

Assisting State Developmental Disabilities Agencies Respond to an Influenza Pandemic: Issues and Recommendations

Presented To

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Introduction

The current outbreak of the H1N1 Influenza A virus is raising concerns among NASDDDS member state agency officials charged with responsibility for managing publicly financed services and supports furnished to individuals with intellectual and developmental disabilities (ID/DD). In their efforts to assure the health and welfare of Medicaid recipients, as well as individuals receiving non-Medicaid state funded supports, program administrators are contemplating the need to take steps to contain the spread of the disease that may impact the amount, frequency, duration, scope and type of services furnished under states' Medicaid waiver and state plan programs. Although such changes would most likely be time limited, decisions regarding temporary service reconfiguration will need to be made on an immediate basis with little time for prior federal approval.

Issues and Recommendations

To comply with clinical and public health protocols regarding infection control and management of individuals with confirmed or suspected cases of swine flu, state developmental disabilities agencies may need to take a number of steps to control the spread of the disease by isolating and treating individuals with ID/DD in place, avoiding groups and public facilities, including hospitals and treatment centers. Such actions may include requirements that people receiving support remain at home during the day with their families or in individualized and group residential settings. Day services, community activities, and contact with staff and volunteers providing ancillary supports may need to be limited or temporarily suspended until the threat of contagion has passed. This may necessitate that significant changes be made temporarily in the amount, frequency, scope, duration and type of services being provided. Although the pattern can be expected to vary both between and within states, additional expenditures can be expected to be incurred across multiple areas including: healthcare delivery, direct support, supervision and monitoring, medication administration, personal hygiene, transportation, quarantine and isolation, facility maintenance and disease control, overtime staff coverage.

NASDDDS member state agency directors are requesting clarification on a number of issues regarding the financial and programmatic flexibility of the Medicaid waiver program and their need to maintain federal funding during this period of national emergency.

Issue 1. Exceeding approved waiver program coverage limits. To ensure the health and welfare of waiver program recipients, particularly those receiving assistance through limited “supports” waiver programs, states may need to provide services that are eligible for waiver reimbursement but are not specifically included in their approved waiver programs.

Recommendation. During this period of national public health emergency that CMS create mechanisms to rapidly approve waiver (auto-approval) amendments, or provide retroactive approval, to permit states to add new waiver services or change existing service definitions to effectively address beneficiaries’ medical needs and their ability to be supported in non-institutional community programs.

Issue 2. Expanding access to existing comprehensive waiver services. Some states may prefer to temporarily transfer current supports waiver recipients who are ill and in need of intensive but time limited personal care and support to an existing comprehensive waiver program that offers a full range of services and care.

Recommendation. CMS assist states in providing timely response to individuals’ needs by approving temporary increases in the number of individuals served under the state’s comprehensive waiver program.

Issue 3. Exceeding approved waiver program utilization caps and reimbursement limits. To ensure the health and welfare of waiver program recipients, particularly those receiving assistance through limited “supports” waiver programs, states may need to provide services in excess of approved utilization rates and incur expenditures that exceed the maximum individual rates or per-capita costs identified in their approved waiver applications.

Recommendation. CMS develop a mechanism to rapidly review and approve revisions in state programs and that the mechanism be shared with all state developmental disabilities and Medicaid agencies as soon as possible.

Issue 4. Facilitating changes in the amount, frequency, duration and scope of services. Related to recommendations 1-3 above, states need flexibility in adjusting the amount, frequency, duration, and scope of services to ensure the provision of necessary healthcare during the pandemic flu outbreak.

Recommendations. CMS develop the means to permit states to focus available resources on meeting the needs of individuals receiving Medicaid waiver services by having the flexibility to:

- a. Increase the number of hours of support that persons with disabilities are able to receive during a given period of time in the residential setting or in the individual's own home so as to improve the ability to support people during periods of quarantine.
- b. Expand opportunities for individuals to receive supports in the home of the staff member.
- c. Waive existing individual to staff ratio requirements that limit the ability to distribute staff responsibilities and supervision.
- d. Waive caseload limits for support coordinators/case managers to enable them to address the needs of additional individuals during periods of staff shortages.
- e. Waive individual contact and observation requirements to permit services and individuals to be monitored by telephone, email or visits from current direct support staff as proxies.
- f. Waive or postpone non-essential administrative activities during the outbreak period that typically involve contact with external staff such as:
 - i. Annual reviews of individual support plans (Plan of Care).
 - ii. Annual quality assurance program reviews.
 - iii. Regularly scheduled contacts with individuals, families and provider agency staff.

Issue 5. Assuring the continued provision of day services. Public health protocols regarding infection control and management of flu outbreaks stress the importance of social isolation and treatment in place. As noted above, for persons with developmental disabilities, this means staying at home and refraining from participation in day programs, work and community activities. In some instances day program staff may be able to be reassigned to provide additional supports to people in their home settings. In a majority of states, however, this approach can be very difficult to implement and may have only limited applicability.

State officials are concerned that extended day program absences will compromise the financial viability of day and employment services causing many provider agencies to close their doors. Medicaid regulations permit States to include a vacancy factor into their provider agency reimbursement rates, but this alone may not be sufficient to retain needed service capacity after the influenza outbreak has subsided. Other Medicaid regulations (42 CFR 447.40) permit States to make payments to "hold" an institutional bed open for a resident while that individual is hospitalized or away from the facility for a short period. CMS guidance applies this principle to waiver services by allowing "personal assistance retainer" payments to enable waiver participants to continue to receive services in the most integrated setting appropriate to their needs while a person is hospitalized or absent from his or her home. This approach would

appear to offer a means for states to continue to reimburse provider agencies during periods that Medicaid waiver beneficiaries are unable to attend the program or receive services because of their medical needs.

Recommendation. CMS provide guidance to states in the application of Medicaid regulations, policies and procedures, based on those at 42 CFR 447.40, that permit states to make provider payments to hold institutional placements or continue to furnish supports while a beneficiary is hospitalized or away from his or her home in the community through “personal assistance retainer” payments. These and other approaches for assuring the continuity of services and the residual capacity of home and community based employment, day and residential programs during periods of Medical emergency or pandemic when Medicaid recipients are absent or unable to participate in normal programming due to their need for treatment, isolation and convalescence.

Request for Assistance and Next Steps

Individuals with intellectual and developmental disabilities present particular challenges to emergency management and response authorities. Significant individual needs for direct support and supervision, difficulties in performing basic living tasks and wide variations in personal communication styles, adaptive behaviors, personal and social skills require a level of direct assistance, and expertise on the part of those providing assistance, that is far greater than that needed by the majority of the population.

The issues and recommendations outlined above were drawn from the experiences of state agency officials engaged in disaster preparedness and response during the past several years. The issues cover broad areas of program responsibility and operational responsiveness that states can be expected to encounter during an influenza pandemic or similar outbreak of contagious disease. The recommendations that are offered reflect the need of states developmental disabilities and Medicaid agencies to react quickly in close coordination with state, federal and local emergency response personnel. The proposed actions will assist states in mounting an effective and appropriate response to a severe influenza outbreak and to the fullest extent possible ensure the health and welfare of Medicaid recipients with developmental disabilities and the public at large.

NASDDDS, on behalf of public developmental disabilities agencies in all 50 states and the District of Columbia requests CMS’ assistance in developing an effective and appropriate disaster response plan, response and recovery strategy for assuring the financial and administrative capacity of state developmental disabilities and Medicaid agencies to address the needs of individuals with developmental disabilities during a national pandemic.

NASDDDS requests a meeting with appropriate Disabled and Elderly Health Programs Group staff to identify a plan for further action in response to the issues and recommendations described above.

