State and Local Strategies for Ensuring Backup Personal Care Services

Introduction

People with disabilities face a particular kind of risk when authorized personal care services (PCS) are not delivered. In some cases, people may not receive the support they need, such as assistance that enables them to go to work or to maintain their independence and self-direction. In other cases, without the timely availability of adequate care, these individuals can find themselves at risk of emotional distress and even physical harm resulting from, for example, going for hours without being transferred from a bed to a wheelchair or to the bathroom, skipping medications, getting insufficient food and water, and being unable to attend to personal hygiene.

This report examines state and local initiatives to ensure that effective mechanisms and safeguards are in place to identify and respond to service delivery failures that require backup coverage for Medicaid PCS.

Findings

States can fulfill their responsibility to ensure that PCS are delivered by using three complementary strategies:

1. **By requiring that provider agencies immediately identify service breakdowns and make necessary backup services available, and by establishing backup service policies that support self-directing consumers.**

2. **By monitoring whether providers fulfill these requirements and whether backup service policies are effective, taking corrective action when they are not.**

3. **By supporting the development of backup management systems and programs, whether at the provider, regional, or state level.**

The state practices identified include the following:

1. **State Strategies for Requiring Backup Service Delivery and Provider Monitoring:** Most states rely on general requirements directing agency providers to deliver the services that they have contracted to deliver and that are authorized in approved care plans. Such requirements implicitly contain the expectation that providers will deliver backup or emergency services when necessary. A few states have begun to adopt detailed and specific regulations, administrative code, and/or contract language specifying uniform provider standards for backup.
2. State Strategies for Tracking and Monitoring that Authorized Services Are Delivered: About three-quarters of states describe systems that rely principally on review of case management records, sometimes combined with periodic review by state agencies using sampling or reconciliation methods. A handful of states have implemented consolidated reporting systems where the tracking takes into account not just a sample of cases, but complete encounter data. These systems often are automated.

3. Models for Creating Backup Management Systems: States identified five different, although not mutually exclusive, approaches to creating backup coverage for Medicaid PCS:

   a. development of consumer backup plans for consumer-directed care;
   b. provider agency gap-coverage procedures and preventive measures;
   c. “call-off” notification systems;
   d. creation of specialized backup agencies and backup pools of PCS workers; and
   e. use of registries for backup coverage.

Conclusions

1. Ensuring backup service should be a required component of states’ oversight of publicly-financed home and community-based services. However, states rarely specify uniform standards for providing backup for PCS service breakdowns, such as required response coverage times and the availability of backup services 24 hours a day, seven days a week.

2. State quality assurance systems with respect to backup tend to be unevenly developed across waiver programs and even less well developed for non-waiver PCS programs.

3. The vast majority of states rely on periodic review of partial records or samples of records to monitor the delivery of authorized services, but it is unclear how well this type of review process captures and relays reliable and timely information on how often authorized services are actually received by consumers and how often they are not.

4. The growth in consumer-directed PCS raises important issues about the role that states can play in ensuring that consumers have access to backup services beyond informal arrangements with family and friends.

5. While most of the programs and policies described in this report are just emerging, experience to date across the states reveals a variety of ways in which state government and other long-term care stakeholders can encourage the development of greater backup coverage capacity at both local and regional levels.

While most states appear to be at the earliest stages of designing comprehensive approaches to ensuring backup service, policymakers, providers, researchers, consumers, and advocates seeking to improve backup services can draw upon the emerging state-level experience and lessons that this report begins to detail.