

Using Data to Make Sure Needed Services Are Funded

a report prepared by Maine's Work Group for Community-Based Living

The *Olmstead* decision requires each state to end “unnecessary institutionalization.” To respond to the *Olmstead* decision, and to go beyond and achieve the broader vision of true integration, home and community based services should be adequately funded. As priorities, we recommend that the State:

- collect better data to measure the needs, unmet need and the anticipated needs of persons with disabilities;
- develop and publish measures that identify the needs, unmet needs, and anticipated needs of persons with disabilities; and
- use better data to develop budget requests and provide sufficient funding to meet anticipated needs.

Findings

The Challenge. The *Olmstead* decision requires that people move out of institutions if they should not and do not want to be there, but inadequate services can prevent people from moving out of institutions. For example, a person in a psychiatric facility may be able to live in the community but the specialized supports necessary to make that possible may not be available. Some persons living in Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) could also be served in less restrictive settings, but because of a shortage of alternative appropriate settings, they may be unable to move.

The *Olmstead* decision is also interpreted to require that people not go into institutions in the first place, if adequate home- and community-based services could have prevented it. We know that inadequate services can cause people to end up in institutions. Examples include the following: An elder might end up in a nursing facility because in-home and community services are inadequate or a parent might be forced to place a child with autism in an institution because available community supports are insufficient. For youths, poor transitioning to inadequate adult services can also lead to dire consequences, including incarceration, institutionalization, poor health, and even death. A young adult might end up in the Augusta Mental Health Institute (AMHI) or be arrested for a crime and end up in jail because he or she needs community mental health services or substance abuse services and cannot get them. A mother might put her daughter in a homeless shelter because she cannot take care of her by herself and she knows that people in homeless shelters will move up the waiting list for services more quickly. After graduation, a young man on a waiting list for job supports becomes bored and develops behavioral problems, causing his parents to fear that he will no longer be able to live in the community.

Preventing institutionalization is not enough. To achieve the vision of the ADA (Americans with Disabilities Act), the barriers to participating in the community also must be eliminated. For example, adequate services and supports can mean the difference between going to school or

work, the grocery store, church, or a baseball game, etc., or living in isolation or on the street. The State has not achieved the vision of the ADA unless it provides the supports necessary to make full and sustainable community participation a possibility and a choice.

To determine whether it is meeting the challenge of the ADA and *Olmstead*, Maine needs to know where people are living, whether they live there by choice, and, if not by choice, what barriers prevent them from moving; Maine needs to understand how effectively existing services are meeting the needs of people with disabilities and where needs are unmet; and Maine needs to anticipate the needs of persons with disabilities, as they transition from one life stage to another.

To anticipate needs, the State needs to have information about those people who are about to transition to the next step in their lives. Transition involves the movement from one level or type of service to another. Transition might occur at different life stages. For example, a child with a disability will move from an early intervention and preschool program into school, and later from school to work and into the community. As a person transitions into the later stages of life, he or she will transition to a higher level of service needs, possibly moving from home to congregate housing or to some other type of assisted living setting. Transition might occur across settings. A person might transition from a hospital to a rehabilitation facility to home, from a psychiatric facility to transitional housing to home, or from a jail or prison back to the community. Transitions across settings mean that service needs will change, with varying impact on the State's budget.

The transition from childhood to adulthood is a good example of the change in service needs as well as the budget impact to the State that the State needs to anticipate. This transition requires state planning on three fronts: replacement of federal and local school funding for services; providing the different services needed by adults; and providing transition services.

While many find fault with the adequacy and availability of children's services, the transition to adult services often means a dramatic decline in the availability of services. The Individuals with Disabilities Education Act (IDEA) creates an entitlement for special education and related services if the services are necessary to ensure a free appropriate public education for a child with a disability. Funding for these services is shared by the federal government (10%), the state government (51 %), and local schools (39 %). Once a child exits the school system, special education services are no longer available. The State pays for those needed services not covered by MaineCare for individuals 21 and above. MaineCare is also an entitlement program for those who qualify financially, entitling an eligible individual to covered services. However, MaineCare-covered services are less generous for adults than children. For example, a child receiving children's services funded under MaineCare and special education is "entitled" to receive those services as long as the child is eligible. Lack of available funds cannot be used as a reason for not delivering the specific service which is necessary. The net that is cast in the early years of life becomes filled with holes as the young person enters the adult service delivery system. These young people find out that eligibility for certain services is limited, there are fewer types of services available. Many people go from receiving services to being denied services or put on waiting lists.

The State also needs to anticipate the impact on the type of services needed, since an adult's needs are different from a child's. An adult needs to make decisions about how to find a job, whether to get more education, where to live, how to travel about, how to develop a social life, and which health care providers to use. Often these decisions are already made for a person when the ability to make choices depends on the availability of services to support those choices. For example, a person's choice of where to live will depend on whether there is accessible, affordable housing, with supports if necessary; employment options are limited by the availability of job supports and access to transportation; the ability to develop friendships and relationships within a community is impacted by housing and transportation options. To provide the same kind of choice available to the general population, the State needs to make sure that the services are available for persons with disabilities to make choice possible.

The State also needs to anticipate the need for transition services. Transition services are needed to make sure the planning aspects of transition are comprehensive and conducted well in advance of the actual move, so that individuals with disabilities and their families receive the necessary support to make the move successful. Transition services are diverse and include but are not limited to discharge planning, case management, technology-related services, in-service training for educational personnel, job coaches, transportation training, housing availability, supported living services and attendant care.

The Role of Data in Determining the Budget. At present, the State does not have adequate data to measure the needs, anticipated needs and unmet needs of persons with disabilities. Within individual departments there are limited data available for identifying the needs of persons with disabilities. A program might collect information about whether a person needs a service offered by that program, but may not have a complete picture of the range of needs that individual or family might have. Most programs conduct an assessment of need and develop a care plan that focuses primarily on needs related to the services offered by the program. Accordingly, any data collected will be limited to the needs related to those programs.

In addition, the State is unable to link the data across programs. That is, the State cannot put together a more complete picture of the people it serves by linking the information collected across programs. Without linked data, the State is unable to produce an accurate count of how many people are receiving services, how many people are receiving services from more than one department, or how many people are waiting for services. Without a more complete picture of the needs that people have, the State is limited in its ability to respond to their needs or its ability to more effectively target its resources.

To develop a more comprehensive budget, the State also needs to collect and use data on unmet need. Given the status of the present information systems, it is impossible to determine the level of unmet need. Information on who is waiting for services is not systematically and consistently collected across programs. Collecting waiting list data and making sure it is accurate and up to date is a big challenge. There is no consistent definition for what should be considered a waiting list. Waiting list information might be collected by a state agency or a provider. The waiting list might be to get into a program or for a service. A waiting list might collect information on all people who requested a service whether or not the need for the service has been recognized by the State or the provider. A person might have needs acknowledged by the State or a provider,

but no one has been identified to provide the needed service or there is a wait for an appointment with a specific provider. Collecting information on unmet needs requires providers and the State to regularly update the information, which means a person responsible for keeping up with waiting list information needs to check in with the people whose names are on the list.

The State also has limited information about the anticipated needs of persons with disabilities. For children transitioning to adulthood, the State does collect anticipated needs data, but the data are limited. The DOE collects and publishes anticipated needs for children in special education programs. The quality of the data is limited by the lack of consistency in the way it is collected. There is no training on how to complete the reports properly or why they need to be completed properly. In addition, some believe schools do not take the reporting requirement seriously since the data is not used in the funding formula to meet the identified needs of the schools. The data are also limited because children in special education are only a subset of the children with disabilities who might need services as adults.¹

State agencies are already required by law to consider the anticipated needs data collected by the DOE when developing their budgets.² We support this significant requirement and recommend it be expanded and enforced by the Legislature. We recommend the Governor and state agencies hold themselves accountable for complying. The State's budget continues to fall far short of adequately meeting the needs of people with disabilities. We know that there are waiting lists for vocational rehabilitation services, respite care, case management and other services. We know from the focus groups that other services are inadequate, including housing and transportation services. (See the AFFORDABLE, APPROPRIATE, INTEGRATED HOUSING and TRANSPORTATION ISSUES AND PROBLEMS reports for a discussion of those services.) (See FLEXIBLE FUNDING TO PROMOTE INTEGRATED SERVICES AND CHOICE AND CONTROL for a discussion of needed infrastructure.)

Recommendations

Some interpret the ADA and the *Olmstead* decision to alter how much discretion the State has about how much or whether to fund state-funded services. To ensure that it is meeting the challenge of the *Olmstead* decision and the ADA, the State should make sure that it knows where it is meeting the requirements of *Olmstead* and where it is not, that it knows what services are needed for improving its performance, and that it anticipates the needs of people in the future. State agencies should also use this data when preparing and modifying their budget requests.

¹ Relying on special education data underestimates the population of children with disabilities and the needs of students exiting the public school systems. Special education programs include only students who have been determined to have a disability (falling within one of 13 categories of disability) requiring special education and supportive services, as defined under Department of Education rules. Not all children with disabilities are determined to require special education services, therefore, DOE's data on anticipated needs do not include data on children who have a disability but do not receive special education. Many of these children are in school, including children protected under Section 504 of the federal Rehabilitation Act of 1973. In addition, we know that some children with disabilities may be home schooled, are expelled from school, dropout, or end up in a correctional facility. No standardized data are collected on the anticipated needs of children who are not in special education.

² Title 20-A, Maine Revised Statutes Annotated, Section 7258(3).

To do that, we make the following recommendations:

Defining “Need.” We recommend that the State do a better job of defining “need” for services and include in its consideration the needs of people who are not now but could be beneficiaries of public services. The definition should be broadly defined to encompass the range of services necessary to support sustained community living and participation, even if the need for services goes beyond those services traditionally offered by the State. Ideally, the need for services would be identified through a single comprehensive, needs driven planning process, where the care plan would address the entire range of services an individual needed rather than the need for services offered by a single funding stream.³ Data from the comprehensive plan developed by the individual or family in collaboration with the independent facilitator should be collected and analyzed to identify the full range of needs of the individual. (See FLEXIBLE FUNDING TO PROMOTE INTEGRATED SERVICES AND CHOICE AND CONTROL for a discussion of comprehensive planning.)

Settings and Preferences. We recommend that the State have data about where the people it is serving reside. For persons in institutions or residential facilities, the State should know what each individual’s needs are, the barriers to moving to a more integrated setting, and where the individual prefers to live. For individual’s residing in an institution or residential facility for an extended period of time, the State also should make sure that each individual’s needs and preferences are re-visited periodically, since that person’s condition and opinions may change with time.

Linked Data. We recommend that the State make sure that it understands how its services are working across programs. It should link data across programs to determine:

- who the State serves (including basic characteristics like age, gender, etc);
- the strengths, preferences and needs of the people the State serves;
- the services received by the people the State serves;
- which departments are serving whom;
- which providers are serving whom;
- the setting in which people receiving services reside;
- who is being served in a restricted setting and is eligible to receive the same type or level of services in more integrated settings;
- the resources the State has available for providing services;
- how much it costs to serve each person; and
- barriers to access.

³ It should be noted that a “comprehensive plan” does not displace or replace the individual plans otherwise legally required under individual programs.

Anticipated Needs Data. We recommend that the State collect better anticipated-needs data. For children, an important first step would be collecting data on children with disabilities who are not in special education, including the “Section 504 kids,” other children in school or in other settings, including prisons, homeless shelters, on the street, children who are home schooled, and children who drop out or who have been expelled. The State should take into account the needs of people who are eligible for special education and for whom data is not currently collected (e.g., are in adult correctional facilities).

In addition, the State should anticipate needs by analyzing trends that influence the need for services, including aging, accidents and other factors that influence the services needed, such as advances in medical technology that save individuals that otherwise might not have lived.

Waiting List Data. We recommend the State collect better data on unmet need. In addition, standards should be set for collecting consistent data on waiting lists for services. We recommend the State collect data on:

- the type of waiting list (*i.e.*, whether a person is waiting to get into a program or for a particular service);
- where a person is in the process of obtaining services (*e.g.*, whether a person needs have been assessed, and a provider identified);
- the type of service for which a person is waiting;
- the reason for the wait (*e.g.*, no funding for services, no provider available, or identified provider has limited availability);
- the provider or provider type for which a person is waiting;
- when the person’s name was put on the waiting list; and
- when the waiting list was last updated. The State should explore automating waiting lists and waiting list tracking so that waiting lists can be regularly updated.

We also recommend that the State link data across programs to develop a more comprehensive understanding of ways the State can more effectively target its resources.

Other Measures of Unmet Need. The State’s quality management system should develop measurements and tools for determining unmet need, other than tracking waiting lists. In the absence of waiting list data, the State can take other steps to measure unmet need. State quality management programs can use claims data, including Medicaid claims data to monitor unmet need. For example, the State can use Medicaid claims data to determine whether people are waiting too long for medication review by a psychiatrist. By establishing a benchmark for the timely review, the State can monitor how many people are waiting too long to see a psychiatrist who can provide that service. By developing these and other benchmarks and monitoring services received against these benchmarks, the State has one tool for getting around the absence of waiting list data.

A pilot study might be considered that would allow the State to collect unmet needs based on individual care plans. In this model, one care plan for the individual is generated that identifies a comprehensive list of identified needs. These needs would be included regardless of availability or the funding source that would typically be responsible for reimbursement. A primary case manager would be assigned to monitor the individual's care plan. This case manager could collect information on the adequacy of services that were being delivered, collect data on what needs were not being met, and document why the need was not met (no service available, no service provider available, too far to travel, no funding available, etc.). The data that is generated should then be used for budget requests, program development, and quality improvement.

Budget Requests. Finally, we recommend that state agencies comply with the statutory requirement that anticipated needs be used to build budget requests for the Legislature. We believe this requirement should also extend to data on needs, anticipated needs and unmet need for all programs and populations. Non-identifying data on needs, anticipated need and unmet need should be available to the public, so that the public can ensure that the State is reflecting these data in their budget requests.