs for services in institutions – an average per capita saving of $40,000.

## D. Conclusion

Our evaluation indicates that the Demonstration waiver has certainly met the budget (cost) neutrality test and has consistently maintained or improved functional status for enrolled children/youth, on average. Thus, we are confident in concluding that this is a cost-effective approach to provide services to children/youth with mental illness or serious emotional

[2] Magellan Health Services. (2008). *Perspectives on residential and community-based treatment for youth and families.* Magellan Health Services Inc.

[3] Data was collected for four waiver years; however, at the time of reporting, data collected from year four was not yet available.

disturbances. Just as encouraging, enrollees and their families are very satisfied with the waiver program outcomes and their level of involvement.

The clinical improvements to children and youth, many who with their families were and severely impacted by behavioral health challenges and the demonstrated cost effectiveness of the PRTF HCBS Demonstration waiver authority provides Congress with the data and information it needs to further consider if (1) defining a psychiatric residential treatment facility (by the authority of section 1905(h)(1) of the Social Security Act as codified in 483.352 of title 42 of the Code of Federal Regulations) as a deemed facility specified in section 1915(c) of the Social Security Act (42 U.S.C. 1396n(c)) and (2) allowing other children and youth with mental illness or serious emotional disturbances to benefit from such successful and cost-saving services.

# CHAPTER 1. INTRODUCTION

## A. History

In 1990, Title II of the Americans with Disabilities Act gave civil rights and protections to individuals with disabilities, guaranteeing equal opportunity for individuals with disabilities in public accommodations, employment, transportation, State and local government services, and telecommunications. In 1999, the U.S. Supreme Court's *Olmstead v. L.C.* decision interpreted this Act as requiring States to administer services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." On June 22, 2009, to mark the 10th anniversary of the *Olmstead* decision, President Obama announced the "Year of Community Living" initiative, reinforcing the commitment to enforcing civil rights for Americans with disabilities and to ensuring the fullest inclusion of all people in the life of our nation. The President's action underscored the importance of the *Olmstead* decision and affirmed the Administration's commitment to addressing the isolation of and discrimination against people with disabilities that still exists today.

A major step forward on the way to enabling children/youth to participate in their communities came in 2002, with creation of the New Freedom Commission on Mental Health, which was charged with making recommendations to the President. In 2003, the Commission released its landmark report, *Achieving the Promise: Transforming Mental Health Care in America*. In addition to outlining barriers associated with providing community-based services for children/youth with mental illness or serious emotional disturbances as an alternative to placing them in psychiatric residential treatment facilities (PRTFs), *Achieving the Promise* noted that when comprehensive community-based options are unavailable, these children and youth are often incarcerated in the juvenile justice system, institutionalized for long periods, or placed in the care of the child welfare system.

The Commission's report provided a crucial impetus to developing non-institutional alternatives for delivering, planning, and financing services for children and youth with mental illness or serious emotional disturbances – as well as providing them and their families with a role in these processes – by recommending that the Centers for Medicare & Medicaid Services (CMS) conduct a Medicaid home- and community-based services (HCBS) waiver Demonstration waiver project that would enable States to provide HCBS as an alternative to residential institutional services for this population. Until that time PRTFs – which are a primary Medicaid-supported treatment setting for children/youth with mental illness or serious emotional disturbances requiring an institutional level of care – were not included in the identified residential institutional settings eligible for the Medicaid home- and community-based services 1915 (c) waiver authority, even though States and advocates had long hoped to extend the HCBS waiver authority to allow these children/youth to remain with their families and receive services in their homes and communities.

Passage of the Deficit Reduction Act of 2005 made possible creation of the Demonstration waiver recommended by the New Freedom Commission. Section 6063 of that Act (P.L. 109-171) authorized up to $217 million for a Demonstration waiver program that allows grantee States to use Medicaid funding for HCBS as an alternative to PRTFs for children/youth with mental illness or serious emotional disturbances.

## B. Demonstration Waiver Objectives

The Demonstration waiver grant waiver program allowed ten States (as defined for purposes of title XIX of the Social Security Act) to compare the cost effectiveness of providing care via HCBS with care in PRTFs for children enrolled in the Medicaid grant program. Through this program, CMS developed cost and utilization data to evaluate community-based models, such as systems of care and wraparound services that can reduce placement in residential institutional settings and allow for shorter lengths of stay and faster returns to the community with appropriate services.

For purposes of the Demonstration waiver, PRTFs were deemed to be a type of facility specified in section 1915(c) of the Social Security Act (in addition to hospitals, nursing facilities, and intermediate care facilities for the mentally retarded). Further, the Demonstration waiver targeted children/youth who were not otherwise eligible for any Medicaid-funded, community-based services or supports in the absence of the 1915(c) home- and community-based waiver.

As an integral component of the Demonstration waiver, an evaluation was required by Congress to assess two outcomes:

1) Whether the Demonstration waiver services resulted in the maintenance of or improvement in children/youths' functional status; and
2) Whether it was cost effective to provide 1915(c) home- and community-based waiver services as an alternative to inpatient psychiatric residential treatment facilities.

Nine States (Alaska, Georgia, Indiana, Kansas, Maryland, Mississippi, Montana, South Carolina, and Virginia) fully implemented the Demonstration waiver.

## C. Demonstration Waiver Evaluation

To conduct the national evaluation of the Home- and Community-Based Alternatives to PRTFs Medicaid Demonstration waiver, IMPAQ International, LLC created a minimum data set (MDS) from three functional assessment instruments (States could choose which among the three was most suited to their program) and then identified common data elements – such as source of enrollment (transition/diversion), law enforcement involvement, school absences, and

substance abuse – measured across all the States, coupled with many other data element requests such as satisfaction and adherence to the wraparound model[4].

The key research questions (improvement or maintenance of functional status and cost effectiveness) and the methodological approaches are common to all analyses. Note that we did not use or request all items from each functional assessment instrument due to instrument (versions, State-specific elements) and data collection variations across States.

## D. Evaluation Design

Since the Demonstration waiver is not a randomized experiment, we conducted pre-post analyses using quasi-experimental methods. The pre-post comparison is defined as the difference between outcomes for the treatment group (enrollees) measured at enrollment in the Demonstration waiver and outcomes for the same group measured at disenrollment from program participation.

The two basic questions set by Congress were further developed in the evaluation design, as briefly summarized below:

- The main evaluation question for both the national and individual State evaluations is whether provision of HCBS to children/youth under this Demonstration waiver results in the maintenance of or improvement in an enrollee's functional status.
- The second evaluation question is whether the Demonstration waiver, on average, costs no more than the anticipated aggregate PRTF expenditures in its absence.

This is a multi-site evaluation due to the uniqueness of the State programs and the diversity of their target populations; it is also a multi-tier evaluation since it builds from State-centric to cross-State analysis. In addition to the State-specific, common functional measures and functional assessment instrument-specific analyses, we used rigorous statistical modeling to conduct the pre-post comparison of functional outcomes.

As part of the evaluation, we collected data on a full range of information on program, children/youth and family characteristics, functional assessments, satisfaction, cost, service utilization, and adherence to the wraparound model. The descriptive analyses characterize the population by demographics (age, gender, and race/ethnicity); health (problem type and severity); and history of PRTF admissions. Certain environmental characteristics of the State programs were also included in the analyses.

[4] The wraparound team includes the child/youth, family members, care coordinators, and service providers and child serving agencies who work together to formulate an individualized person-centered plan of care that allows the child/youth to receive supports and services in the community rather than in an institution. The team, including child/youth and family, then work together to ensure the plan is implemented.

The minimum data set (MDS) specifies the data elements (outcome and control variables) that are crucial to the evaluation of all domains associated with the Demonstration waiver; these data are collected from all Demonstration waiver participants for each of the grantee States at different points in time.

## E. Functional Outcomes Analyses

Since pooling data across States provides greater statistical power and the ability to examine changes for specific subgroups, we analyzed groups of States to the extent possible. For the final evaluation, we relied on two types of analyses to measure outcome changes. First, we used outcomes that are common across all States. Second, since the number of variables for which this is possible across all nine States is very limited, we pooled participants across subsets of States with sufficiently similar program designs, populations served, and measures of functioning to yield reliable outcome estimates.

Six common functional outcomes were used to answer the main research questions, where feasible, for all State grantees – mental health, social support, school functioning, juvenile justice, alcohol and other drug use, and family functioning outcomes (Exhibit 1). Although there is some variation in the definitions/data sources across States – such as whether they are from self-assessment or agency reported, or whether the case manager or the school fills in the information on school absences – there was enough consistency across States to assess cross-State outcomes for the six measures.

**Exhibit 1: Research Areas**

| Functional Outcomes |
| --- |
| ▪ Mental health |
| ▪ Social support |
| ▪ School functioning |
| ▪ Juvenile justice |
| ▪ Alcohol and other drug use |
| ▪ Family functioning outcomes |

In the case of functional assessment instrument-specific analyses, we have chosen to pool the data from States according to the functional assessment instrument used by their grantee program. For the functional domain, family functioning outcomes, enrollees and their families were surveyed to understand their perspective on the extent to which they perceived the Demonstration waiver to be achieving its objectives.

To the extent that sample sizes are sufficient, differences in functional outcomes across subgroups that may differentially respond to the waiver program, or start out at very different baseline levels of functional status, are examined. The subgroups were selected to be consistent with moderators (such as age and diagnosis, length of program stay, or program

exposure) that previous studies on children's mental health services have indicated are likely to differentially affect outcomes.

In addition to the general functional assessment question, we addressed several questions of interest to CMS and policymakers, the answers to which depended on the size of the samples and the similarity in data elements collected by State grantees. For example, we formulated questions about various subgroups of interest and how they differed on functional assessment and other outcomes.

Qualitative knowledge of each State's programmatic structure and relevant events/activities during the course of implementation were important considerations in developing the final structure of the analytic models. Taken together, these strategies increased our confidence in the estimates of whether the Demonstration waiver services maintained or changed enrollee functioning.

## F. Cost Effectiveness/Cost Neutrality

While traditional a traditional definition of cost effectiveness could not be assessed, findings from our evaluation indicate that the Demonstration waiver has certainly met the budget (cost) neutrality test and has consistently maintained or improved functional status for enrolled children/youth, on average. By assessing the functional outcomes and the cost neutrality findings independently, we are able to answer the cost effectiveness question posed by Congress. Cost neutrality for all waiver years was evaluated by comparing each State's aggregate fiscal year's expenditures on HCBS services provided under the Demonstration waiver to typical PRTF expenditures on the basis of data States submit annually on an annual Cost Neutrality modified SF-372 Report form. This form provides information on expenditures by service per waiver year. The sum of these services is used to represent the average per capita cost of all services provided to individuals in the waiver program and the average per capita cost of services provided to individuals in PRTFs. Average per capita costs for waiver participants include HCBS services as well as other services provided to participants. To calculate the average per capita cost, the 372 Report form also records the number of users per service and the total number of unduplicated waiver participants for which claims were paid.

The Cost Neutrality formula is $\mathbf{D+D' \leq G+G'}$, where:

> **D** = estimated annual average per capita Medicaid cost of HCBS for individuals in the waiver program.
> **D'** = estimated annual average per capita Medicaid cost for all other services provided to individuals in the waiver program.
> **G** = estimated annual average per capita Medicaid cost for hospital, NF, or ICF/MR care that would have been incurred for individuals served in the waiver, were the waiver not granted.

**G′** = estimated annual average per capita Medicaid costs for all services other than those included in factor G for individuals served in the waiver, were the waiver not granted.

States were also required to provide average length of stay (ALOS) in the waiver (Form 372). This measure describes the number of days on average during a waiver year that a child/youth participated in the waiver. ALOS is calculated by dividing the total number of enrolled days of all participants by the unduplicated number of participants.

# CHAPTER 2. STATE PROGRAMS

In this chapter, we first examined the Demonstration waiver implementation. Next, we examined the similarities and differences in the approaches followed by the State grantees throughout the development of the waiver program. We looked at the types of services offered and strategies used to increase enrollment and expand their provider network during waiver Year 1 through waiver Year 4. We then summarized the successes and challenges still facing grant waiver programs at the end of waiver Year 4.

## A. Demonstration Waiver Implementation

States recognized the wraparound team-based approach as an ideal model to provide community-based services to children/youth with mental illness or serious emotional disturbances. All nine Demonstration waiver States included some form of wraparound approach in their waiver. The wraparound team usually included the child/youth, family members, care coordinators, and service providers and child serving agencies who worked together to formulate an individualized person-centered plan of care that allows the child/youth to receive supports and services in the community rather than in an institution. The team, including child/youth and family, then worked together to ensure the plan is implemented.

Implementation of the three program types varies across Demonstration waiver States. While each State grantee was expected to provide community-based services, their implementation varied based on the model chosen by the State (Exhibit 2).

**Exhibit 2: Programs across Demonstration Waiver States**

| State | Wraparound | Respite | Peer to Peer |
|---|---|---|---|
| **Alaska** | High Fidelity | Hourly and Daily Rate | N/A |
| **Georgia** | High Fidelity | Short-term basis and unexpected situations | N/A |
| **Indiana** | High Fidelity | Short-term basis and unexpected situations | N/A |
| **Kansas** | Based on John Vandenberg's model | Short-term basis | Parent Support and Training |
| **Maryland** | High Fidelity | In-Home and Out-Of Home Respite | Caregiver and Youth Peer Support |
| **Mississippi** | High Fidelity | Short-term basis and Out-of Home Services | N/A |
| **Montana** | High Fidelity | In-Home and Out-Of Home Respite | Caregiver Peer Support |

| State | Wraparound | Respite | Peer to Peer |
|---|---|---|---|
| **South Carolina** | High Fidelity | Short-term basis | Caregiver and Youth Peer Support |
| **Virginia** | High Fidelity | Short-term basis | N/A |

In addition to variations in service models across States, each State set its own policies in target population and assessment instruments based on the unique needs of that State.

Target populations included (1) children/youth currently living in PRTFs (Transition), (2) children/youth currently in the community but at risk of institutionalization (Diversion), or (3) a combination of the two. Virginia targets only Transition children/youth; all the other Demonstration waiver States target both Transition and Diversion children/youth.

## B. Program Waiver Similarities and Differences across State Grantees

***Home- and Community-Based Services:*** States recognized that the wraparound approach was an ideal model to serve children and youth in the community. All nine States included some form of wraparound approach in their waiver application and executed that approach in their States. States offered a core of HCBS as part of their alternatives to psychiatric residential treatment. The three most commonly provided services were respite, family training or supports, and employment services. It should be noted that all nine States offered respite services although there were some cross-State differences in the nature of those services. Respite services provided were short-term, offered both inside the home and in community settings, reimbursed at an hourly or daily rate, and accessed in both routine and crisis situations.

One notable difference among States in the provision of respite services is that Mississippi allowed respite to take place in PRTFs for up to 29 days, while Montana explicitly prohibited the provision of respite in PRTFs. Seven States offered some form of family training or support; the exceptions were Mississippi and South Carolina. The States that provided family training to parents, unpaid caregivers, or the youth themselves, covered key topics such as mental illness diagnoses, medication management, financial management, and social skills.

For other states, frequently used services included habilitation services, case management, peer-to-peer support, family support specialists, mental health counseling, and mentoring. Maryland provided expressive and experiential behavioral services which, when used as an adjunct to traditional therapy, provided techniques for participant self-expression and personal growth.

Alaska, Georgia, Kansas, and South Carolina offered employment services through the Demonstration waiver. The supported employment services focused on helping youth identify the type of job that interests them and develop skills to acquire and maintain such a job.

Specific supported employment services offered by these States included assessment of the participant's employment stability, job skills refresher training, regular worksite observation and feedback, and transportation to and from work. Compared to the other four States, South Carolina took a more general approach to preparing the participant for paid or unpaid employment by teaching participants basic concepts like adherence, attendance, task completion, problem solving, improving attention span, and safety. Five States did not provide employment services to young adults because this group was not in their target population.

***Peer-to-Peer Support:*** Peer-to-peer support was provided in four states at the beneficiary and caregiver level. Within those four states, peer-to-peer support was one of the most frequently used service and highest in demand. Other services in high demand included habilitation, case management, family support specialists, mental health counseling, and mentoring.

***Waiver Program Staffing and Organizational Changes:*** Five States experienced minimal staffing changes throughout waiver Year 1 through waiver Year 3, which they attributed to previous collaborations within the respective State agencies. During development of the waiver, these States were staffing key personnel to implement the Demonstration waiver program. Plan managers were staffed to oversee the development of their site. Plan managers were responsible for provider recruitment and retention and identifying the target population. Waiver coordinators were placed on site to accelerate the process of identifying eligible children/youth and providing aid throughout the waiver application process. Finally, staff was brought into the waiver to collect and process the data for each State.

Four States, in contrast, experienced significant staff turnover during the early stages of their implementation. During waiver Year 2, Alaska and Georgia experienced 100 percent turnover of their waiver staff. Alaska suffered a significant loss during the early stages of its implementation, when it experienced frequent turnover of its program directors and state evaluators. South Carolina and Virginia experienced the most substantial changes during waiver Year 3. South Carolina's Demonstration waiver program staff activities were transferred to the Department of Health and Human Services (SCDHHS) from the South Carolina Department of Mental Health (SCDMH). One of the changes in South Carolina included scaling down the Demonstration waiver size, which included reducing the number of staff. Virginia's Demonstration waiver program was relocated within the State Medicaid office to a new division under the Office of Behavioral Health.

***Policy/Political Changes:*** Policy changes included changes to fiscal funding, age limits, costs of services, and waiver program amendments. States continued to face fiscal challenges that affected their Demonstration waiver program services, including resource allocation changes by State agencies. Due to budget cuts, South Carolina experienced staff layoffs, enrollment was frozen, site expansions were cancelled, and for a time the feasibility of the program was in jeopardy.

Financial eligibility policy changes affected the enrollment for children/youth. In South Carolina, the number of days the applicant was given to complete the eligibility paperwork was reduced

from 21 to 10 (South Carolina). In Virginia, financial eligibility was changed from including the family's income to only including the child/youth's income as a family of one, enabling more children to be eligible for waiver participation.

Policy changes that affected what and how beneficiaries were served within the waiver programs included lowering the age limit to serve more children/youth, providing services for children/youth to stay in-state versus in out-of-state placements, and increase service duration. For example, Alaska was able to change regulations to serve children/youth under age 14. Montana developed a policy to increase enrollment by requiring a child/youth to obtain three in-state referrals before being sent out-of-state to receive services.

States also requested amendments to their Demonstration waiver program, such as eliminating some duplicative services available to children/youth in foster care that were provided through other service programs (Kansas).

***Participant Recruitment:*** State waiver programs focused their efforts on recruiting new participants. Increasing participant enrollment was a difficult task for several reasons, including families' skepticism about the new program and reluctance to have their child/youth return home, fiscal and policy concerns, and budget constraints. Marketing campaigns and community outreach were two recruitment strategies that State grantees found beneficial. For example, Kansas collaborated with an organization to provide family education forums statewide. Wraparound facilitators were also responsible in multiple States for coordinating community outreach.

***Provider Recruitment and Training***: All state grantees focused on expanding their network of providers, by both expanding their provider base and increasing their geographic jurisdiction. States attributed their increased provider recruitment to different factors, including by word-of-mouth and by using program staff to visit different parts of the State and give public presentations on the waiver program. States increased the geographic coverage of their grant waiver program by building on the pre-existing provider infrastructure from other grant streams.

Six out of the nine State grantees did not provide additional training for their provider network. The other three invested in their provider network to improve treatment effectiveness and wraparound fidelity. Maryland and Mississippi developed and provided continuous in-state provider training throughout the Demonstration waiver. Montana provided "Wraparound Facilitation 101" training to explain the program, which had some success in recruiting private and agency providers.

***Demographic and Enrollment Characteristics:*** For most States, the expected demographic distribution of participant enrollment and demographics between States matched the actual demographics presented in their grant application. Deviations from the expected demographics were due to State-specific variables or program features. For example, Alaska's State regulations did not correspond to the population targeted for services. After waiver program

implementation the State identified a number of youth under age 14 who met level of care criteria but could not be served through the Demonstration waiver program. New regulations were adopted that expanded the age range of the population served to ages 0-21 years. The youngest child reportedly served was 4 years old while several states reported expanding their age requirements past the participant's 18th birthday. As another example, Kansas reported anticipating that the demographics of the enrollees would be similar to youth on the serious emotional disturbances (SED) waiver. However, the Demonstration waiver participants in that grant waiver program tended to be older than the SED enrollees.

In addition, a number of States found that the projections of the number of diversions and transitions did not match the actual figures encountered by the waiver program. The mix of transitions/diversions was significantly different in at least three states (Kansas, Indiana, and Montana). For example, Indiana experienced lower than projected rates for transition; Kansas experienced higher than projected rates. Montana had close to an equal number of diversions as there was transitions.

## Exhibit 3: Services by State

| Alaska | Georgia | Indiana | Kansas | Maryland | Mississippi | Montana | South Carolina | Virginia |
|---|---|---|---|---|---|---|---|---|
| Plan of Care Coordination Services | Care Management | Care Coordination | | | Case Management | | Case Management | Transition Coordination |
| | Wraparound Services-Unskilled | Wraparound Facilitation/ Technician | Wraparound Facilitation | | Wraparound | Wraparound Facilitation | Wraparound Para-Professional Services | |
| Respite Hourly and Daily Rate | Respite | Respite | Short Term Respite Care | In-Home and Out-of-Home Respite | Respite | Respite Care | Respite | Respite |
| Supported Employment Ongoing Supervision | Supported Employment | Flex Funds | Employment Preparation/ Support | | | Education and Support Services | Prevocational Services | |
| Supported Employment Development Services | Financial Support Services | | Independent Living/Skills Building | Crisis and Stabilization Service | | | Service Plan Development | Companion Services |

| Alaska | Georgia | Indiana | Kansas | Maryland | Mississippi | Montana | South Carolina | Virginia |
|---|---|---|---|---|---|---|---|---|
| Community Transition Services | Community Transition Services | | Community Transition Supports | | | Home-Based Therapist | | Environ-mental Modifi-cations (Home Accessibility Adaptations) |
| Treatment and Intervention Mentor Services | Family Training and Supports | Training and Support for Unpaid Caregivers | Parent Support and Training | Caregiver/Youth Peer-to-Peer Support | | Caregiver Peer-to-Peer Support | Peer Support Services | Family/ Caregiver Training |
| Residential/ Day Habilitation | Community Guide | Habilitation | Attendant Care | Family and Youth Training | | Family Support Specialist | Psychiatric Medical Assessment | In-Home Residential Supports |
| Para-professional Training and Consultative Services | Consultative Clinical and Therapeutic Services | Consultative Clinical and Therapeutic Services | Professional Resource Family Care (Crisis Stabilization) | | | Consultative Clinical and Therapeutic Services | Diagnostic/Therapeutic Services | Therapeutic Consultation (Clinical and Therapeutic Services) |
| | Customized Goods and Services | | | Expressive and Experiential Behavioral Services | | Customized Goods and Services | Customized Goods and Services | Service Facilitation |
| | Transportation | Non-Medical Transportation | | | Functional Assessment | Non-Emergency Transportation | | |

## C. Successes and Challenges

### Staffing and Organizational Changes

The strength of the State's program infrastructure was reported almost universally as the most important factor and the fundamental determinant of whether the program was successful. States with a strong infrastructure saw rapid growth of enrolled participants, whereas those that experienced staff turnover could not track their current participants efficiently. See Exhibit 4 for the successes and challenges the grant waiver programs faced as reported by the grantee.

Successful States typically developed their own particular strategy as their program was evolving. Some developed their focus around a certain activity. For example, Mississippi focused its waiver program around the Mississippi Youth Program Around the Clock Training, a special training program for waiver providers. Mississippi developed a secure web-based application for sharing and gathering data. Maryland focused on its Residential Treatment Center (RTC) waiver staff to increase enrollment and reduce the amount of time spent completing the enrollment application. Indiana created a sustainability plan that ensures continued funding and infrastructure through 2014 to sustain intensive community-based services. Each program hired additional staff as necessary to facilitate the development and success of its chosen focus and needs.

Other States focused on expanding sites and hired additional staff members to provide support either for the entire program or for a particular activity. Montana focused on the expansion of its waiver program sites to increase the number of children/youth served and to increase geographic coverage across the State. Montana also hired staff as its program expanded sites and specific staff members were made responsible for creating a sustainable site. For example, plan managers in newly developed sites were responsible for taking referrals, assisting with capacity development, and meeting with children/youth and their family members to provide in-person support to complete their functional assessment instruments.

States that struggled to increase enrollment or expand to additional sites were invariably challenged by a weak infrastructure development. For example, South Carolina was not able to expand its waiver because of delays experienced while the grant waiver program was transitioned from one department to another and in turn caused staff turnover.

### Policy and Political Changes

The growth of several of the grantees' waiver programs depended on policy development that benefited the children/youth in the program and fostered increases in services provided to current and future enrollees. States that were supported by such policy and political changes experienced growth in their programs; those that faced policy and political barriers to the program resulted in program stagnation.

States experiencing change due to policy and political interventions include Montana, which implemented a policy as of May 1, 2010 that made it more difficult to send youth to out-of-state facilities by requiring three in-state denials before an out-of-state transfer was approved. This policy change was further strengthened on February 1, 2011, by requiring yet an additional denial from in-state PRTFs.

States that experienced setbacks in their policy development had issues with budget shortfalls, decreases in services provided, and regulations that push their waiver programs towards PRTF placement. Policy changes in the Indiana led to the State's Department of Child Welfare (DCS) encouraging youth to be served through PRTFs instead of state funded community care. Virginia experienced difficulty in its respite program due to a policy change that reduced the respite service maximum from 720 hours to 480 hours per year.

**Participant Recruitment and Enrollment**

The major theme of participant recruitment and enrollment were efforts focused on expanding services to additional children/youth, typically by expanding to new sites. Increasing participant enrollment over time was a strong indicator that a State implemented a strong program.

Successful States focused on outreach and awareness efforts of the program, having already built partnerships with within departments and agencies, private providers, and other State agencies serving children/youth. Montana, for example, led a successful effort in the number of new sites that were expanded and the number of children/youth enrolled, by using wraparound trainings to heighten waiver program awareness. Plan managers engaged with staff from child-serving agencies and conducted outreach in child-serving agencies, provider and advocacy agencies, and other groups. Virginia partnered with the State's Office of Protection and Advocacy (VOPA), which provided waiver program information to families with children/youth in PRTFs.

Some States found regulations were the major obstacle to increased participant enrollment. Maryland, for example, was unable to move children into available openings made vacant by children who were disenrolled, due to contract capacity. After a reinterpretation of the State's regulations Maryland was able to increase its available waiver program slots.

**Provider Recruitment**

The grantees focused on finding and expanding their provider networks to increase the services provided to their expanding population under the waiver program. Provider recruitment was most evident in States that had a strong program infrastructure and constructive organizational changes.

States with greater success in expanding their provider network focused their efforts on promoting awareness of their programs to in-State providers. Montana experienced the least

difficulty obtaining providers for its expanding waiver program. Part of that State's strategy was identifying and training peer-to-peer support in all its waiver sites.

Where States experienced difficulty with provider recruitment for their waiver program, the impediments included difficulty serving certain populations, challenges in finding respite providers, and inconsistencies in the ratio of service providers to participants in different counties within a State. Alaska, for example, experienced difficulty attracting providers due to unique characteristics of the population in its waiver program. Maryland focused its recruiting efforts on respite providers but experienced difficulties recruiting and retaining such providers. Indiana experienced difficulty in the matching of service providers to participants within its waiver counties. This difficulty was most frequent in rural counties but happened in some urban areas as well.

## Exhibit 4: State-Reported Successes and Challenges

| | Alaska | Georgia | Indiana | Kansas | Maryland | Mississippi | Montana | South Carolina | Virginia |
|---|---|---|---|---|---|---|---|---|---|
| **Successes** | Increased awareness of how Fetal Alcohol Spectrum Disorder affects behavioral challenges | Development and implementation of statewide Care Management Entity system | Large number of participants enrolled | Waiver provision of infrastructure and a vast provider network for the implementation of the PRTF CBA on April 1, 2008 | System of Care recognition and support in Medicaid regulations | Annual MYPAC mission training for 150+ provider staff hosted by MS division of Medicaid | Engagement with providers once they understand the waiver | Relationship with our advocacy group (Federation of Families) | Decision to allow financial eligibility to be based solely on the child/youth's income |
| | Successful diversion from PRTF and criminal justice system | Implementation of wraparound model | Grant team use of all data available to assist providers with quality improvement | Since April 1, 2008, 601 youth served | Quality assurance plan development and implementation | Development of secure web-based application for sharing information and gathering data | Serving high-needs youth and their families in their homes and communities | Positive outcomes for youth enrolled and positive feedback from families | Children/youth served in the program doing well |
| | Maintenance of youth in community placements longer, behaviors not escalating to PRTF levels. | Provision of Services to over 500. Only 15% returned to PRTF for longer than 60- day period. | | | | | Family and Youth Empowerment and development of self-efficacy | | |

| | Alaska | Georgia | Indiana | Kansas | Maryland | Mississippi | Montana | South Carolina | Virginia |
|---|---|---|---|---|---|---|---|---|---|
| **Challenges** | Lack of frontline workers | Needing to make a cultural shift for system to accept Wraparound model and Community Based Alternatives for Youth | In adequate communication with providers and participants | The children/youth served on the Demonstration waiver tending to remain on the grant waiver program for shorter durations, but return more frequently than on the serious emotional disturbances waiver | Difficulty building sufficient provider capacity | Lack of technical assistance to begin the data collection piece for the National Evaluation | Some psychiatrists' concerns about liability when serving high-needs youth at home | Poor coordination of care between partners | Low enrollment |
| | | Sustainability | Providers lacking knowledge to effectively do their job | | Cumbersome Medicaid application process | Getting the communities in the Mississippi Delta to "buy-in" to the program | Engaging some providers in serving high-need youth and families through non-traditional approaches | Built-in conflict of interest due to providers conducting initial level of care assessment | |
| | | | | | | | Provider development in very rural areas | | |

# CHAPTER 3. FUNCTIONAL OUTCOMES AND PROGRAM SATISFACTION

## A. Introduction

One of the key evaluation questions was whether there is an improvement or maintenance of children's functional status. Functional status (or functional outcome) is a broad concept. The functional outcomes identified by CMS span a number of domains. This chapter presents our findings on functional status change across the following five domains: mental health, juvenile justice, school functioning, alcohol and other drug use, and social support.

The grantee States used one of three instruments to assess changes in children's behavioral and mental health functional outcomes: the *Child and Adolescent Needs and Strengths* (CANS), the *Child & Adolescent Functional Assessment Scale (CAFAS)* and *the Child Behavioral Checklist* (CBCL). Each of these instruments collects a set of outcome measures that relates to the functional domains under review. Functional outcomes data from these instruments and other Demonstration waiver-specific measures were collected to form a Minimum Data Set (MDS). These data were then used to generate an overall picture of children/youth's functional outcome changes after program participation. The MDS collected data at 6-month intervals and disenrollment, which enables us to evaluate – at each follow-up point – a child/youth's change in functioning from baseline.

## B. Functional Assessment Instruments and other Data Collection

The CANS assessment refers to a group of outcome management tools developed by John Lyons (Lyons, 2009) together with many stakeholders across multiple States. The CANS instrument is used in *Indiana, Maryland, Mississippi,* and *Virginia*, which together covered more children in the Demonstration waiver than were covered by each of the other two instruments.

The CANS was developed to assess the strengths and needs of children/youth who have emotional and behavioral disorders, and to aid in the development of treatment plans to guide service delivery. The core domains of the CANS Comprehensive Multisystem Assessment are life functioning, child strengths, acculturation, caregiver strengths, caregiver needs, child behavioral/emotional needs, and child risk behaviors. Extension modules are triggered by core questions and include developmental disability, health, sexuality, adoption, trauma, substance use, violence, juvenile justice, fire setting, and psychotropic medication. Specific items or questions are the same across all versions.

Each CANS item has four levels of assessment and each level translates into separate needs and strengths assessments. The basic scoring metric for CANS items is 0 through 3. In the case of needs assessment, a score of 0 indicates no evidence of need, while a score of 3 indicates that immediate/intensive action is required. In the case of strength assessments, 0 reflects a centerpiece strength while 3 shows no strength identified.

In the CANS scale, a *lower outcome score in any given functional domain (or item-level) indicates a higher functional status*. We categorize *domain* scores into three different groups following the CANS ratings system: low needs/prevention (0 to 1), intermediate needs/action (1 to 2), and immediate/intensive action (2 to 3). For the item-level analysis, we classify scores 0 to 1 as low needs and scores 2 to 3 as high needs. These ratings enable comparison across domains and rating levels and allow us to aggregate outcomes to a more representative measure.

The CBCL (Achenbach & Rescorla, 2001) is an extensively used parent-report questionnaire that allows clinicians and researchers to assess a wide range of behavior problems and competencies in children/youth. The CBCL functional assessment instrument is used in *Kansas, Montana*, and *South Carolina*.

The CBCL uses T scores to sort subjects into three groups: in the normal range, on the border line, or in the clinical range. These clinical categories would have been ideal for developing the low, middle, and high needs categories (as done in the CANS), while offering enhanced clinical implications of the results. However, due to the lack of T scores in the Demonstration waiver's MDS, in determining children/youth's baseline needs categories the cut-off points were based on the raw score. In particular, the profile of competence/syndrome score sheet in the CBCL Manual was used to identify the cut-off points closest to those by T scores to approximate the clinical categorization. This enhances the clinical implications of cut-off points by raw scores and, thus, our analysis results.

The CAFAS (Hodges 1990, 1994) is an inventory for measuring functional impairment in children and adolescents originally designed for use in a mental health policy research project. The CAFAS inventory used in the Demonstration waiver consists of five child scales: Role Performance, Thinking, Behavior toward Self and Others, Mood/Emotions, and Substance Abuse, as well as two child caregiver scales: Basic Needs, and Family Social Support. The CAFAS scale is used in *Alaska, Georgia*, and *Kansas.*

Unlike the CANS and CBCL instruments, the CAFAS instrument does not divide children into groups according to their level of needs at baseline. Since the evaluation needed to do this to take into account the potential heterogeneity of effects across enrollee groups, we divided the children/youth into three groups according to their baseline level of impairment as defined by the CAFAS developer.

Since the main outcome measure for the evaluation is the functional assessment score *change* from baseline to particular follow-up points, we have consolidated the different categorizations within instruments as appropriate into a single category. For example, level of needs is categorized for all three instruments by lower, middle, and high (rather than retaining the different terminologies used across instruments). For a detailed list of variables by instrument and our six chosen domains and each domain focus, see Exhibit 5.

Exhibit 5 (below) discusses the specific variables within each domain (social support, mental health, school functioning, family functioning outcomes, juvenile justice, and alcohol and other drug abuse). The variables are categorized by instrument (CANs, CBCL, COMMONs, and CAFAS). Based on this chart, it was shown that each instrument examined different components within each variable. For example, within the domain of school functioning, each instrument looked at different components such as school achievement, severity of school absences, and work performance.

**Exhibit 5: Variables by Domain and Instrument**

| | School | Mental Health | Social Support | Family Functioning Outcomes | Juvenile Justice | Alcohol and Other Drug Abuse |
|---|---|---|---|---|---|---|
| **CBCL** | School (Poor school work, truancy) | Anxious/Depressed | Social Support (physically attacks others, not liked by others) | | | |
| | | Withdrawn/Depressed | | | | |
| | | Somatic Complaints | | | | |
| | | Social Problems | | | | |
| | | Thought Problems | | | | |
| | | Attention Problems | | | | |
| | | Rule-Breaking Behavior | | | | |
| | | Aggressive Behavior | | | | |
| **CANS** | School Achievement | Adjustment to Trauma | Family Social Support | Family Safety | Juvenile Justice (Crime/Delinquency) | Substance Use (Severe/Including detoxification) |
| | School Attendance | Depression/Anxiety | Interpersonal Social Support | Family Involvement | | |

| | School Functioning | Mental Health | Social Support | Family Functioning Outcomes | Juvenile Justice | Alcohol and Other Drug Abuse |
|---|---|---|---|---|---|---|
| | School Behavior | Attention Deficit/Impulse Control/ Hyperactivity | Relationship Permanence | Family Knowledge | | |
| | | Danger to Others | | Supervision | | |
| | | Oppositional Behavior | | | | |
| | | Psychosis | | | | |
| | | Sexual Aggression/Abusive Behavior | | | | |
| | | Danger to Self/Suicide Risk | | | | |
| | | Social Behavior | | | | |
| **CAFAS** | School Work Performance | Self-harmful Behavior | Family/Social Support | Home Role Performance | | Substance Abuse (Severe) |
| | | Moods/Emotions | | | | |
| | | Thinking | | | | |
| **COMMON** | Number of Absences from School (Past 6 months) | | | | Number of Arrests (Past 6 months) | Severity of Substance Abuse |
| | Severity of School Absences | | | | Any involvement with law enforcement in the Past 6 months | |

In addition to the outcomes measured by the functional assessment instruments, the MDS also captured children/youths' and their families' experience with the Demonstration waiver through survey data. Measuring this experience from several perspectives enabled the evaluation to develop an enhanced story of program effect – that is, whether waiver program recipients and their families perceived real involvement in the children/ youth treatment and their subjective assessment of program outcomes.

The sections below describe our evaluation method and data (Section C), our findings on children/youth's assessment-based functional change in each domain (Section D), and the survey-based enrollee and family perceptions of their Demonstration waiver experiences (Section E).

## C. Methodology

We begin our discussion of methodology with our estimation method. This is followed by a similar discussion of the data used in the evaluation.

**Estimation Method**

The evaluation of the Demonstration waiver used a pre-post comparison of children/youth outcomes at different follow-up points. As noted, we could not attribute the change (if any) in children's functional outcome directly to the program since we did not know what the functional outcomes would have been without the Demonstration waiver program (i.e., we did not have a counterfactual). Without a counterfactual, changes observed for participants could not be attributed to the program because of the potential contribution of non-Demonstration waiver factors to the observed changes.

To help reduce the potential distortion introduced by such factors, we used the Heckman sample selection model (Heckman, 1979)[5], which is a regression model widely used in economic and program evaluation analyses. The Heckman regression models the process of sample selection (such as whether a child is enrolled in the program at a specific point of time) in addition to the outcome of interest (in this case, functional status change). Basically, the model is a two-stage regression model. In the outcome equation, we used a set of explanatory variables that includes a measure of the baseline level of needs, gender, age, time elapsed since the first PRTF admission, time elapsed since exiting from the most recent PRTF, and program admission status (transition or diversion). In the selection equation we modeled children's enrollment status at each follow-up using a similar set of variables as the outcome equation plus a few other variables (including program maturity and enrollee living arrangement).

Enrollment status may affect children/youth's program experience in a variety of ways. Enrollees who live at a family's or other relative's home might find it easier to stay enrolled in

[5] Heckman, James J. 1979. "Sample Selection Bias as a Specification Error." Econometrica 47(1): 153-161.

the program, thus having a higher probability of continued participation, than children with non-relative living arrangements. Our use of the Heckman model alleviates the possible bias introduced into the estimates of how children's functional outcomes change during the Demonstration waiver program by taking into account the enrollment process.

The *outcome score change* measured the average effect of all children and youth in terms of the instrument score differences at each follow-up point. It is important to note that *the score changes (negative or positive) may not be large enough to move children to a different level of needs category.* In this case, although a small change (positive or negative) may have been found, the functional status remains the same; that is, the children maintained their level of functional status. This was a positive outcome in terms of the Demonstration waiver goals.

A notable feature of the evaluation was our examination of how the program effects may vary by length of program stay. The expected direction of such effects was not clear *a priori.* On the one hand, the Demonstration waiver might affect the mental health of a child/youth only after a certain period of time; but on the other hand, it might have an effect up to a certain point but not thereafter. To capture any pattern of outcome changes over time, we considered three time periods – (1) baseline vs. 6 months follow-up, (2) baseline vs. 12 months follow-up, and (3) baseline vs. 18 months follow-up – and compare the results across the different periods.

Since the State grantees used different functional assessment instruments, we applied the Heckman model with minor adjustments for each subset of states based on their choice of functional assessment instrument. Since we could not apply the Heckman model to the states using CAFAS due to data limitations (e.g., small sample size across follow-up points), findings for the states using CAFAS *(Alaska, Georgia*, and *Kansas*) were not included in this report.[6]

The approach presented above describes the foundation for the analysis presented here. We conducted multiple Heckman model regressions to estimate of functional assessment changes by domain (mental health, juvenile justice, etc.), by functional assessment instrument (common measures, CANS, CBCL), and at each follow-up point. In this report, we summarized the findings by domain to enable a more concise presentation of the results.

**Data**

Our final analytical sample for all states had 3,198 children/youth. (Tables 6 – 8 present enrollee characteristics at baseline. Almost two-thirds were boys. Only slightly over a quarter of them were children under 12 years; almost all the remaining enrollees were teenagers, among whom about half are middle-school age and half are high-school age. Almost three-quarters (62 percent) were white, and getting on for one-third (30 percent) were black. Only 6 percent were Hispanic. The admission rates are similar for transition and diversion (with 3

[6] In the case of CAFAS states, a statistical t-test was conducted to compare children's outcomes between baseline and each follow-up point. However, due to the differences in the methodological approach, these findings could not be consolidate in this report.

percent having no clear admission status indicated) according to the MDS, although State-specific data indicated that this distribution varies substantially across States. The majority of enrollees, based on DSM-IV codes, had either “ADD/ADHD, oppositional defiant disorder”, or “mood, depressive, bipolar disorders

**Exhibit 6: Baseline Statistics: Gender and Age**

| Key Individual Characteristics | Total | Gender | | Age | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | Male | Female | <6 | 6 to 11 | 12 to 14 | 15 to 18 | >18 | Unknown |
| N | 3198 | 2036 | 1162 | 26 | 904 | 996 | 1206 | 21 | 45 |
| % | 100 | 63.7 | 36.3 | 0.8 | 28.3 | 31.1 | 37.7 | 0.7 | 1.4 |

**Exhibit 7: Baseline Statistics: Race and Ethnicity**

| Key Individual Characteristics | Total | Race | | | Ethnicity | | |
|---|---|---|---|---|---|---|---|
| | | White | Black | Other | Hispanic | Non Hispanic | Other |
| N | 3198 | 1986 | 964 | 248 | 117 | 2994 | 87 |
| % | 100 | 62.1 | 30.1 | 7.8 | 3.7 | 93.6 | 2.8 |

**Exhibit 8: Baseline Statistics: Admission Status and DSM-IV**

| Key Individual Characteristics | Total | Admission Status | | | DSM IV | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | Transition | Diversion | Unknown | ADD/ADHD, Oppositional Defiant Disorder | Mood, Depressive, Bipolar Disorders | PTSD, Anxiety Disorders | Other Disorders | Unknown |
| N | 3198 | 1532 | 1578 | 88 | 1267 | 1143 | 204 | 273 | 311 |
| % | 100 | 47.9 | 49.3 | 2.8 | 39.6 | 35.7 | 6.4 | 8.5 | 9.7 |

## D. Findings on Assessment-Based Functional Outcome Changes

The findings presented below draw a high-level picture of the evaluation results. We pooled data for all nine grantee States for the set of common functional items. We also pooled data for subgroups of grantee States, as noted, according to which instrument they used to assess enrollee changes in functional outcomes. Findings are summarized below by functional domain across both the common outcomes and the functional assessment instruments. This is followed by an overall assessment across functional domains.

The results are presented by level of need (LON) category at each of the three follow-up periods (6, 12, and 18 months).[7] Results from the a*bsolute outcome score changes* are indicated by their ultimate effect on the children/youth LON category: decline, maintenance, or improvement from the baseline level of needs category. It is important to re-emphasize here that *the changes in functional outcomes presented here indicate a change in the LON*; that is, the changes are beyond a simple change in outcome scores. For example, the word "maintain" in the lower LON category at the 6-month follow-up would indicate that on average a child/ youth with a lower LON maintained the same LON *category* at the corresponding follow-up, irrespective of whether the actual *score* had changed.

Note that in these tables we summarize the information from the CANS and CBCL versions of the common measures into one net effect on functional status (by LON/admission status and follow-up point). Note also that the specific LON (e.g. lower LON) or admission status type (e.g. transition) with the largest number of beneficiaries at a particular follow-up point was given primary weight in defining the sign/direction of the functional status. For example, although the CANS (used by *Indiana, Maryland, Mississippi,* and *Virginia)* covered more than 50 percent of the Demonstration waiver participants, it may not always have had the largest number of participants in a particular cell (e.g. lower LON at t-month follow-up).

*Thus, the change in functional status of the largest number of participants was defined as the primary outcome and shown as such in the tables.* If there was another direction from another subset of States (functional instrument) with a substantial number of enrollees that was different from the primary outcome, that opposite effect is shown in parenthesis below the main functional status change*. This approach minimizes the risk that findings from a relative small number of participants cancel out the functional status change for a larger population of program participants.*

### Mental Health

The main goal of the Demonstration waiver was to provide supports and services in the community to children/youth with mental illness or serious emotional disturbances. Therefore,

[7] Although there were children/youth who stayed longer than 18 months in the program for some functional assessment instruments, these are excluded from the analysis because their number was too small to produce robust estimates.

it is important to highlight changes in mental health functioning, and variations in mental health functioning across the LON categories. Based on the overall effects by LON, mental health status was maintained for most children in the Demonstration waiver from baseline to 18 months (See Exhibit 9, row 4). In the findings by LON, there was a secondary pattern of (a) improving mental health outcomes for a small proportion children with higher baseline LON (see parentheses) and (b) declining mental health outcomes for a small proportion of children/youth with lower baseline LON (see parentheses).

**Exhibit 9: Mental Health Functional Status Changes by Level of Needs (LON) and Admission Status at 6-, 12- and 18-Month Follow-ups**

| Domain | Duration in Demonstration Waiver | | |
|---|---|---|---|
| | 6 Months | 12 Months | 18 Months |
| **Lower LON** | Maintained (Declined) | Maintained (Declined) | Maintained |
| **Middle LON** | Maintained | Maintained | Maintained |
| **Higher LON** | Maintained (Improved) | Maintained (Improved) | Improved |
| **Overall Effect By LON** | Maintained | Maintained | Maintained |
| **Transition** | Improved | Improved (Maintained) | Improved |
| **Diversion** | Maintained | Maintained | Maintained |
| **Overall Effect By Admission Status** | Maintained (Improved) | Maintained | Maintained (Improved) |

Note: The table indicates the primary functional status change per subpopulation (i.e., lower LON or transition) at a particular follow-up. The secondary effect (in parenthesis) is noted when the functional status change is in the opposite direction of the primary finding. Primary versus secondary findings are determined by the relative number of total participants across instruments at the LON and across LON for overall effect in each cell.

Based on the overall effect by admission status (Exhibit 9, row 7), for the majority of children/youth the Demonstration waiver maintained mental health function, with a smaller group improving function (see parentheses). Interestingly, children that transitioned from PRTFs had better outcomes relative to diverted children. The large majority of transitioned children improved their mental health status at each follow up while diverted children maintained their same level. These findings support the earlier finding that overall children/youth in the Demonstration waiver maintained or improved their mental health functioning.

Based on these outcomes, children/youth with more severe mental health concerns (middle and higher LON and transitioned children) received the greatest benefit from the Demonstration waiver in their mental health functioning. This finding for children/youth with

most needs is appealing because mental health functioning was closer to the clinical condition of a Demonstration waiver-eligible child/youth.

**Juvenile Justice**

In the juvenile justice domain, the discrete nature of the outcome – whether there was involvement with the juvenile justice system or any arrests – implies two LON (lower or higher LON), and the CANS items are measured by a dichotomous variable. Overall, there was no improvement in juvenile justice involvement across LON categories over the Demonstration waiver period (See Exhibit 10 Row 3). That is, children maintained their levels of juvenile justice involvement at each follow-up period. The main factor limiting a more positive outcome was an increase in the number of instances of law enforcement involvement. Similar to the findings for mental health functioning, there was a more positive outcome for children/youth with higher LON than for children with lower LON. The trend for children with more problems on the juvenile justice domain was actually toward improving their level of functioning.

Based on admission status, the primary finding for the Demonstration waiver was maintaining function in the domain of juvenile justice involvement. For this domain, it was particularly important to note the changes over time, as children who transitioned remain in the community and gain the ability to make independent decisions. Our analysis by admission status showed a slight tendency toward a decline in functioning for both admission groups (see Exhibit 10, line 6). There are two explanations for this overall outcome: (a) the increased opportunity of children/youth who transitioned for independent decision-making, as noted, and (b) the fact that the large majority of children/youth in both the admission and diversion groups had low LON in the juvenile justice domain at baseline, and it was this population that showed a slight decline in functioning on this domain over the Demonstration waiver.

**Exhibit 10: Juvenile Justice Functional Status Changes by LON and Admission Status at 6-, 12-, and 18-Month Follow-Ups**

| Domain | Duration in Demonstration Waiver | | |
|---|---|---|---|
| | 6 Months | 12 Months | 18 Months |
| **Lower LON** | Maintained | Maintained (Decline) | Declined (Maintained) |
| **Higher LON** | Improved to Maintained | Improved (Maintained) | Improved (Maintained) |
| **Overall Effect by LON** | Improved (Maintained) | Maintained | Maintained |
| **Transition** | Maintained | Maintained (Declined) | Maintained (Declined) |
| **Diversion** | Maintained | Maintained (Declined) | Maintained (Declined) |
| **Overall Effect by Admission Status** | Maintained | Maintained (Declined) | Maintained (Declined) |

Note: The table indicates the primary functional status change per subpopulation (i.e., lower LON or transition) at a particular follow-up. The secondary effect (in

parenthesis) is noted when the functional status change is in the opposite direction of the primary finding. Primary versus secondary findings are determined by the relative number of total participants across instruments at the LON and across LON for overall effect in each cell.

### School Functioning

School functioning outcomes varied substantially by baseline LON and through time in the Demonstration waiver (Exhibit 11). The variation highlighted the findings presented earlier on how children with different baseline LON profiles responded differently to the Demonstration waiver. Children with higher baseline levels of school functioning needs benefited the most from the Demonstration waiver services, while children with lower baseline LON showed a steady decline. The net primary effect was that children/youth maintained their school functioning status (Exhibit 11, row 4). However, a large number of children under the CANS functional assessment instrument showed improvement over time on school attendance, which may be a more reliable measure of school functioning than the more commonly used (as defined for the evaluation) measure of school absences. This was one instance where the aggregation of outcomes and the varying effects across instruments involves large enough numbers to prevent an unambiguous choice of which findings are "primary."

The same caveat as in the juvenile justice domain should also be kept in mind for school functioning with respect to enrollees who transitioned from institutions (where school attendance is unlikely to be subject to individual decision-making and classrooms sometimes coexist with living quarters). Again, it was particularly important to highlight the changes over time, which give some indication of an upward trend by the end of 18 months, except for those with lower LON at baseline.

**Exhibit 11: School Functioning Functional Status Changes by LON and Admission Status at 6-, 12-, and 18-Month Follow-ups**

| Domain | Duration in Demonstration Waiver | | |
|---|---|---|---|
| | 6 Months | 12 Months | 18 Months |
| **Lower LON** | Maintained (Declined) | Decline (Maintained) | Decline (Maintained) |
| **Middle LON** | Maintained | Maintained | Maintained (Improved) |
| **Higher LON** | Maintained | Improved (Maintained) | Improved (Maintained) |
| **Overall Effect by LON** | Maintained | Maintained | Maintained |
| **Transition** | Maintained (Declined) | Declined (Improve) | Maintained |
| **Diversion** | Maintained | Declined (Improved) | Improved (Maintained) |
| **Overall Effect by Admission Status** | Maintained (Declined) | Declined (Improved) | Improved (Maintained) |

Note: The table indicates the primary functional status change per subpopulation (i.e., lower LON or transition) at a particular follow-up. The secondary effect (in

parenthesis) is noted when the functional status change is in the opposite direction of the primary finding. Primary versus secondary findings are determined by the relative number of total participants across instruments at the LON and across LON for overall effect in each cell.

### Alcohol and Other Drug Use

Findings related to alcohol and other drug use showed maintenance to improvement on LON for most children, with no cell showing decline (Exhibit 12). This is an important finding, given the difficulty associated to designing programs that addressed such problems in children/youth. The finding is even more positive when we looked at it from the perspective that (1) children and youth with middle to high LON at baseline on this domain show improvement at all follow-ups and (2) children who had the least issues with substance abuse at baseline maintained their lower LON status.

**Exhibit 12: Alcohol and Other Drug Use Functional Status Changes by LON and Admission Status at 6-, 12-, and 18-Month Follow-ups**

| Domain | Duration in Demonstration Waiver | | |
|---|---|---|---|
| | 6 Months | 12 Months | 18 Months |
| **Lower LON** | Maintained | Maintained | Maintained |
| **Middle LON** | Improved | Improved | Improved |
| **Higher LON** | Improved | Improved | Improved |
| **Overall Effect by LON** | Maintained (Improved) | Maintained (Improved) | Maintained (Improve) |
| **Transition** | Maintained | Maintained | Maintained (Improved) |
| **Diversion** | Maintained | Maintained | Maintained |
| **Overall Effect by Admission Status** | Maintained | Maintained | Maintained |

Note: The table indicates the primary functional status change per subpopulation (i.e., lower LON or transition) at a particular follow-up. The secondary effect (in parenthesis) is noted when the functional status change is in the opposite direction of the primary finding. Primary versus secondary findings are determined by the relative number of total participants across instruments at the LON and across LON for overall effect in each cell.

The additional freedom provided to children/youth receiving supports and services in the community rather than in an institution did not affect their overall LON. This finding is not surprising given that the large majority had lower levels of alcohol and substance abuse issues at baseline. However, the maintenance of the level of needs is important in the sense that transitioned children maintained their functioning in this domain, and a subset even improved.

### Social Support

The findings for social support functioning, both primary and secondary, are particularly encouraging (Exhibit 13). No cell showed declined functioning in this domain, and children with middle and high LON at baseline improved their functioning through all follow-ups. This is the area where the Demonstration waiver was most successful in integrating children/youth into the community.

**Exhibit 13: Social Support Functional Status Changes by LON and Admission Status at 6-, 12-, and 18-Month Follow-ups**

| Domain | Duration in Demonstration Waiver | | |
|---|---|---|---|
| | 6 Months | 12 Months | 18 Months |
| **Lower LON** | Declined to Maintained | Maintained (Improved) | Declined to Maintained |
| **Middle LON** | Improved | Improved | N/A |
| **Higher LON** | Improved | Improved | Maintained to Improved |
| **Overall Effect by LON** | Improved | Improved | Maintained to Improved |
| **Transition** | Maintained to Improved | Improved (Maintained) | Improved to Maintained |
| **Diversion** | Improved to Maintained | Improved to Maintained | Improved to Declined |
| **Overall Effect by Admission Status** | Improved to Maintained | Improved to Maintained | Improved to Declined |

Note: The table indicates the primary functional status change per subpopulation (i.e., lower LON or transition) at a particular follow-up. The secondary effect (in parenthesis) is noted when the functional status change is in the opposite direction of the primary finding. Primary versus secondary findings are determined by the relative number of total participants across instruments at the LON and across LON for overall effect in each cell.

Admission status findings provide a consistent story with the analysis by LON. There was a clear tendency for improvement on the social support domain. As expected, children that were diverted performed better and had more positive outcomes perhaps due to their current living status where they already rely on families and other people to participate in the community and the Demonstration waiver reinforced and enhanced the current available services that allowed them to perform better.

### Global Effect

This section combines the overall domain results from the domain-specific LON tables. Each overall domain result was aggregated at each follow-up point to present a pattern of functioning over time at the domain level. Exhibit 14 shows the global effect as analyzed by

functioning status at baseline. Exhibit 15 shows the global effect as analyzed by admission status.

As shown in Exhibit 14, the global effect shows that the functioning status for children/youth who participated in the Demonstration waiver was maintained in all domains, with the subsidiary findings (in parentheses) showing a tendency for behavior to improve. There was not one cell where we see an overall functioning decline.

In sum, by providing supports and services in the community over time, the Demonstration waiver was generally improving overall outcomes in mental health and social support, while maintaining overall outcomes in juvenile justice, school functioning, and alcohol and other drug use.

**Exhibit 14: Summary of Overall Functional Outcome Changes by Baseline Level of Need**

| Domain | Duration in Demonstration Waiver | | |
|---|---|---|---|
| | 6 Months | 12 Months | 18 Months |
| **Juvenile Justice** | Maintained | Maintained | Maintained |
| **Mental Health** | Maintained | Maintained | Maintained |
| **Social Support** | Improved | Improved | Maintained (Improved) |
| **Alcohol & Other Drug Use Transition** | Maintained (Improved) | Maintained (Improved) | Maintained (Improved) |
| **School Functioning** | Maintained | Maintained | Maintained |
| **Global** | Maintained (Improved) | Maintained (Improved) | Maintained (Improved) |

Note: The table indicates the global functional outcome change per domain at a particular follow-up. The secondary effect (in parenthesis) is noted when the functional status change is in the opposite direction of the primary findings.

Summarizing overall functional outcome changes by admission status (Exhibit 15) showed that the Demonstration waiver enrollees maintained status throughout program participation. For the domains of juvenile justice, mental health, alcohol and other drugs, being in the community among friends and families maintains the LON outcomes for children/youth at all three follow-ups. For social support, Demonstration waiver services improved functioning at all follow-ups. For school functioning the results were mixed, with a slight tendency for improved functioning by the 18-month follow-up.

**Exhibit 15: Summary of Overall Functional Outcome Changes by Admission Status**

| Domain | Duration in Demonstration Waiver | | |
|---|---|---|---|
| | 6 Months | 12 Months | 18 Months |
| **Juvenile Justice** | Maintained | Maintained (Declined) | Maintained (Declined) |
| **Mental Health** | Maintained (Improved) | Maintained | Maintained (Improved) |

| Domain | Duration in Demonstration Waiver | | |
|---|---|---|---|
| | 6 Months | 12 Months | 18 Months |
| **Social Support** | Improved (Maintained) | Improved (Maintained) | Improved (Declined) |
| **Alcohol & Other Drug Use Transition** | Maintained | Maintained | Maintained |
| **School Functioning** | Maintained (Declined) | Declined (Improved) | Improved (Maintained) |
| **Overall** | Maintained (Improved) | Maintained | Maintained (Improved) |

Note: The table indicates the global functional outcome change per domain at a particular follow-up. The secondary effect (in parenthesis) is noted when the functional status change is in the opposite direction of the primary findings.

Half of the children were transitioned into the Demonstration waiver from institutions, where their decision making freedom was limited. Overall, transitioned children benefited from the Demonstration waiver in terms of their level of functioning as well as with engagement in the broader community. Using the net effects by admission status, children still performed well in the Demonstration waiver. However, there were a few instances where we could observe a decline in functioning at some points in time for subsets of the population (Juvenile Justice and school functioning).

## E. Summary of Children/Youth and Family Perspectives

We examined children/youth and family perspectives on the public mental health services they receive under the Demonstration waiver using the Youth Services Survey (YSS) and the Youth Services Survey for Families (YSS-F).[8]

Our focus was on five core domains in these surveys: (1) access to care, (2) participation in treatment, (3) cultural sensitivity, (4) appropriateness, and (5) outcomes. Exhibit 16 displays these domains and associated survey questions. The same domain and item structure was used for both YSS and YSS-F.[9]

**Exhibit 16: YSS Domains and Associated Items**

| Domain | Items |
|---|---|
| **Access to Care** | The location of services was convenient. |
| | Services were available at times that were convenient for me. |
| **Participation in Treatment** | I helped choose my services. |
| | I helped choose my treatment goals. |

[8] YSS was developed by Dr. Molly Brunk (2011) as part of the State Indicator Project funded by the Center for Mental Health Services (CMHS). It was adapted from the Family Satisfaction Questionnaire used with the CMHS Comprehensive Community Mental Services for Children and their Families Program and the national Mental Health Statistics Improvement Program (MHSIP) Consumer Survey.

[9] The questions are scored using the five-point Likert scale: 1=Strongly Disagree, 2=Disagree, 3=Undecided, 4=Agree, and 5=Strongly Agree.

| Domain | Items |
|---|---|
| | I participated in my own treatment. |
| **Cultural Sensitivity** | Staff treated me with respect. |
| | Staff respected my family's religious/spiritual beliefs. |
| | Staff spoke with me in a way that I understood. |
| | Staff were sensitive to my cultural/ethnic background. |
| **Appropriateness** | Overall, I am satisfied with the services I received. |
| | The people helping me stuck with me no matter what. |
| | I felt I had someone to talk to when I was troubled. |
| | I received services that were right for me. |
| | I got the help I wanted. |
| | I got as much help as I needed. |
| **Outcomes** | I am better at handling daily life. |
| | I get along better with family members.<br>I get along better with friends and other people.<br>I am doing better in school and/or work.<br>I am better able to cope when things go wrong.<br>I am satisfied with my family life right now. |

**Source:** Brunk, M. (2011). Youth Services Survey . CMHS Comprehensive Community Mental Services for Children and their Families Program and MHSIP Consumer Survey.

The State grantees included in this analysis are *Indiana, Maryland, Mississippi*, *South Carolina*, *Kansas, and Montana.* Other states either did not submit the data or miscoded the data elements. According to the YSS and YSS-F data submission requirements, State grantees were to submit 12-month follow-up and disenrollment surveys. In some instances, State grantees reported data at the preferred interval of 6 months. We use the most recent data (2011) in this analysis.

We calculated domain scores based on the YSS and YSS-F scoring guidelines and present the results as the percentage of children/youth and/or families who report positive responses on each of the domains, and we conducted two sets of analyses. First, we conducted aggregate and State-specific analyses for YSS (or YSS-F) to examine the percentage of children/youth (or families) who reported positive responses for each domain at the 6-month follow-up and at disenrollment.[10] Second, we compared the YSS (YSS-F) to see whether and how children/youth (families) responded differently to each domain.

Main findings from the aggregate analysis indicate that the majority of children/youth and families responded positively regarding the program services in the access to care, participation in the treatment, cultural sensitivity, appropriateness, and outcome domains (Exhibit 17). Cultural sensitivity ranks highest among the core five domains for both children/youth and

[10] For the aggregate analysis, we aggregated the State data by measurement time (i.e., 6-month or disenrollment). For the 6-month analysis, we aggregated Indiana, Mississippi, Maryland, and South Carolina data. For the disenrollment analysis, we aggregated Indiana, Mississippi, Montana, and Kansas data.

families (88 percent and 91 percent for children/youth at the 6-month follow-up and at disenrollment, respectively, and 96 percent and 93 percent for families).

**Exhibit 17: Percentage of Positive Responses**

| Percentage of Positive Responses | 6 months | | Disenrollment | |
|---|---|---|---|---|
| | N[1] | % | N[1] | % |
| **YSS** | **(N=142)** | | **(N=140)** | |
| **Access to Care** | 114 | 80.3% | 110 | 78.6% |
| **Participation in Treatment** | 103 | 72.5% | 99 | 70.7% |
| **Cultural Sensitivity** | 125 | 88.0% | 127 | 90.7% |
| **Appropriateness** | 113 | 79.6% | 110 | 78.6% |
| **Outcome** | 105 | 73.9% | 104 | 77.0% |
| **YSS-F** | **(N=527)** | | **(N=558)** | |
| **Access to Care** | 474 | 89.9% | 470 | 84.2% |
| **Participation in Treatment** | 449 | 85.2% | 477 | 85.5% |
| **Cultural Sensitivity** | 508 | 96.4% | 519 | 93.2% |
| **Appropriateness** | 436 | 82.7% | 417 | 74.7% |
| **Outcome** | 308 | 58.4% | 283 | 53.1% |

**Source.** IMPAQ International LLC National Evaluation of the Medicaid Demonstration Waiver Home- and Community-Based Alternatives to Psychiatric Residential Facilities.

**Notes**. N denotes the total number of youth or families who answered each domain question at each data measurement point. $N^1$ is the number of youth or families who answered positively on the corresponding domain at each data measurement point. Total number of children/youth who answered the outcome question at disenrollment is 135. Total number of families who answered the cultural sensitivity question at disenrollment is 557. Total number of families who answered the outcome question at disenrollment is 533.

In the State-specific analysis, children/youth ranked the participation domain the lowest (e.g., only 58 percent of children responded positively about their Demonstration waiver experience in Mississippi at the 6-month follow-up), while families ranked the outcome domain the lowest (e.g., only 35 percent and 46 percent of families responded positively regarding the Demonstration waiver outcome in Kansas and Indiana, respectively, at disenrollment).[11]

When we compared children/youth and family Demonstration waiver experiences we found that, on average, families were less satisfied than children/youth with the enrollees' improvements in handling daily life and/or school work, getting along with other people, or being resilient in face of difficulties (Exhibit 18). This finding is not surprising given that families are likely to have higher expectations for improvement than the enrollees themselves, despite the stability or improvement in functional status of the child/youth. In contrast, children/youth

[11] Results are available upon request.

were less satisfied than families with their participation in service selection and treatment goals, as well as their participation in the treatment.

**Exhibit 18: Comparison of YSS and YSS-F**

| Comparison of YSS and YSS F | YSS | | YSS F | | P value |
|---|---|---|---|---|---|
| | N[1] | % | N[1] | % | |
| **6 Months (N=132)** | | | | | |
| **Access to Care** | 104 | 78.8% | 117 | 88.6% | 0.0192* |
| **Participation in Treatment** | 97 | 73.5% | 116 | 87.9% | 0.0013** |
| **Cultural Sensitivity** | 115 | 87.1% | 132 | 100.0% | 0.0000*** |
| **Appropriateness** | 105 | 79.5% | 105 | 79.5% | 1.0000 |
| **Outcome** | 96 | 72.7% | 74 | 56.1% | 0.0007*** |
| **Disenrollment (N=127)** | | | | | |
| **Access to Care** | 100 | 78.7% | 109 | 85.8% | 0.1628 |
| **Participation in Treatment** | 90 | 70.9% | 108 | 85.0% | 0.0051** |
| **Cultural Sensitivity** | 115 | 90.6% | 118 | 92.9% | 0.6291 |
| **Appropriateness** | 99 | 78.0% | 93 | 73.2% | 0.4050 |
| **Outcome** | 94 | 77.0% | 79 | 64.8% | 0.0059** |

**Source**. IMPAQ International LLC National Evaluation of the Medicaid Demonstration Waiver Home- and Community-Based Alternatives to Psychiatric Residential Facilities Minimum Data Set, 2011.

**Notes.** The percentage (%) for each domain is the proportion of observations with scores > 3.5 (range of 1 to 5) among non-missing observations. N denotes the total number of children/youth (or families) who answered both YSS (YSS-F) at each measurement point. $N^1$ is the number of children/youth (families) who answered positively on the corresponding domain at each data measurement point. Total number of children/youth and families who answered either survey for the outcome question at disenrollment is 122. McNemar's test is used to test the equality of the proportion of reporting positive answers on YSS and on YSS-F. *P<0.05. ** P<0.01, ***<0.001

As is clear from these findings, children/youth and their families were generally satisfied with the outcomes of the Demonstration waiver and their involvement in the treatment, as well with other Demonstration waiver aspects. This finding is encouraging because it indicated that the Demonstration waiver was successful in allowing families and their children/youth to have control over the services provided and how they were treated.

# CHAPTER 4. COST EFFECTIVENESS

The second question posed by Congress in the legislation calling for the Demonstration waiver was: Was it cost-effective to provide coverage of home- and community-based services (HCBS) for children/youth in the Demonstration waiver? The findings in the previous chapter make it clear that, overall, Demonstration waiver enrollees benefited from the HCBS by either maintaining or improving their functional status in all domains. Furthermore, there is evidence of an improving trend over time in the Demonstration waiver. The evidence of program effectiveness is clear.

The next element was the cost component, in particular the cost neutrality of the Demonstration waiver grant program. For this component, we reviewed the annual CMS Mod-PRTF Demo 372 Report form submitted by State grantees.[12] The calculation of cost neutrality on the CMS Mod-PRTF Demo 372 Report is straightforward and is independently checked by CMS as a condition for continued grantee participation in the waiver program.

Exhibit 19 displays data recorded on the 372 Report by each State for waiver Year 1 through Year 3.[13] The second column is the average per capita waiver cost plus the average per capita cost of all other Medicaid services to Demonstration waiver enrollees. The third column shows the average per capita cost for comparable services in PRTF institutions. This figure is based on paid PRTF claims and provides a point of comparison for the Demonstration waiver expenditures.

**Exhibit 19: CMS MOD-PRTF DEMO 372 Report – Average Expenditures by Waiver Year**

| Waiver Year | Average Per Capita 1915(c) Waiver Costs + Other Medicaid Services (D + D') | Average Per Capita Total Medicaid Costs for Services in Institutions (G + G ) | Cost Neutrality (Subtract D + D' from G + G ) | Waiver Costs as Percentage of G + G' | Average Length of Stay (Days) |
|---|---|---|---|---|---|
| **WY 1** | $9,792 | $42,343 | $33,300 | 22% | 145 |
| **WY 2** | $12,244 | $55,783 | $43,539 | 28% | 135 |
| **WY 3** | $23,122 | $79,452 | $56,329 | 32% | 192 |
| **Average Years 1 to 3** | $15,869 | $55,107 | $39,655 | 31% | $157 |

Source. Department of Health and Human Services, Centers for Medicare & Medicaid Services: Medical Assistance Expenditures by Type of Service for 1915(c) HCBS Waiver, CMS MOD-PRTF DEMO 372 report: Expenditures for

[12] No other cost data were mandated. The cost-neutrality question is answered only indirectly in this evaluation, since a full cost-effectiveness analysis that would require developing cost and effectiveness estimates of the residential institutional settings.

[13] The CMS Mod-PRTF Demo 372 Reports for Year 4 are due six months after September 2011 (i.e., the end of Year

Waiver Year. Estimates are for 2,808 children. Waiver and Medicaid costs for less than 5 children per waiver year per state were excluded from the waiver year calculations.

The positive numbers in the cost neutrality column (column 3) indicate that waiver program expenditures on services were substantially less than expenditures on services in PRTF institutions. Thus, the Demonstration waiver generated actual savings – more than meeting the cost neutral standard. These savings have been consistent across all State grantees and through all waiver years, with waiver costs averaging less than 50 percent of the comparable institutional costs. And this is despite increases in the number of Demonstration waiver participants.

The Year 3 savings provide specific examples. Montana had the greatest percentage savings, with Demonstration waiver services costing only 15 percent of comparable services in PRTF institutions. Indiana and Mississippi served the highest numbers of children and youth (620 and 491, respectively) and cost less than 50 percent of comparable PRTF services.

Kansas, Maryland, and South Carolina all had similar rates of savings in Year 3 – with Demonstration waiver services costing 30 percent, 29 percent, and 27 percent of comparable services in PRTF institutions, respectively. As in Year 2, Alaska had the greatest per person savings in Year 3, at $157,295. Although Year 3 was the first waiver year for which Demonstration waiver services were purchased in Georgia, its grantee waiver program achieved per capita savings close to $50,000, 38 percent of comparable service costs in PRTFs.

Exhibit 20 shows the average savings for all States by waiver Year. For all three waiver years, there has been an average savings of 69 percent. In other words, Demonstration waiver services cost 31 percent of comparable services in PRTFs. Although there has been a slight increase in the ratio of waiver costs over the Average Per Capita Total Medicaid Costs for Services in Other Institutions, this increase may be due to participation increases and additional services being provided as part of the Demonstration waiver. Many State grantees attribute these savings to a favorable response within their State to the Demonstration waiver services. For example, Kansas noted that participants who receive waiver services are often able to decrease the need for service provision by almost half within six months. There has also been an effective effort over the waiver years to increase access to and training in wraparound, family/caregiver support, and peer-to-peer support services. This has been cited by participants and their families as an important part of enabling participants to successfully remain in the Demonstration waiver, thus continuing to reduce the overall cost of treatment services by receiving them in the community rather than in PRTFs.

## Exhibit 20: CMS MOD-PRTF DEMO 372 Report – Expenditures by State

| State | Waiver Year | Unduplicated Participants for Claims Paid | Average Per Capita 1915(c) Waiver Costs + Other Medicaid Services (D + D') | Average Per Capita Total Medicaid Costs for Services in Other Institutions (G + G ) | Cost Neutrality (Subtract D + D' from G + G ) | Waiver Costs as Percentage of G + G | Average Length of Stay (Days) |
|---|---|---|---|---|---|---|---|
| **Alaska** | **WY 1** | n/a | n/a | n/a | n/a | n/a | n/a |
| | **WY 2** | 1 | $21,047 | $135,949 | $114,901 | 15% | 112 |
| | **WY3** | 22 | $46,567 | $203,863 | $157,295 | 23% | 185 |
| **Georgia** | **WY 1** | n/a | n/a | n/a | n/a | n/a | n/a |
| | **WY 2** | n/a | n/a | n/a | n/a | n/a | n/a |
| | **WY3** | 154 | $29,492 | $78,406 | $48,913 | 38% | 213 |
| **Indiana** | **WY 1** | 77 | $7,684 | $42,293 | $38,353 | 18% | 126 |
| | **WY 2** | 329 | $13,739 | $18,265 | $4,526 | 75% | 206 |
| | **WY3** | 620 | $20,579 | $42,023 | $21,444 | 49% | 220 |
| **Kansas** | **WY 1** | 28 | $2,281 | $23,263 | $20,982 | 10% | 60 |
| | **WY 2** | 157 | $7,771 | $33,033 | $25,262 | 24% | 143 |
| | **WY3** | 350 | $8,477 | $28,580 | $20,103 | 30% | 185 |
| **Maryland** | **WY 1** | n/a | n/a | n/a | n/a | n/a | n/a |
| | **WY 2** | 1 | $604 | $3,630 | $3,025 | 17% | 16 |
| | **WY3** | 25 | $24,384 | $82,800 | $58,415 | 29% | 171 |
| **Mississippi** | **WY 1** | 107 | $18,857 | $48,601 | $29,744 | 39% | 137 |
| | **WY 2** | 304 | $23,282 | $49,337 | $26,055 | 47% | 159 |
| | **WY3** | 491 | $25,953 | $55,250 | $29,297 | 47% | 183 |
| **Montana** | **WY 1** | 3 | $10,635 | $43,159 | $32,524 | 25% | 253 |
| | **WY 2** | 13 | $21,342 | $83,176 | $61,834 | 26% | 153 |
| | **WY3** | 37 | $12,792 | $83,176 | $70,383 | 15% | 180 |
| **South Carolina** | **WY 1** | | | | | | |
| | **WY 2** | 3 | $1,924 | $67,596 | $65,672 | 3% | 90 |

| State | Waiver Year | Unduplicated Participants for Claims Paid | Average Per Capita 1915(c) Waiver Costs + Other Medicaid Services (D + D') | Average Per Capita Total Medicaid Costs for Services in Other Institutions (G + G ) | Cost Neutrality (Subtract D + D' from G + G ) | Waiver Costs as Percentage of G + G | Average Length of Stay (Days) |
|---|---|---|---|---|---|---|---|
| | **WY3** | 64 | $16,734 | $61,515 | $44,780 | 27% | 197 |
| **Virginia** | **WY 1** | 4 | $9,503 | $54,400 | $44,897 | 17% | 151 |
| | **WY 2** | 30 | $8,246 | $55,279 | $47,033 | 15% | 199 |
| | **WY3** | | | | | | |
| **Total** | **WY 1** | **219** | **$9,792** | **$42,343** | **$33,300** | **22%** | **$145** |
| | **WY 2** | **838** | **$12,244** | **$55,783** | **$43,539** | **28%** | **$135** |
| | **WY3** | **1763** | **$23,122** | **$79,452** | **$56,329** | **32%** | **$192** |

Source. Department of Health and Human Services, Centers for Medicare & Medicaid Services: Medical Assistance Expenditures by Type of Service for 1915(c) HCBS Waiver, CMS MOD-PRTF DEMO 372 report: Expenditures for Waiver Year.

The answer to the second question posed by Congress regarding the cost-effectiveness of the services can be indirectly answered with the two elements listed above (effectiveness and cost neutrality), and the answer would be yes. The services and its associated costs make this Demonstration waiver a cost-effective alternative to institutional services.

The question is answered only indirectly since we did not conduct a proper cost-effectiveness analysis that would require developing cost and effectiveness estimates of the residential institutional settings.

# CHAPTER 5. SUMMARY AND CONCLUSION

As posed by Congress, one of the two main questions for the Demonstration waiver was whether the Demonstration waiver treatment services resulted in maintaining or improving children's functional status. To address that question, we examined several behavioral and mental health domains, including involvement with the juvenile justice system, school and family functioning, and alcohol and other drug use. We analyzed data on children/youth characteristics and functional assessment scores across all grantee States using regression models to control for non-Demonstration waiver factors that might bias the findings. The second question posed by Congress is whether Demonstration waiver services provided in the community were cost-effective. We addressed this question by combining effectiveness outcomes and cost neutrality issues (particularly whether treatment costs, on average, total no more than anticipated aggregate PRTF expenditures in the absence of the Demonstration waiver.)

Over the four years of the program, more than 4,000 children/youth had enrolled in the Demonstration waiver. Of these, partial or full information on functional assessment and participant characteristics existed for 3,198. The participants were more likely to be boys (64 percent), and about 40 percent were between 15 and 18 years old. There were very few participants younger than 6 (pre-school-age) or over 18. Sixty-two percent were white and 30 percent black. Enrollment in the program was divided almost evenly between diversions (49 percent) and transitions (48 percent), although as mentioned earlier, we noted substantial differences across State policies in this regard. About 20 percent of the program participants in this sample lived in a foster home or other setting. In terms of their mental health conditions, nearly 40 percent of the children had the types of primary disorders usually first diagnosed in infancy, childhood, or adolescence (i.e., oppositional defiant disorder and attention deficit/hyperactivity disorder). Mood, depressive, and bipolar disorders, also considered a major type, accounted for 36 percent of the children/youth's conditions at program admission. Although children in the waiver program had varying degrees of emotional disturbance, close to one-third had not had any prior PRTF stays before enrolling in the program.

Results across all behavioral and mental health domains, from data collected across all States, on common and instrument-specific (CANS, CAFAS, and CBCL) items, present a clear answer regarding the functional status of children participating in the Demonstration waiver. *On average, children/youth either maintained or improved their functional status while in the Demonstration waiver.* Exhibit 21 presents an itemized summary, per mental and behavioral domain, by each of the three functional assessment instruments (repeated from Exhibit 15 for convenience).

**Exhibit 21: Summary of Overall Functional Outcome Changes by Admission Status**

| Domain | Duration in Demonstration Waiver | | |
|---|---|---|---|
| | 6 Months | 12 Months | 18 Months |
| **Juvenile Justice** | Maintained | Maintained | Maintained |
| **Mental Health** | Maintained | Maintained | Maintained |
| **Social Support** | Improved | Improved | Maintained (Improved) |
| **Alcohol & Other Drug Use Transition** | Maintained (Improved) | Maintained (Improved) | Maintained (Improved) |
| **School Functioning** | Maintained | Maintained | Maintained |
| **Global** | Maintained (Improved) | Maintained (Improved) | Maintained (Improved) |

Note: The table indicates the global functional outcome change per domain at a particular follow-up. The secondary effect (in parenthesis) is noted when the functional status change is in the opposite direction to that of the primary findings.

Although the findings vary by domain, most children showed improvements for most domains and most follow-up periods. The functional improvements, which reflect changes in LON rather than simple changes in the absolute score for a particular instrument, indicate a substantial likelihood of improvement on average for children at most LON and regardless of their admission status (diversion or transition). These findings are quite positive and reflect the need for a more permanent format for HCBS mental health programs for children and youth.

The findings also provide rich information on what behavioral and mental health domains are more susceptible to change and which groups of children are likely to see the most positive changes in functioning as a result of Demonstration waiver services. More detailed findings indicate that the Demonstration waiver had particularly positive effects on mental health, family functioning, and alcohol and other drug use. School functioning and juvenile justice tended to show declines in functioning or marginal improvements in absolute (scores) and more scattered instances of improvement.

The common theme across all State grantees is that children/youth with the highest LON at baseline benefited the most from participating in the Demonstration waiver. These children showed the most improvement, across the most domains, and over the most follow-up periods. In terms of admission status, one finding is consistent; children who were diverted as well as children who were transitioned into the Demonstration waiver showed overall improvement. However, we did find that transitioned children had better outcomes on average than children who were diverted.

A majority of the States reported an increase in participant enrollment, provider recruitment and enrollment over time in the Demonstration waiver. This led to an expansion of waiver sites to provide wider geographical coverage within each State and to increase the potential to enroll more children/youth. Policy and political changes benefited the development of the Demonstration waiver in most states, although more negative changes hindered a few. Overall,

the States were successful in initial implementation and development of the Demonstration waiver program.

Finally, as a result of the Demonstration waiver, all participating States have seen significant savings in the costs of caring for children and youths with severe emotional disorders, although the extent of the savings varies by State. The three States with the largest number of participants (Indiana, Kansas, and Mississippi) had savings of $20,000 to $30,000, close to 45 percent savings on average over comparable PRTF services.

Across the waiver Year 1 through waiver Year 3, all States taken together had waiver costs around 31 percent of the average per capita total Medicaid costs for services in institutions, an average per capita saving of $20,000 to $70,000 across States. Waiver costs are increasing as a proportion of the Average Per Capita Total Medicaid Costs for Services in Other Institutions, however, even though all the grantee waiver programs are still safely cost-neutral. The rising trend may be due to more Demonstration waiver services added as States solidify their program.

The State grantees have reacted positively to the improved outcomes seen on children participating in the Demonstration waiver, with several planning to continue the waiver beyond the Demonstration waiver period. To sustain the waiver, some States, such as South Carolina, have had high-level meetings between agency directors and the Governor to discuss funding for mental health services and plans to expand the waiver. Other States, including Montana, Indiana, Georgia, Maryland, Mississippi, and Virginia, have applied for or intend to apply for 1915 (c) and 1915 (i) waivers. Indiana's sustainability plan for the program includes a 1915 (c) PRTF waiver for youth, a small Money Follows the Person (MFP) grant to transition youth, and possibly a future 1915 (i) waiver program. Kansas has submitted ideas to CMS for sustaining the program and has explored the option of transitioning youth in the program into its HCBS Severely Emotionally Disturbed waiver. However, many of the Demonstration waiver States have not had any State-level legislative actions regarding the program. State-level changes may provide additional funding sources and programmatic capacity to maintain the program if Federal legislation is not changed or Federal waiver funding is not available for (1915 (i) and 1915 (c) waivers. But it is uncertain whether State applications for 1915 (i) and 1915 (c) waivers will be granted to continue the Demonstration waiver because such waivers have been traditionally awarded to provide HCBS to adults with disabilities and elderly adults. It is unclear if CMS will change this tradition to provide services in the community for children/youth.

The findings described highlight the positive benefits of the program and the desire of States to sustain the waiver beyond the Demonstration waiver period. The improved outcomes and positive reactions to the Demonstration waiver may increase involvement of participating children and families, which is likely to make the program even more successful in program adherence and behavior modification. Current plans from the State Medicaid agencies are based on the unprecedented CMS waiver policy or hoped-for Federal legislation to make the waiver a permanent solution for children/youth. For all these reasons, States are hopeful that the United States' Congress will pass legislation making the grantee waiver evaluated in this report a sustainable option for current and future participants.