ASK THE DOCTOR

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PUBLIC SYSTEMS SUPPORTS FOR PEOPLE WITH INTELLECTUAL DISABILITY AND MENTAL HEALTH NEEDS IN THE UNITED STATES

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Since the mid 1980s there have been a number of publications and policy papers with regard to the need for a comprehensive service system to support individuals with intellectual disabilities and behavioral health needs. In spite of the expanded knowledge of this population and its service needs, the results have been mixed in the United States. In some states there is a lack of a service infrastructure equipped to provide effective services over time. It is time to take a closer look at the Home and Community Based Waiver under the national Medicaid program to assist in the development of a more effective community based support system throughout the United States.
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Q. Dr. Beasley, how are we doing from a national perspective in meeting the needs of individuals with co-occurring disorders?

A. There have been model programs developed in a number of locales throughout the United States. going back to the early 1980s.[2,3,4,5] In most cases, however, these program models rarely translated to consistent public policy initiatives. In some cases, only those who lived in the region where the model took place benefitted from the resource. In many cases, model programs did not sustain the funding needed because they were not part of the state infrastructure. Many programs with proven track records and once believed to be national models no longer exist as a result. The exceptions came, for the most part, when initiatives or program models evolved into statewide plans in a relatively short period of time.[6]

Q. How are resources attained in states that have moved forward with a more comprehensive strategy?

A. For individuals with intellectual disabilities, in addition to legislated dollars for program initiatives, an important element to promote sustainability over time in some states has been the use of the Medicaid State Waiver Program. Under HCBS Waiver Section 1915, states are allowed to offer a variety of services and the number of services has no limitations. Although traditional medical services can be provided (including mental health services), non-medical services can also be developed under the waiver. This includes respite, specialized case management, crisis support services and other services usually described in what most view as essential elements of an effective service system for individuals with co-occuring disorders. The services should not be designed to replicate other services under Medicaid, but they can be used quite effectively to enhance and support the existing service delivery system.

Q. Has the waiver been used successfully anywhere to date?

A. Some states have developed home and community based waivers and state mental health plans to include enhanced services and services to fill service gaps with the expressed goal of preventing long term placements in state hospitals and the frequent use of community emergency services. Massachusetts, Vermont and Washington are among those states that have state wide practices to support individuals with co-occurring needs. In both Massachusetts and Vermont, although their waivers are very different from each other, waivers cover both the potential

and current need for mental health related enhancements and supports as part of waiver services to all who are included under the waiver. The state of Tennessee is now exploring ways to incorporate their demonstration project, TNSTART (an acronym for Tennessee, Systemic, Therapeutic, Assessment, Respite and Treatment) into their Medicaid waiver. The START program was acknowledged in the 2002 Surgeon General's report as a national model. START originated in Massachusetts, and is funded as a clinical team through their state's Medicaid waiver.[1,2,6]

Q. What do these service systems look like?

A. Statewide waiver services often include respite and a crisis and consultation team. The goal is to enhance services provided by the state mental health plan whenever possible through linkages to outpatient mental health services, inpatient units, services, day treatment, day services and other respite resources or generic community emergency mental health services. Community education and access to services along with the development of affiliations and linkages with existing services help to fill the gaps in the service delivery system. In order to access appropriate mental health services and to facilitate a coordinated service approach and foster service linkages, waiver services in some states provide a number of opportunities for consultation, education and individualized treatment planning. The services include cross systems crisis prevention and intervention, on call emergency supports, planned respite for families and emergency respite services used for step down from hospitals and/or hospital diversion.[3,4,5]

Q. What about individuals who live with their families and are dependent on them for care?

A. Outreach services to families who support individuals at risk at home are also included. This helps reduce the risk of emergency out of home placements and hospitalizations. Families could access a respite care worker for help or be able to schedule a "break" from the individual to take a vacation through a respite care center. This also helps to provide support for individuals on residential placement waiting lists.

Q. Why are respite services so important?

A. Crisis and planned respite services decrease the need for inpatient hospitalization and long term care in congregate settings such as state facilities and hospitals. Crisis respite can be used to enhance services already provided by the state mental health plan. Services can focus on individuals with complex needs who cannot benefit from other mental health respite or diversion services offered in the community. For example, an individual with autism and bipolar disorder may have acute episodes that could be handled well in a crisis respite center. Planned respite services for individuals living with their families but who are not able to benefit from other forms of respite due to their needs should also be made available. It is strongly recommended that crisis and planned respite services be offered through a non-unit contract in order to insure availability when needed for the first 18 months of start-up, then reimbursed as a unit contract in future years. In locations where this has not occurred, respite services were unable to sustain the financial burden associated with a unit contract while in early development.

Q. Can general outpatient services be tailored specifically to people with intellectual disability with Medicaid waiver support?

A. Enhancements that help outpatient providers can effectively support individuals with developmental disabilities and mental health needs. This includes capacity for cross systems and interdisciplinary collaboration—working with state mental health agencies and developmental disability agencies together. In the state of Washington, for example, psychiatric services for medication evaluation and monitoring under psychiatric consultation services was developed to allow psychiatrists the extra time needed to provide effective treatment.

Q. What will help to motivate some states to move forward with improving their state plan to address this issue?

A. State governments must be strongly encouraged to recognize the need for enhancements and specialized services to effectively serve individuals with intellectual disabilities. States should be reminded of this important resource. Advocates should focus on how to assist in the attainment of resources so that the need for resources can become less of a barrier for states to move forward. This includes added financial incentives through federal matching funds.

Q. How can a state government get started?

A. Not all states are equipped to begin with a policy to provide services across the state all at once or to develop services new to the state without the use of pilot programs. Pilots can be developed under the Medicaid Waiver. Section 1915(c) of the Social Security Act permits the Secretary of Health and Human Services to limit the development and operation of waiver services to specified geographic areas of the state. Therefore, program models could be developed as part of the waiver without a statewide commitment at onset. However, as the need statewide becomes evident, the waiver service should be expanded over time to cover all waiver recipients who need them.

There is a very user friendly website with a great deal of information about the waiver and how it can be used (see Resources). In addition, all state waivers are public documents so that it is relatively easy to access a variety of waiver descriptions. I have found in researching this issue that most state offices are willing to help in providing information and technical assistance.

Q. Dr. Beasley, how are these services consistent with new federal initiatives such as "no wrong door"?

A. The use of the safety net and enhancements just described are consistent with a policy of "no wrong door" because all individuals who need services can access them. Under the waiver, the services will be available on an as needed basis without the need to navigate a very complex service system and fall through its gaps. Since there is a high prevalence of mental health problems in the intellectual disability population with a wide range of needs, the most effective plan is one which allows all Medicaid waiver recipients access as needed through a capitated rate to cover all services. What is needed is clearer support and guidance from the federal government to promote these initiatives with incentives to incorporate the mental health needs of individuals with co-occurring mental health issues and intellectual disability into both the state mental health plan and the Intellectual Disability/Developmental Disability Home and Community Based Medicaid waiver.

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Resources: More information can be found in the CMS website www.cms.hhs.gov.

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