This report describes the Home and Community Based Services (HCBS) Waiver to section 1915 (c) of the Federal Social Security Act that was obtained by the New York State Office of Mental Health. The HCBS Waiver affects the services provided to children and adolescents with serious emotional disturbances. Three statutory requirements are included in the HCBS Waiver: (1) the statewide and comparability requirements were waived to allow the implementation of the HCBS Waiver on a demonstration basis in seven counties and the five boroughs of New York City; (2) the requirements relating to amount, duration, and scope of services were waived which makes it possible to offer six new Medicaid services (individualized care coordination, respite care, skill building services, intensive in-home services, crisis response services, and family support services) in addition to existing Medicaid services; and (3) a requirement relating to the parental deeming rule was waived, which allows the parents' income and resources not to be considered when determining a child's eligibility for Medicaid. The report outlines the goals of the HCBS Waiver, the target population, the local infrastructure in each waiver site, and the HCBS Waiver services. A cost evaluation is also provided. (CR)
KEEPING CHILDREN AT HOME: NEW YORK'S HOME AND COMMUNITY BASED SERVICES WAIVER

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Mission Statement

The New York State (NYS) Office of Mental Health is identified as the NYS government agency which creates opportunities for children and adults who have psychiatric disabilities to safely and effectively work toward recovery. These opportunities shall:

- Recognize that persons can recover,
- Include comprehensive services organized at the local level to promote recovery, and,
- Promote a holistic approach for services that are:
  - Individualized,
  - Flexible,
  - Measurable in terms of outcomes, and
  - High quality and user friendly.

Background

In Chapter 170 of the Laws of 1994, the NYS Legislature provided the authority for the NYS Department of Social Services to apply for a general waiver on behalf of the Office of Mental Health, pursuant to section 1915(c) of the Federal Social Security Act. The general waiver provides Medical Assistance to children and adolescents who meet the eligibility criteria and reimbursement of several home and community-based services not previously included in the Medical Assistance program. The children and adolescents that the HCBS Waiver is designed to serve are those who, but for the Waiver, would be admitted to institutional levels of care including long term Residential Treatment Facilities and intermediate inpatient care.

Federal approval of the Home and Community Based Services (HCBS) Waiver was granted January 1, 1996.

The Federal Health Care and Finance Administration approved New York’s request to waive three statutory requirements of Section 1915(c) of the Social Security Act. The statewideness and comparability requirements were waived to allow the implementation of the HCBS Waiver on a demonstration basis in 7 counties and the five boroughs of New York City. Secondly, the requirements relating to amount, duration and scope of services were waived which made it possible to offer six new Medicaid services (individualized care coordination, respite care, skill building services, intensive in-home services, crisis response services and family support services) in addition to existing State Medicaid Plan services.
The third statutory requirement waived was **parental deeming rules**. For children who are enrolling in the HCBS Waiver, their parents/guardians' income and resources are not considered when determining a child's eligibility for Medicaid; children are considered a "family of one".

The goals of the HCBS Waiver are to:

- Enable children to remain at home or in the community, thus decreasing institutional placements;
- Use the individualized care approach to service planning, delivery and evaluation; this approach is based on values of planning for one-child-at-time, partnerships with families and focuses upon the strengths of the family;
- Expand funding and service options currently available to children and adolescents with serious emotional disturbances and their families;
- Provide services that promote better outcomes and are cost-effective; and
- Demonstrate a model of service delivery that fosters a transition to managed care.

**Target Population**

The target population for the HCBS Waiver is children and adolescents:

- with serious emotional disturbance;
- between the ages of 5 and 17 years (prior to 18th birthday);
- who demonstrate complex health and mental health needs;
- who require institutional level of care;
- who are at imminent risk of admission to institutional level of care or have a need for continued hospitalization;
- whose service and support needs cannot be met by just one agency/system;
- who are capable of being cared for in the home and/or community if services are provided; and
- have a viable and consistent living environment with parents/guardians who are able and willing to participate in the HCBS Waiver and support their child in the home and community.
Local Infrastructure

In each waiver site there exists an Individualized Care Coordination (ICC) Agency, or lead agency, that is responsible for:

- the development and administration of a network of Waiver service providers;
- hiring, supervising and training the Individualized Care Coordinators (ICC);
- coordinating all the services the child and family receive under the Waiver;
- being the primary biller of Medicaid Waiver services;
- monitoring the costs associated with each child's care; and
- program reporting requirements.

Each lead agency is required, in consultation with the respective county Department of Mental Health, to ensure that a network of service providers is available and to guarantee access to the full array of HCBS Waiver services whenever a child and family are in need or as the individualized service plan determines. This includes recruiting additional providers should a service area not be available or accessible as the population requires.

The county Department of Mental Health is responsible for: determining the individual need for the HCBS Waiver level of care by evaluation of referral information; review of initial service plan and budget; and approval of 30 day and 90 day service plan reviews. The county departments assist the ICC agency in monitoring the costs associated with service provided through the HCBS Waiver. This monitoring of costs serves as a learning tool for a county's entire system of care.

Services

The services that are integral to the HCBS Waiver were developed as a result of a survey of county departments of mental health and families. The survey collected information related to the services and supports that are most needed by the target population and their families to remain at home and in the community. The six HCBS Waiver services must be available in each site to enrolled children and their families. Individualized Care Coordination is the only service of the six that is required for each child, while the others are available as determined by individual need.

The HCBS Waiver services are defined as follows.

1. **Individualized Care Coordination** includes the components of intake and screening, assessment of needs, service plan development, linking, advocacy, monitoring and consultation.

2. **Crisis Response Services** are activities aimed at stabilizing occurrences of child/family crisis where it arises. Provides the ability to do an assessment, provide consultation, and immediate intervention wherever necessary, for
example, in schools, at home, at work sites, in clinic programs.

3. **Intensive In-home Services** are ongoing activities aimed at providing intensive interventions in the home when a crisis response service is not enough. These interventions may include psychoeducation, crisis de-escalation, parent-child relationship building, and improvement of parenting skills.

4. **Respite Care** are activities that provide a needed break for the family and the child to ease the stress at home and improve family harmony. These activities include aid in the home, getting a child to school or program, aid after school, aid at night or any combination of the above. It may be provided on a planned or emergency basis either in-home or out-of-home by trained respite workers.

5. **Family Support Services** are activities designed to enhance the ability of the child to function as part of a family unit and to increase the family's ability to care for the child in the home and in community based settings.

6. **Skill Building Services** are activities designed to assist the child in acquiring, developing and accessing functional skills and supports, both social and environmental, needed to function more successfully in community environments, i.e., family, school and community.

**Evaluation of Child and Family Outcomes**

To evaluate child and family outcomes associated with the HCBS Waiver, a strategy of data collection was developed. Data on children and families are collected at intake, 6, 12, 24 months and/or discharge. Basic information about the enrolled child is gathered at intake through the Child Description Form (CDF). The CDF includes items on:

- basic demographic information,
- functional status and education levels,
- behavior symptomatology and treatment history.

In addition, data are collected on family stressors and strengths. Follow-up data collection at 6, 12, and 24 months repeat assessment of the child's functional status and symptomatology, as well as information on the utilization of services and family strengths. In addition, follow-up instrumentation elicits data on the provider's assessment of level of need in nine life domains and the strategies that have been devised by the individualized care planning process to address unmet need. Parent satisfaction with services is measured at 6, 12 and 24 months. At discharge, a Program Discharge Form is completed to assess the child and family's status as well as reasons for discharge and post-discharge service utilization.
Cost Evaluation

Costs incurred for each child enrolled in the HCBS Waiver are collected and monitored through reports generated from the Medicaid Management Information System (MMIS). The NYS Department of Social Services provides all Medicaid adjudicated claims for each child enrolled in the Waiver. These data are summarized and reports produced which identify total Medicaid expenditures for each child and site. For each agency and each child, expenses are totaled by service category for the current month, each calendar quarter, and year-to-date. Annualized year-to-date amounts are compared to the agency’s budgeted amounts per service category and to the total ambulatory mental health service cap (approx. $44,267) and to the total Medicaid expenditure cap ($54,254). The cap was calculated by examining historical Medicaid expenditure data of a similar target population of children, as well as surveys of counties and families regarding needed capacity of each service category. Agencies are expected to use the reports as a tool for managing their enrollees’ costs within their budgets. Technical assistance is given as needed to providers with cost overruns. The Office of Mental Health utilizes the data to report to the Federal Government regarding costs of services, that must be below the cost of institutionalization. One of the premises of receiving approval for an HCBS Waiver is the expectation that the provision of services in this manner will not cost more than institutional level of care.

Summary

Implementation of the Home and Community Based Services Waiver has been an important step for New York State. The opportunities to learn are immense as data begin to reveal the best complement of services and supports for the target population. This information will guide the development of managed care plans for children with serious emotional disturbance. To date, data reveal that children and families are being served well by the HCBS Waiver.
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