



Rutgers Center for
State Health Policy

NATIONAL ACADEMY
for STATE HEALTH POLICY

July 2005

State Policy in Practice

Community Living Exchange

Funded by Centers for Medicare & Medicaid Services (CMS)

Individualized Backup Planning and Independence Plus in Louisiana and New Hampshire

Susan C. Reinhard
Nirvana Huhtala
Ann Bemis

INDIVIDUALIZED BACKUP PLANNING AND INDEPENDENCE PLUS IN LOUISIANA AND NEW HAMPSHIRE

Susan Reinhard
Nirvana Huhtala
Ann Bemis

July 2005

Summary

States are developing home and community-based services (HCBS) and supports for older adults and individuals with disabilities that promote participant-direction. The use of Medicaid Section 1915(c) waivers and Section 1115 demonstrations enables states to offer individuals who require long-term supports and services, greater opportunities to take charge of their own health and direct their own services. Under these Independence Plus Medicaid programs, states must assure that necessary safeguards have been taken to protect the health and welfare of persons receiving services. A key component of participant-direction includes individualized backup planning to ensure that essential supports are available in situations that pose a risk of harm to the participants. This *State Policy in Practice* technical assistance document describes the individualized backup planning process in two states. It should be noted that the Centers for Medicare & Medicaid services (CMS) has updated its policy on individualized backup planning since the agency approved these waiver programs.¹ Nevertheless, these two examples are instructive to other states that are considering Independence Plus applications. Subsequent briefs will feature additional states.

¹ In the spring of 2005, CMS released a new Section 1915 (c) waiver application that incorporated the CMS Independence Plus requirements, including individualized backup planning and policy updates included therein. As a direct result of feedback from meetings with states and various associations, CMS updated its policy on individualized backup planning. The new 1915 (c) waiver application placed “individualized backup planning” within Appendix D, “Service Plan Development”. Instructions accompany the waiver application guide states in the information that they must provide in the application. The Section 1115 Independence Plus requirements mirror the Section 1915 (c) requirements for individualized back-up planning. **For information about the Section 1915 (c) waiver application, states may contact Anita Yuskauskas at Anita.Yuskauskas@cms.hhs.gov. For information about the Section 1115 Independence Plus requirements, states may contact Marguerite Schervish at Marguerite.Schervish@cms.hhs.gov.**

Major Points

- If states wish to pursue a Medicaid Independence Plus program under Section 1915 (c) or Section 1115 of the Social Security Act, states must assure that necessary safeguards are in place to protect the health and welfare of persons in these programs.
- CMS expects states' applications to provide a description of the procedure and process for service plan development, including how the plan development process ensures that identified risks are addressed, including responsibilities and measures for reducing risks such as backup plans and risk management agreements. A complete description of backup arrangements should be included in the individualized backup plan.

Background

Independence Plus waivers incorporate the fundamental principle of *self direction, consumer direction or participant direction* into their service delivery approaches, permitting individuals the option to exercise control and choice in identifying, accessing and managing services they obtain to meet their long-term health care and support needs. The Centers for Medicare & Medicaid Services defines a participant-directed program as one that allows participants to have decision-making authority over their workers (e.g., hiring, supervising, managing, firing) and/or over a budget (e.g., deciding how their budgeted amount is spent, managing the budget, setting workers' rates of pay) for waiver services. (Note: Participant-direction will be the term used throughout this paper to describe this concept.)

Independence Plus programs require states to assure "participant protections" are in place. One of the participant protections is an individualized backup plan as discussed with and decided upon by the participant during the person-centered planning process. States' applications must set forth their procedure and process for how individualized backup planning will occur during the person-centered planning process. For example, states should consider how participants at risk will be provided with relevant information and how they will be assisted in accessing and using existing agencies and services. The resultant individualized backup plan needs to be included in the participant's service plan, and must assure the participant's ability to receive prompt assistance when the identified services or supports, if unavailable, would pose a risk of harm to the participant. The plan must have no impediments to accessing the essential services and all prior authorizations need to be addressed up front within the procedure the state describes.

This *State Policy in Practice* brief describes the individualized backup planning procedure and process from two Independence Plus Section 1915 (c) waiver programs.

Louisiana

The New Opportunities Waiver is Louisiana's 1915(c) – Independence Plus Waiver. The target population is age three or older and has a diagnosis of mental retardation/developmental disability (MR/DD) that manifested prior to age 22. The

waiver has been fully operational since January 2004. Case managers have been trained on backup planning and advocacy groups, such as Families Helping Families, are helping to train families and participants on backup planning.

Design Features

An individual's backup plan is part of what Louisiana calls the "comprehensive plan of care." The backup plan is used in situations when a worker cannot come to the individual's home. This plan is developed on an annual basis and is updated as needed. The case manager (known as the "assistance broker") and the individual identify the backup needs and secure contact information. A list of backup workers is listed in the plan of care. Some individuals keep a list of the people they work with so that, they have that information right at hand to implement their backup plan immediately.

In Louisiana, case management agencies in each region of the state provide support planning and quality assurance. These are independent agencies that coordinate the process for the annual planning and serve as service brokers for the participants. They play a pivotal role in the development of the backup plan and oversee that the individualized plan is executed when an individual is at risk of harm. They have beepers and are on call 24/7.

Associated Costs

The cost associated with the individualized back-up plans have been minimal because they are built on existing infrastructure. Contracts were already in place with independent case management agencies and they have been asked to take on this additional work without additional charge during their current contract period. Case management agencies have been asked to document the additional time that is required in this new waiver. The current case management caseload size is a maximum of 35 participants per case manager. According to state officials, if the data indicate they need more time, those concerns will need to be addressed in the contract process when new contracts are established. There may some possible options for changes, which may include caseload size, roles, responsibilities, and rates.

New Hampshire

New Hampshire's 1915(c) Independence Plus Waiver was the first approved Independence Plus Waiver. The In Home Support Waiver for Children with Developmental Disabilities serves children up to the age of 21 with developmental disabilities who are living at home with their parents. The children on the waiver have a number of individual and family factors that can make their care more difficult and challenge the family's ability to stay intact. It is likely that many of these families already have created some form of an informal backup program because of the demands that arise with home care of minors.

The waiver currently serves 200 children. The waiver covers a group of discrete services, which in the aggregate are referred to as a “consolidated service.” It includes personal care, respite, home and vehicle modifications, consultative services and care coordination. Waiver participants have a service plan that is organized through one of the Developmental Services Area Agencies.

Design Features

An individual’s -backup is reflected in the participant plan of care, which New Hampshire calls the “service agreement” template. The service agreement is the document that identifies and describes what services the individual will receive. The service agreement is prepared by the Family Support Care Coordinator with the individual and his or her family. The service agreement is developed on an annual basis or more often, as needed.

The service agreement template helps the Family Support Care Coordinators to identify, discuss and plan for emergencies based on the unique needs and circumstances of the individual and his or her family. There is a section for each of the component services in the service agreement. For instance, the personal care contingency plan needs to be identified for the provision of that service should the provider not be available at the last minute or something interferes with the provision of that service. This is an important issue to many families because they are often getting pulled out of situations, such as work, to address an issue with their child.

The service agreement also includes a section to indicate whether there are safety issues or behavioral issues that have to be addressed. There is also a section focused on medication administration and requirements if someone other than the family member is going to be giving medications to that child. A list of individuals such as family members, physicians, and others that are to be contacted in case the individual is at risk of harm is also included.

New Hampshire places a great emphasis on local control. All of the Developmental Services Area Agencies have their own system in place that is customized to work best for their particular families and each models its approach depending on the regional demands. There are cases in which the Care Coordinator has a pager and the specific families that are on that Care Coordinator’s list call that person. All of these Area Agencies have a central number for off-hours and weekend hours, so that families in need can call and be put in touch with whomever is on call.

Every Area Agency has a different way of providing “24/7” availability, but they all have it. For example, during the holiday season last winter a family ran out of fuel, called their Care Coordinator on a weekend and within 24 hours they were able to get oil for their tank. In one case, a child had a behavioral problem on a weekend. The Care Coordinator was able to work through the behavioral protocol with the mother and arrange an emergency admission for that child to have medications adjusted.

Associated Costs

The cost for the backup service is typically included in the Care Coordination salary. The annual charge in a family's budget for Care Coordination through the agency is about \$3,000.

Conclusions

The two states that were described have procedures and processes in place to assure that necessary safeguards have been taken to protect the health and welfare of persons receiving services under the state's *Independence Plus* waiver. In both states, costs to implement individualized backup planning have been minimal. This technical assistance document provides information about potential approaches to individualized backup planning in *Independence Plus* Waivers. Future *State Policy in Practice* briefs will provide examples from other states.

Acknowledgements

The authors express their gratitude to the following people who contributed to the creation of this publication: Anita Yuskauskas, Theresa Pratt and Marguerite Schervish from the Centers for Medicare & Medicaid Services; Suzanne Crisp from The MEDSTAT Group; Judy Moore from Louisiana; Barbara Reed and Leslie Boggis from New Hampshire; and all of the Independence Plus grantees, awarded under the CMS Real Choice Systems Change initiative.

References

Centers for Medicare & Medicaid Services. (n.d.). Independence Plus: A demonstration program for family or individual directed community services. Accessed on Jan. 27, 2005 from <http://www.cms.hhs.gov/independenceplus/summary.pdf>

Centers for Medicare & Medicaid Services. Independence Plus 1915(c) Waiver Version. Retrieved May 19, 2005 from <http://www.cms.hhs.gov/independenceplus/1915temp.pdf>

Centers for Medicare & Medicaid Services (CMS) (2005, March 7). Revised Application for §1915(c), Draft Version 3.0.

Department of Health and Human Services (HHS) Press Release (2002, May 9) HHS Announces Steps to Facilitate State Programs to Foster Community Integration. Retrieved on May 19, 2005 <http://www.hhs.gov/news/press/2002pres/20020509a.html>

Community Living Exchange Collaborative at Rutgers/NAHSP (2004, April 26). Emergency Back-up and Independence Plus. Audio conference provided through Rutgers Center for State Health Policy, moderated by Susan Reinhard. Retrieved on May 19, 2005 from <http://www.hcbs.org/moreInfo.php/nb/doc/878>