Coordination of Services

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

It is recommended that the State address the issue of coordination in a system for delivering services to persons with disabilities. The system appears to be fragmented between many different departments, bureaus, agencies, and contract providers. We recommend that the State of Maine:

- create a system for **assessing and reviewing** the coordination of disability-related services;
- create an **integrated statewide information and referral system** for disability-related services;
- integrate **access to services** so that a consumer can be linked to all appropriate services through any entry point into the service system; and
- expand **eligibility for service coordination** (*e.g.*, case management under MaineCare) to cover a broader array of disabilities.

Introduction: Outlining the Need

Many state departments have missions directly related to meeting the needs of persons with disabilities. For example, the Department of Behavioral and Developmental Services (BDS) was created expressly to serve adults with serious mental illness, adults with mental retardation or autism, persons with addiction disorders, as well as children with developmental delay, serious emotional disability, mental retardation or autism. Other departments, whose missions are not directly related to persons with disabilities, can have a significant impact on the lives of persons with disabilities. For example, the Department of Corrections (DOC), Maine State Housing Authority (MSHA), the Department of Public Safety, and the Department of Transportation (DOT) were created for purposes unrelated to the needs of persons with disabilities, yet each of those departments can directly impact the ability of a person with disabilities to receive needed services, or participate fully in life activities such as work, school and family. A state agency can impact the lives of persons with disabilities by determining the accessibility of state resources. For example, the Department of Conservation, the Department of Fisheries and Wildlife, or the Bureau and Office of Tourism can influence the accessibility of recreational resources for persons with disabilities.

The Work Group brings together five of these departments, including the:

- Department of Behavioral and Developmental Services (BDS);
- Department of Corrections (DOC);
- Department of Education (DOE);
- Department of Human Services (DHS); and
- Department of Labor (DOL).

While each of these departments might have a different mission, many serve some of the same people and may even offer some of the same services. The possibilities for overlap abound. An elder with a mental illness might be eligible for services through both the Bureau of Elder and Adult Services (BEAS) within DHS, and through BDS. Or an adult with mental retardation might be receiving MaineCare-funded services administered by BDS while also receiving job support through DOL. A child receiving special education services within the domain of the DOE might be residing in a homeless shelter paid for by the BCFS receiving MaineCare-funded services administered through BDS, while in the protective custody of the Bureau of Child and Family Services. Or an adolescent might be transitioning to adult services offered through different departments and agencies. The DOC touches the lives of persons with disabilities, children and adults, when a court sentences an individual with a disability to a prison term or probation. Correctional facilities tend to include a high proportion of adults and youths with mental illness, addiction disorder, mental retardation or a learning disability. See THE ROLE OF STATE GOVERNMENT in WHAT WE HAVE NOW for a discussion of the different roles that the State fills and the different functions of the departments participating in the Work Group.

With each consumer potentially receiving services from multiple departments, the need for inter-departmental coordination is apparent. From the perspective of a person attempting to access services, the services needed are often spread across multiple departments. Without a central resource to explain what services are available and where to find them, it is up to the individual or family in need of services to track down what is offered. Even with that information, accessing those services often means multiple application processes, usually in different locations. Once services are accessed, a person can be overwhelmed with providers, all with different roles and different service requirements. Consumers, unaware that they are part of a multi-layered system, can become confused and frustrated when they try to navigate across departmental boundaries to address grievances and resolve conflicts.

Although there are many efforts to coordinate services, lack of coordination can undermine the State's attempts to manage limited resources as effectively as possible. Through the prism of its own program, each department has a limited view of the broad scope of services provided across all departments. Each department can only evaluate its own services and, even then, might not have the information it needs to determine whether its services are truly effective or how they might be improved. With only fragmented information about the services provided, Maine is unable to make sure that it is providing services to persons with disabilities in the most integrated and efficient setting appropriate to their needs and preferences.

Recognizing the need for coordination, Maine has already made a number of efforts to do so. For example, BDS employees are assigned to work within the juvenile community corrections systems and BDS provides substance abuse and mental health services within correctional facilities. Some schools work closely with the Bureau of Rehabilitation Services (BRS) in the DOL to provide transition services for adolescents with disabilities looking to future opportunities for employment. Local case resolution councils attempt to resolve issues of treatment, services and community supports for people with complex service plans requiring inter-departmental coordination.

While the State has, in some instances, identified the need for interdepartmental coordination, effecting full coordination is a significant challenge. First, the different missions of departments

and their bureaus can mean that the departments have very different, not necessarily compatible objectives. With these different missions come different approaches and different priorities. For example, some agencies will have statutory responsibility for ensuring the safety of those they serve. Others will be responsible for maximizing independence. Sometimes these different objectives can create an inconsistent approach to using services and may even be in conflict. For instance, an adult with mental illness needing protective services (for safety) from BEAS may also be receiving services from a community mental health agency which emphasizes choice and independent judgment.

Second, these departments and their bureaus have different, sometimes uncoordinated or inconsistent, limitations and restrictions on their activities and roles, in some cases these limitations are imposed by federal law. The State receives federal funding for many different state-administered programs. Each of these federal programs will have its own restrictions, not necessarily coordinated with those of other federal programs. For example, different programs will target different population groups by establishing eligibility criteria for services. When the federal government fails to coordinate the services provided through the different programs, the resulting state programs may leave gaps, as sometimes happens when the state participates in various Medicaid options, with some people falling through the cracks, and services being either nonexistent or duplicative.

Third, even after eliminating the barriers related to mission and statutory and funding restrictions, the departments do not have the necessary infrastructure for coordinating efforts. No one has responsibility for collecting, managing, and maintaining current information about programs across departments, including eligibility, providers, and covered services. No one has responsibility for coordinating or unifying the State's efforts to link data so that the State can find out whom it is serving. Often, when responsibility is assigned, the additional resources required are lacking. Many efforts at inter-departmental coordination are added responsibilities absorbed by existing staff into their regular workload, without funding for developing or implementing needed changes.

All of these barriers have combined to create a challenge that can be overcome with improved statewide coordination of these departmental services.

Assessing and Reviewing the Coordination of Services

Inter-departmental coordination is recommended in order to maximize the effective use of the State's resources. For example, to evaluate its own performance, a department might need information from another agency. BDS might be interested in identifying opportunities for improving the well-being of the adolescents it serves by finding out how many are staying in school, how many are linked to employment resources, or how many end up in a correctional facility. Also, the State might want to look at the use of resources across departments to minimize unnecessary duplication of effort or to analyze gaps in services. In the context of the *Olmstead* decision, the State must ensure that its resources are used most effectively across departments so that services are delivered in the most integrated setting appropriate. The State should evaluate both whether services are delivered in the most integrated setting and whether a

lack of coordination itself has caused unnecessary segregation in whatever setting individuals with disabilities are served.

Part of the problem is vocabulary. Again driven by the different missions and governing statutes and funding streams, each agency has different terminology and definitions for key terms. Most agencies do not have a common definition of "disability," let alone a shared approach to categorizing types of disability. Each program will also define "service" differently. For some departments, the difference in definition might relate to different restrictions on scope, duration, type of provider, etc. In other cases, the difference might relate to the difference in mission and function. There is no common definition of the "least restrictive" or "most integrated" setting appropriate for services. In the school setting, "least restrictive" describes a classroom setting and is determined based on educational needs. The DOC determines whether a setting within a correctional facility is unnecessarily restrictive based on a different set of considerations, including an assessment of treatment needs, resources, and security risk. For BEAS or BDS, "least restrictive" or "most integrated" may include clinical information as well as consumer choice. Each program might also define "community" differently, with, for example, some including a residential care facility within this category, and others not. There is not necessarily a shared understanding of what is meant by the State's role in supporting "community integration." Is the State's job done when a person is living at home? Or does the State play a role in making sure that an individual or family has access to supportive services that permit full participation in community life.

With different definitions, there is no common standard for measuring the effectiveness of services across departments. For example, with respect to the *Olmstead* decision, there is no common measure of whether an individual with a disability is subjected to an unnecessary level of restrictiveness either in the four-walls sense, or as a result of isolation, or because of the lack of community support infrastructure. And there is no common measure for determining whether waiting lists are fairly administered, and whether people move off waiting lists at a reasonable pace. Standard definitions or measures for disability, setting, restrictive or "most integrated setting," services, and other terms are necessary to permit cross-agency comparison or analysis. Having common measures would create a framework for comparing populations served, settings and services across agencies. The State could then create an inventory of services provided throughout state agencies and develop the means to assess the effectiveness of those services.

Even if the State could develop common measures, individual departments currently do not have access to the data that would allow state agencies to use these measures. There is no comprehensive, unduplicated count of the persons served, the services they are receiving or the departments and community agencies providing those services. As outlined in the *Roadmap for Data System Integration*[1], data integration requires an investment in infrastructure and an investment in developing the capacity to maintain and use integrated data on an ongoing basis. Developing the capacity to integrate data would allow the State, for the first time, to create an unduplicated count of the number of persons with disabilities receiving state-funded and state-authorized services in Maine, as well as reliable measures of the types and volume of services being provided. (However the State may still not define it the same across departments.)

[1] Tan, D. and Griffin, E. (2001) *Roadmap for Data System Integration*, Edmund S. Muskie School of Public Service: Portland, ME.

To develop the capacity to evaluate effectiveness across programs, we recommend that Maine develop:

- a common vocabulary for key terms;
- a common set of measures for assessing the effectiveness of the State's services, including measures of whether services are provided in the most integrated setting, whether waiting lists are fairly administered, and whether people move off waiting lists at a reasonable pace; and
- the capacity to integrate data, as well as the capacity to maintain the infrastructure to use and evaluate integrated data. This development process should be sensitive to concerns about the security of integrated data and the protection of confidential information.

Creating Statewide Integrated Information and Referral System

We recommend that Maine create a statewide, integrated information and referral (I&R) system that covers all disability-related services. Information about services could be made available through a variety of methods including an interactive searchable website, by phone, by TTY, or in-person at a one-stop disability services intake office (see below), or through a person's existing service coordinator.

A unified I&R system would allow consumers to find information about needed services and service eligibility criteria in one place. Such a system would not only save time for consumers, their families, and their existing service coordinators or providers, but also would reduce the chances of failing to learn about appropriate but hard-to-find services. Finally, such a system would strengthen already-existing, privately developed guides to services.

The new system could be built by using commonly available, off-the-shelf I&R database software and modeling it after existing regional and statewide unified I&R systems like those in Florida, West Virginia or the Research Triangle region of North Carolina. A number of resource directories have already been developed in Maine, so some of the initial data gathering has already been done. However, all departments would need to commit resources to keep information about their own programs and services accurate, comprehensive and up to date. The different departments would also need to continue working together to develop a consistent format for types of data to be entered, for accessible website design, and for links to other Internet sites.

Not all consumers and their families will be able to access a computer or the web, so the State will need to provide other means of access to the I&R system. The State could address this by establishing a statewide toll-free telephone hotline with TTY access. In other states, including Indiana, 211 has become a new standard phone number for accessing I&R services. The State could also encourage and train service coordinators and other professionals both within and outside of State government to use the I&R database to provide information to consumers face-to-face.

A well-designed I&R system can also help to identify and document unmet service needs by type of service and geographic area. Both the web and phone-based systems should be designed to record, by geographic region, the volume of requests for both types of services, those that are available and those that are not available.

We recommend the State take these first steps toward building an integrated Information and Referral system.

- Research other states' I&R systems and methods.
- Research/inventory what is already available on the State of Maine website and individual State agency websites, as well as other efforts to coordinate information and referral, such as the 211 phone access system.
- Become involved in the DHS effort to revise its website. Some initial changes could be included to enhance the information to be included on the site and input can be provided for the long-term strategy.
- Research and integrate the available information in Maine's existing disability-related resource directories.
- Develop phone-based and other alternative methods for providing the information to consumers and providers.
- Develop an education/outreach campaign to make sure consumers and providers know where they can obtain information about services and eligibility for services.
- Explore ways for consumers and providers to have up-to-date information about service availability (vacancies and wait lists) by service type and disability category.

The State should also develop outcome measures to determine how well the new system is working and whether it needs revision or improvement. Measures might include:

- conducting a follow-up survey of a sample of consumers to determine how many I&R calls or visits resulted in useful referrals, using a method that will encourage consumers to provide truthful responses (*e.g.*, anonymous surveys conducted by independent third parties); and
- surveying of service provider agencies to measure the number of I&R referrals resulting in appropriate or inappropriate referrals.

No Wrong Door

In addition to providing integrated access to information and referral, we recommend that the State integrate access to services so that consumers can obtain information and be linked with all needed services no matter where they enter the service system, streamlining the application process wherever possible. This recommendation is made recognizing that there are many challenges to integrating access to services:

- Information systems need to be integrated in order to minimize duplicative steps in the application process.
- It will take a significant investment of resources to give providers and state agency staff the training they need in order to link people with services across programs. Maintaining that expertise, as well as keeping that training up- to- date will also require an investment of resources.
- Developing an integrated application form and process is by itself challenging, given the complexity of different program requirements. Keeping the application form and process up-to-date will also be difficult, since rules and requirements change.

Access to services would be offered at three levels. The first level would be a self-directed model using a "touch screen" device in which a consumer could enter basic information based on need, and receive service options. Additional information, such as eligibility criteria, service availability, service locations, could be accessed in the same manner. These touch screens would be available at any community and institutional provider that has a contract with the State, in any state regional office, in Career Centers, or through correctional caseworkers and probation officers.

The second level would involve very well informed staff who could offer additional information about services and the processes and application procedures. Staff would be cross-trained so that they could help consumers identify the range of needed services and aid in linking them to those services.

The third level would integrate the application process to the degree feasible, minimizing as much as possible the need to repeat steps at multiple entry points. As a first step toward integrating the application process, we recommend the State explore the feasibility of developing a generic application module that contains a core set of information required across multiple agencies. With the consumer's permission, this core information (*e.g.*, name, address, financial eligibility information, etc.) would be collected once and then shared with other departments and providers to determine eligibility for other services. To implement this integrated process, the State would need to integrate information systems, permitting information to be shared across departments and providers.

We recommend the State also explore the feasibility of further degrees of integration, allowing consumers to actually apply for services using a generic cross-agency electronic application form, which would reflect a composite of the application requirements for all available services. The consumer would complete the sections of the form that applied to their needs and situation instead of repeating the same information on multiple separate application forms. Ideally, this application process could be completed with or without the assistance of the information support staff.

In integrating the application process, there needs to be a balance between increased access to options and information versus increased layers of intake and process that come between consumers and the services they need. If people know what they want, they should be able to

jump directly to those services without going through a multiple-step, more comprehensive process.

The State would need to take the lead in coordinating these efforts of integrating information about programs, cross-training staff and providers, and the integrating the application process. At the start the various departments would need to enter into memoranda of understanding (MOUs) that describe how they would provide the necessary information and training about their programs to staff and providers on a regular basis.

The departments would also need to maintain the integrated information, notifying departments and providers of any changes to the service offerings or eligibility requirements. A secure and confidential computer information system would need to be designed to automate the delivery of the appropriate information about each consumer to those departments and agencies that will be delivering the actual services. To the degree possible, the data integration effort would minimize the need for departmental updates by providing integrated computerized information.

To implement these recommendations successfully, we recommend the State invest in and maintain the resources and equipment necessary for sustaining an integrated I&R system. We also recommend that the State build protections into the integrated application process to make sure that people have control over sharing their personal information.

Integrating Access to Information and Services

Fragmented programs can mean that it is up to the individual or family in need of services to find out what services are available and how to access them. Finding out about one program does not mean that a person automatically is linked to all other services. Sometimes finding out about available services can be more a matter of luck (*e.g.*, saying the right word to the right person) than the result of a properly functioning information and referral system.

Information regarding the availability of services and eligibility for coverage of services is located in many different locations across the state. Persons seeking information about the availability of existing services and service eligibility requirements often need to contact many different offices and agencies, if they know where to look to find them.

While most, if not all, of the eligibility information is contained in policy manuals, it is not always accessible to individuals. While there are various resource directories around the state, service availability is most often determined by contacting individual service providers. Some existing state agency websites offer information about services, but not always in an accessible or complete manner.

After identifying programs and services, people need to apply for them. In Maine, that means finding one's way through a confusing maze of different information sources and different offices and locations to apply for the different community services required.

Most services administered by state agencies have their own unique point of entry for information, their own application forms and procedures, and their own unique eligibility

criteria. These "entry points" are traditionally defined not by the service itself but rather by the funding source, both state and federal. This means that people who need more than one service have to find and contact different offices in different locations, repeat much of the same information on different application forms, and navigate different application procedures at each place.

This system, designed for administrative convenience and accountability, is often very inconvenient or difficult for consumers who need information or access to the "service system." While the present multiple entry-point system may provide administrative efficiency for individual agencies, there is some question whether the duplication of effort across agencies makes the overall system administratively efficient. However, there is no question about the negative impact on consumers or that the resulting fragmentation prevents some consumers from receiving the proper mix of services best suited to their needs and abilities.

Expanding Eligibility for Service Coordination

Even after successfully accessing services, a person with complex needs may want help procuring and coordinating services from multiple providers. The service coordination function was created to meet this need.

For the purposes of this report, we use “service coordination” to mean the case management services offered under the MaineCare program’s Targeted Case Management services and by Community Support Workers.[2] Service coordination offers consumers information and assistance in accessing services and resolving problems. Service coordinators also help coordinate services across different bureaus and providers and coordinate services for consumers who have complex care needs. Service coordination is available to a wide range of consumers, at no cost to consumers or with a co-payment based on ability to pay.[3]

See HEALTH, MENTAL HEALTH AND SUPPORTIVE SERVICES for a description of the service coordination provided in Maine. Depending on the service or the population group served, the types of provider that can provide service coordination will vary. See Table 18 on p. 56 of WHAT WE HAVE NOW for types of service coordinators funded through MaineCare.

Service coordination is funded primarily by MaineCare, with limited state funding for some services, and is provided both by state agencies and community agencies under contract with the State. Coordination services are offered for targeted population groups. To access these services, consumers must meet the specific eligibility requirements for each of the various needs mentioned earlier, established by state agencies and agreed to by the Bureau of Medical Services

[2] DHS Rule 10-144 CMR, Chapter 101, MaineCare Benefits Manual, Chapter II, Sections 13 and 17.

[3] The MaineCare Benefits Manual defines "case management" as

> "…those services provided by a social services or health professional or other qualified staff, to identify the medical, social, educational and other needs of the eligible member, identify the services necessary to meet those needs, and facilitate access to those services. Case management consists of intake/assessment, plan of care development, coordination/advocacy, monitoring, and evaluation."[3]

DHS Rule 10-144 CMR, Chapter 101, MaineCare Benefits Manual, Chapter II, Sections 13.01.

(BMS) (in DHS), the State's Medicaid agency. (See Table 19 on p. 60 in WHAT WE HAVE NOW for a listing of selected categories of eligibility criteria for MaineCare's targeted case management services.) These targeted case management services are the product of the State's "Medicaid maximization" strategy. Under this strategy, Maine maximized the federal dollars paying for services by converting state-funded services to Medicaid services. Thus, coordination services offered by case workers for the BCFS or community support services offered by mental health clinics are funded through MaineCare, and draw down federal dollars to pay for two-thirds of the cost of those services. MaineCare's targeted case management services, then, are not a comprehensive array of coordination services. Instead it reflects the array of coordination services that were offered across state agencies and the associated collection of funding streams that pre-date Medicaid maximization. There may be others who need coordination services but who do not fit in one of the specified categories (*e.g.*, persons with brain injury) or do not meet the income eligibility criteria to qualify for MaineCare. There are several problems with the current system of service coordination services:

- Despite the wide range of providers, some people who could greatly benefit from service coordination, including persons with multiple sclerosis, cerebral palsy, severe arthritis, and persons transitioning from institutions, cannot access those services because they do not meet the very specific eligibility requirements.
- Many persons with disabilities, who are not MaineCare-eligible and who lack the appropriate private insurance, cannot afford service-coordination services.
- People with disabilities who employ their own personal in-home care providers have limited access to service-coordination services.
- For people with co-occurring (or multiple disabilities), case coordination services are inadequate and limited.
- Service coordinators that work for community agencies sometimes broker their own agency's services, which might not be what consumers want or need. For example, some residential services also provide service coordination and other services. People are sometimes afraid they risk losing their housing if they ask the service coordinator for a referral for psychiatric services from someone other than those offered by the facility.
- Many service coordinators could benefit from additional on-going training on independent living issues and better access to information on the services and resources available in the geographic areas they serve.
- Service coordinators could also benefit from additional on-going training and education in respecting confidentiality and in avoiding the tendency to substitute one's own judgment and preferences for that of the client. Ineffective service coordination could result in a person's condition deteriorating, leading to unnecessary institutionalization and causing both avoidable suffering for the individual and avoidable costs for the State.
- Service coordinators should only provide services consistent with their job descriptions and their qualifications. Often much of service coordinators' time is spent providing counseling for clients, which they are usually not trained to do. Likewise, therapists and counselors spend too much time providing service coordination because that service is not available and it's the more pressing practical need.

- Some geographic areas do not have enough service coordinators to meet the current need. While the intensity of need is taken into account when determining case loads, some service coordinators can have caseloads with the recommended number of consumers, but may be still overburdened by having too many cases that are difficult or complex. The average number of consumers served by each service coordinator for the following services is:

Service	Number of Consumers
Adult Mental Retardation Services	35
Children's Services, Level 1	25
Children's Services, Level 2	15 *(acuity factors)*
Adult Mental Health Services	35-40 *(acuity considerations exist)*[4]

Recommendations

We recommend the State take steps to improve service coordination and expand access to service coordination services. In particular, we recommend that the State:

- Research how service coordination is provided and funded in other states to identify new or recommended practice models and take action to ensure consistency with our beliefs.
- Make more training available on an ongoing basis for current providers of service coordination, to improve skills and update knowledge about regulations and resources.
- To the degree possible, ensure that service coordination is provided by independent providers who do not provide other direct services
- To the degree possible, ensure that service coordination providers are able to serve anyone, regardless of need or disability.
- Review federal and state policies and regulations to identify and recommend changes, cooperative agreements, and legislation needed to make the previous recommendation possible.
- Develop systems for monitoring and assuring quality and consumer satisfaction (especially regarding respect for consumer choice and confidentiality), and a plan for funding this function.
- Provide more public education/information about service coordination, especially if and when expanded models are developed.
- Support a variety of different types of service coordination models that are flexible enough to meet the particular needs and choices of individuals.

[4] Ratios supplied by Linda Jariz, Maine Department of Behavioral and Developmental Services, via an e-mail dated Jan. 24, 2002.