

**Report to the President and Congress
Medicaid Home and Community-Based Alternatives to
Psychiatric Residential Treatment Facilities Demonstration**

**As Required by the
Deficit Reduction Act of 2005 (P.L. 109-171)
From the
Department of Health and Human Services
Office of the Secretary**

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Executive Summary

In 2005, Congress authorized a five-year Demonstration project to test whether children and youth who meet the requirements to be served in a psychiatric residential treatment facility (PRTF) could successfully and cost effectively be served in the community.

The Centers for Medicare & Medicaid Services (CMS) selected ten states to compare effective ways of providing home and community-based services (HCBS) as an alternative to care in PRTFs for children and youth with serious emotional disturbances enrolled in the states' Medicaid program. The Demonstration served children and youth who were either "diverted" from being served in a PRTF, or were "transitioned" from a PRTF into the community, often earlier than would have been possible without the Demonstration. By the fourth year of the Demonstration, the states provided community-based alternatives to institutional treatment to over 4,000 children and youth. Using a "systems of care" approach, the Demonstration successfully enabled participants to either improve or maintain their functioning status at less than a third of the cost of serving them in an institution.

The functional status for the children and youth, diverted or transitioned, was measured in the domains of mental health, juvenile justice, school functioning, alcohol and other drug use and social support. All participants improved or maintained their functional status in these domains. However, the children and youth with the highest levels of need consistently showed improved mental health status, less frequent interaction with law enforcement, better performance in school, reductions in substance abuse and better relationships with peers and family throughout periods measured during the project.

Background

Over the last decade, PRTFs have become a major provider for children and youth with mental illness and serious emotional disorders requiring an institutional level of care. PRTFs are not recognized as hospitals, nursing facilities, or intermediate care facilities for individuals with intellectual disabilities under the Medicaid statute. Therefore, states have been unable to use the 1915(c) waiver authority to provide home and community-based alternatives to institutional care, which would keep children and youth in their homes and with their families or in the community.

In July 2003, the New Freedom Commission on Mental Health released a report, *Achieving the Promise: Transforming Mental HealthCare in America*, which outlined significant barriers to providing community-based services for children and youth with serious emotional disturbances as an alternative to placing them in PRTFs. Children, youth, and families typically have little influence over decisions affecting service delivery, planning, and the use of financing to deliver care. When comprehensive community-based options are unavailable, some children and youth may end up incarcerated in the juvenile justice system, institutionalized for long periods, or in the care of the child welfare system. To address this problem, the Commission recommended that CMS conduct a Medicaid Demonstration project to test community-based alternatives to institutional care.

In response to the statutory barriers to providing Medicaid HCBS to children and youth with serious emotional disturbances, the Medicaid Home and Community-Based Alternatives to Psychiatric Residential Treatment Facilities Medicaid Demonstration project was authorized by the Congress in section 6063 of the Deficit Reduction Act of 2005 (DRA, P.L. 109-171). The Demonstration project allowed up to ten states to compare effective ways of providing care for children and youth enrolled in the state's Medicaid program. Specifically, the demonstration tested the effectiveness of HCBS as an alternative to care in PRTFs. To eliminate the statutory barrier to providing HCBS to children and youth who meet a PRTF institutional level of care, for purposes of the Demonstration, PRTFs were deemed facilities as specified in section 1915(c) of the Social Security Act so participating states could receive federal Medicaid matching funds for these services.

The project targeted children and youth who might not have otherwise been eligible for Medicaid-funded, intensive community-based services and supports available through a 1915(c) waiver authority. CMS awarded \$217 million to ten states, with each state receiving between \$15 million and \$50 million each over the grant period (FY 2007 through FY 2011) and the remaining \$1 million was awarded for the evaluation of the demonstration. Each participating state was required to provide non-federal Medicaid matching funds. One of the ten states, Florida, did not continue in the Demonstration after the first year due to difficulty securing the non-federal matching funds necessary to implement the program. The nine fully participating states were Alaska, Georgia, Indiana, Kansas, Maryland, Mississippi, Montana, South Carolina, and Virginia. The development of home and community-based services in these states was built on historical funding to create systems of care from the Substance Abuse and Mental Health Services Administration (SAMHSA) Children's Mental Health Initiative (CMHI) grant program.

An independent national evaluation of the Medicaid Home and Community-Based Alternatives to Psychiatric Residential Treatment Facilities Demonstration was conducted by IMPAQ International and submitted to CMS in May of 2012. Data and lessons learned from this Demonstration and a national evaluation of SAMHSA's Systems of Care grant program were used to issue the recent SAMHSA-CMS Informational Bulletin, "Coverage of Behavioral Health Services for Children, Youth and Young Adults with Significant Mental Health Conditions."

Design of the Evaluation

As part of the Demonstration, Section 6063 of the DRA required an evaluation. For purposes of this evaluation, CMS constructed two specific questions:

Question One: Did the Demonstration services result in the maintenance of, or improvement in, a child's or youth's functional status?

Question Two: Was it cost-effective to provide coverage of home and community-based services as an alternative to psychiatric residential treatment for children and youth enrolled in the Demonstration?

The evaluation addressed these two questions, as well as additional questions introduced by CMS to help identify successful strategies and the subpopulations for which those strategies are most effective. The evaluation was designed to develop reliable cost and utilization data to evaluate the effectiveness of community-based service-delivery models.

Summary Findings

The evidence from the evaluation yields the following results:

Question One: Did the Demonstration services result in the maintenance of, or improvement in, a child's or youth's functional status?

Findings: Overall, the project successfully enabled children and youth to either maintain or improve their functional status. The common theme across all states is that children and youth with the highest level of need at baseline benefited the most from participating in the Demonstration. These participants showed the most improvement in the following areas: decreased juvenile justice involvement, increased school functioning, decreased alcohol and other drug use and increased social support, over the most follow-up periods. The findings also indicate that children and youth that were transitioned out of PRTFs had better outcomes on average than children who were diverted from PRTFs.

Question Two: Was it cost effective to provide coverage of home and community-based services as an alternative to psychiatric residential treatment for children and youth enrolled in the Demonstration?

Findings: For all nine states over the first three Demonstration years for which cost data was available to be collected, there was an average savings of 68 percent. In other words, the waiver services cost only 32 percent of comparable services provided in PRTFs.

Major Findings

1. Children and youth generally maintained or improved their functional status when receiving services in the community.
2. Waiver services cost about a third (32 percent) of comparable services provided in PRTFs.

The Demonstration proved cost effective and consistently maintained or improved functional status on average for all enrolled children and youth. As discovered through satisfaction surveys, it is encouraging that enrollees and their families liked the outcomes of the Demonstration and their involvement in the treatment, as well as other aspects of the Demonstration.

State Demonstration Enrollment Profiles

The Demonstration enabled states to use the 1915(c) waiver program for the first time and receive Medicaid reimbursement to serve a population of children and youth with serious emotional disturbances in their homes and communities, rather than in PRTFs. With any

Demonstration, challenges are expected. The nine states, to varying degrees, experienced initial delays in enrollment due to factors such as:

- Recruiting providers of home and community based services;
- Training staff to address the complex needs of the children who would have typically been served in an institutional setting;
- Educating families to assure them that their children could safely be served in the community with the appropriate planning and intensive services;
- Developing partnerships among the child-serving systems that may not have been accustomed to working together;
- Addressing the requirements associated with receiving Medicaid reimbursement including programming for Medicaid Management Information Systems (MMIS); and,
- Implementing state regulatory changes as needed.

The initial slow enrollment patterns changed and actual enrollment grew over the four waiver years included in this report. The growth of state provider networks and geographic expansion of the project helped spur enrollment.

Demonstration Project Growth

Year	2008	2009	2010	2011
Children and Youth Served	253	978	1300	4000

Mississippi and Indiana had the largest number of children enrolled in the project since its inception, together accounting for over half of the total children and youth enrolled in the Demonstration. Some of Mississippi’s early success lies in its education and outreach initiatives. Indiana’s success can be attributed both to an existing workforce trained in the wraparound practice model within a system of care framework and a team of statewide staff dedicated to working only on the Demonstration project.

Male children were more likely to be enrolled in the Demonstration than female children. The project served children across different age groups, the highest percent being youth between the ages of 15 and 18.

Final Analytical Sample by Gender and Age -All States

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

Findings on Assessment-Based on Functional Outcomes

One of the key evaluation questions was whether there was an improvement or maintenance of the children’s functional status. To address this issue, it was important to assess changes in the level of functioning of the children and youth in the Demonstration by focusing on several outcomes that are common across grantees. All the common outcome measures reflect changes in five selected domains: mental health, juvenile justice, school functioning, alcohol and other drug use, and social support.

The grantees 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)*. Detailed information about each of the instruments can be found in Appendix A. 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 and youth’s functional outcome changes after project participation. The MDS collected data at 6-month intervals and disenrollment, which enabled the evaluation – at each follow-up point – to analyze a child or youth’s change in functioning from baseline.

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 level of need (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 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 the Demonstration. More detailed findings indicate that the Demonstration had particularly positive effects on mental health, family functioning, and alcohol and other drug use. The common theme across all state grantees is that children and youth with the highest LON at baseline benefited the most from participating in the Demonstration. These children showed the most improvement, across the most domains, and over the most follow-up periods.

Children and Youth with Highest Level of Need (LON)

Functional Status Domains	Duration in Demonstration Waiver		
	6 Months	12 Months	18 Months
Mental Health	Maintained	Maintained	Improved
Juvenile Justice	Improved	Improved	Improved
School Functioning	Maintained	Improved	Improved
Alcohol & Other Drug Use	Improved	Improved	Improved
Social Support	Improved	Improved	Maintained

Findings Related to Cost Effectiveness

In response to question two, as a result of the Demonstration, all participating states have seen significant savings in the costs of caring for children and youth 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 average savings of \$20,000 to \$30,000, close to 45 percent savings over comparable PRTF services. Initial outreach/education in Mississippi and access to a trained and existing provider networks in Indiana and Kansas may explain why these states experience higher cost than the 9 states on average. The ability to provide and expand services rapidly to meet the needs of the participants in a more comprehensive manner could explain overall high community based costs.

Cost effectiveness of the Demonstration was evaluated by comparing each state’s fiscal year’s expenditures on HCBS services provided under the Demonstration to data on PRTF expenditures that states submitted annually. This information provided data on expenditures by participant, by service, per waiver year. To calculate the average per capita cost, the data submission included the number of users per service and the total number of unduplicated waiver participants for which claims were paid. These calculations were made by using the three years of cost data available for the evaluation.

Across the first year of the Demonstration and through year three of the evaluation, all states taken together had Demonstration costs around 32 percent of the average per capita total Medicaid costs for services in PRTFs, an average per capita savings of \$36,500 to \$40,000 across the states. Demonstration costs increased as a proportion of the average per capita total Medicaid costs for services in institutions; however, all the Demonstration projects remained cost effective. The rising trend may be due to more Demonstration waiver services being added as states solidified their project.

Waiver Year	Average Per Person 1915(c) Cost	Average Per Person PRTF Cost	1915(c) Cost as a Percentage of PRTF Cost
WY 1	\$9,792	\$42,343	22%
WY 2	\$12,244	\$55,783	28%
WY 3	\$23,122	\$79,452	32%
Average Years 1 to 3 ⁽¹⁾	\$15,869	\$55,107	32%

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: (1) Waiver years (WY) 1 to 3 include all expenditures for an estimated 2,820 children, however, expenditures for the average years row, excludes Waiver and Medicaid costs for Grantees with less than 5 children per waiver year because of the likelihood of a biased estimate due to the small number of observations. Estimates for this row are based on 2,808 children.

Conclusion

The Demonstration has easily met cost effectiveness tests and on average has consistently maintained or improved functional status for all children and youth. In addition, as discovered through satisfaction surveys, families and children liked the outcomes of the Demonstration and their involvement in the treatment, as well as other Demonstration aspects.

States have reacted positively to the improved outcomes seen for children and youth participating in the Demonstration and seven states have received approval for “bridge” 1915(c) waivers. These bridge waivers permit states to continue services to the children and youth who started receiving services under the Demonstration but not to additional children or youth because of the statutory barrier to providing 1915(c) waiver services to children and youth meeting a PRTF level of care. The seven states operating bridge waivers have indicated that they would be interested in applying for a 1915(c) waiver if the statute permitted a waiver for this purpose. Three states are using or considering the use of the 1915(i) state plan authority which allows children and youth to receive services in the community without the institutional level of care as long as the participants are at or below 150 percent of the Federal Poverty Level (FPL). However under this authority, the only way to increase the income limits would be for the children or youth to meet the same institutional level of care required for 1915(c) waivers. Income level restrictions, statewide requirements and the inability under the authority to regulate the number of participants in the program make this alternative less attractive to states.

The findings highlight the positive benefits of the project and the desire of states to sustain the waiver beyond the Demonstration period. The improved outcomes and positive reactions to the Demonstration may have increased the involvement of the participating children, youth and families, which is likely to have made the project even more successful in program adherence and behavior modification. In order for the objectives of the Demonstration to continue, the statutory barrier to providing HCBS to children and youth who meet a PRTF institutional level of care criteria would have to be eliminated by identifying PRTFs as a designated institution under section 1915(c) of the Social Security Act so states could receive federal Medicaid matching funds for waiver services.

For more detailed information regarding findings described in this report, please see “The National Evaluation of the Medicaid Demonstration Waiver Home- and Community-based Alternatives to Psychiatric Residential Treatment Facilities Final Evaluation Report” that can be found on the Medicaid.gov website: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Alternatives-to-Psychiatric-Residential-Treatment-Facilities-Demonstration-PRTF.html> .

Appendix A:

Functional Assessment Instruments

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 the remaining states using the other two instruments.

The CANS was developed to assess the strengths and needs of children and 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.

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 and 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 and 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, 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.