CHCS

Center for
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RESOURCE PAPER

Toward a Single Coherent Vision

Sustaining Interdepartmental Collaboration to Support Community Integration for Persons with Disabilities

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TABLE OF CONTENTS

Summary 1

Introduction 3

The Case for Collaboration 4

Specialization and Fragmentation in Maine 7

A Single Coherent Vision 9

Putting the Parts Together 13

Summary

Modeling automobile manufacture after uncoordinated human services illustrates the shortcomings of a delivery system without cohesion. Rather than selling a car fully assembled, it would be up to the customer to figure out which parts are needed, where to buy them, and how to put them together. There would be no overall design for the car and no quality management to make sure the parts fit or to determine how well the car was working. There would be no way to measure how much each car cost or to determine the most effective allocation of resources.

While the delivery of human services is considerably more complex than car manufacture, comparing the assembly of an automobile to coordinating the interdepartmental delivery and management of human services helps to illustrate the need for investing in collaboration. An automobile manufacturer sees bringing the parts of a car together and assembling them into an automobile as part of the series of steps required to produce a car. No one expects it to happen for free. Someone at Ford Motor Company is paid to know how the different parts are related and to have a plan for how they should come together. There are people paid to assemble the car; assembly is not something they try to find time for, in between their other responsibilities.

In contrast, the "assembly" of the disparate services provided by the state into a comprehensive human service system is seen as either an unnecessary step or something that should happen automatically, without additional resources. Interdepartmental coordination and collaboration might be a stated goal, but often departments are not given or do not make available the necessary resources to make it happen. As a result, the "specialization" within individual departments and bureaus results in "fragmentation." For a state, the cost of not collaborating means an inefficient use of resources and ineffective services. From the consumer perspective, lack of coordination means frustration, wasted time, and can sometimes lead to more dire medical consequences such as institutionalization or incarceration, poor health or death.

This Resource Paper is written in the wake of a two-year process of developing Maine's response to the *Olmstead* decision. The purpose of this document is to marry the resulting vision for coordination and consistency across department with a sustainable, collaborative governance structure that will incorporate that vision into the workings of Maine's state agencies. Other states facing the same scenario may benefit from Maine's work.

Recommendations

To create an environment and infrastructure to support sustainable interdepartmental collaboration, the following recommendations are made:

1. *Recognize the need for investing in collaboration.* If the state wants to coordinate services, the executive branch, the Legislature, and consumers have to see

collaboration as a necessary step in the process, requiring dedicated resources and investment.

2. *Charge interdepartmental cabinet with responsibility for addressing needs of persons with disabilities.* The cabinet would build on the foundation laid by the Maine Children's Cabinet and it would comprise at least six member departments:

   - Behavioral and Developmental Services (BDS)
   - Corrections (DOC)
   - Education (DOE)
   - Human Services (DHS)
   - Labor (DOL)
   - Public Safety

   Two other departments also could serve as full members or adjunct:

   - Transportation (DOT)
   - Maine State Housing Authority (MSHA)

   In addition to the original mission of the Children's Cabinet, this cabinet would have responsibility for promoting community integration for person with disabilities of all ages by ensuring that community services support living and participating in community life.

3. *Establish a dedicated staff position in the Governor's office to be liaison to cross-systems collaborative.* This person would assure that interdepartmental initiatives are recognized as priorities in the Governor's budget and legislative programs.

4. *Partner with legislative committees to foster cross-systems coordination.* Making sure that legislators can cross committee and departmental boundaries to better understand interdepartmental relationships will help to minimize the pull against interdepartmental collaboration.

5. *Designate a consortium of consumer advisors.* Like other aspects of collaboration, cultivating consumer input requires and investment of time and resources.

6. *Cultivate an assembly of cross-disability consumer advocates.* While Maine needs advocates who understand the needs of particular groups, cross-disability advocacy can strengthen the consumer voice and strengthen cross-systems change.

7. *Establish staff positions within departments dedicated to interdepartmental collaborative efforts.*

8. *Develop interdepartmental standards for community integration*. One of the cabinet's first missions could be developing a common vocabulary and measures.

9. *Invest in integrating information systems*. Data integration is the lynchpin for coordinating services and for cost-effective cross-systems management of services.

Introduction

This document was written in the wake of a two-year process of developing Maine's response to the *Olmstead v. L.C.* decision. In response to the *Olmstead* decision and direction from the Health Care Financing Administration (now the Centers for Medicare and Medicaid Services), Maine's Department of Human Services brought together representatives from four other departments, including staff from the Department of Behavioral and Developmental Services, the Department of Corrections, the Department of Education's Special Services Team, and the Department of Labor's Bureau of Rehabilitation Services.

Staff from these departments formed the Steering Committee for Community-Based Living, which took responsibility for developing Maine's response to the *Olmstead* decision. The Steering Committee reviewed the *Olmstead* decision in the context of Maine's history of reduced reliance on institutional services. Maine had already closed its only state-operated facility for persons with mental retardation and had significantly reduced reliance on nursing facilities and state mental health institutes. Rather than relying too extensively on institutional care, the Steering Committee identified the shortcomings of community services as the state's major barrier to adequately meeting the needs of persons with disabilities. As a result, the Steering Committee agreed that it needed to "go beyond" the *Olmstead* decision. The Steering Committee expanded its focus form compliance with the *Olmstead* decision to the more comprehensive goal of developing the services and supports a necessary to achieve the vision of community integration embodied under the Americans with Disabilities Act (ADA). The Steering Committee explicitly recognized that to achieve that goal, Maine needed a "coherent, interdepartmental vision" for serving persons with disabilities.

In May 2000, the Steering Committee convened Maine's Plan Development Work Group for Community-Based Living and asked it to develop a "single coherent vision of what it means to provide community-based services across all state agencies." The Work Group is composed of consumer representatives and state staff representing the five departments on the Steering Committee. The Work Group has completed a draft of its "roadmap" for community integration, to be final in the spring of 2003. The purpose of this document is to marry the Work Group's shared vision for supporting community integration with a sustainable, collaborative governance structure that will incorporate that vision into the workings of Maine's state agencies.

The Case for Collaboration

Modeling automobile manufacture after uncoordinated human services illustrates the shortcomings of a delivery system without cohesion. Rather than selling a car fully assembled, it would be up to the customer to figure out which parts are needed, where to buy them, and how to put them together to the best effect. There would be no overall design for the car and no quality management to make sure the parts fit or to determine how well the cars were working. There would be no way to measure how much each car cost or to determine the most effective allocation of resources.

While the delivery of human services is considerably more complex than car manufacture, there is no less need for coordination. Lack of coordination imposes a cost both on the state and on the people it serves. The ADA and the *Olmstead* decision create additional incentives to comprehensively address the needs of person with disabilities.

The Cost of Not Collaborating

Viewed from two sides of the same coin – from a state's perspective as the administrator of services, and from the consumer's perspective on the receiving end – the absence of coordination imposes costs. For a state, the cost of not collaborating means:

- The effectiveness of services is undermined, decreasing the quality and increasing the cost of services.
- The relative effectiveness of services and the need and unmet need for services is unmeasured, meaning a state does not know where it can most effectively allocate scarce resources across services.
- Cost shifting to another agency goes unsanctioned because the organizational framework fails to recognize that every agency is spending the public's money.
- No one is responsible for making sure that the infrastructure needed to support coordination (e.g., integrated information systems, legal pathways for sharing information) is in place and maintained.
- Administrative costs are unnecessarily duplicated across agencies.
- A state risks legal jeopardy if the impact of uncoordinated services is unjustified institutionalization or another denial of rights (e.g., entitlements).

From the consumer perspective, lack of coordination means frustration, wasted time, and can sometimes lead to more dire health consequences such as institutionalization or incarceration, poor health, or death. These costs appear when:

- Gaps in eligibility and covered or funded services go unfilled.

- Boundary disputes between agencies (e.g., Is a service "educationally necessary" and therefore the responsibility of a school? Or is it "medically necessary" and therefore the responsibility of another agency?) leave the individual or family caught in the middle.

- No one is responsible for comprehensive planning, including discharge or transition planning, making sure that all needs are met.

- Time is wasted trying to find out what services are available through and unorganized patchwork of information sources.

- Access to services is through multiple entry points, with each agency requiring a separate application form and process.

- Consumers have to accept duplicative packages of services, when a selection of services across funding streams is sufficient.

- Agencies "pass the hot potato," reluctant to take on the more difficult challenges or provide the more expensive services.

- People with complex needs crossing disciplines and services (e.g., persons with psychiatric and addiction disorders who are homeless; people who cannot comply with treatment plans because they do not have access to transportation) cannot get their needs met in a fragmented delivery system that views their needs as a series of unrelated problems.

Olmstead, Community Integration, and Collaboration

Nowhere in the *Olmstead* decision does the U.S. Supreme Court tell states that compliance with the Americans with Disabilities Act requires cross-systems governance. Yet the complexity of ensuring compliance with *Olmstead* suggests the need for joint action across multiple components of state government.

The breadth of the ADA automatically implicates multiple state agencies. Reaching across a wide population of people, the ADA protects all persons with any type of impairment that "substantially limits one or more of the major life activities," including persons with a physical disability, a mental illness, a developmental disability, a chronic illness, an addiction disorder, blindness, and deafness.

Several aspects of the ADA and the *Olmstead* decision would suggest that interdepartmental collaboration, if not specifically required, is prudent:

Discrimination Based on Disability. The prohibition against discrimination based on disability suggests that persons with the same needs for services should not be denied services based on the type of disability they have. For example, a person with traumatic brain injury and a person with mental retardation might both have a similar need for supportive housing services. Can a state defend itself against a claim of discrimination if persons with traumatic brain injury are denied access to supportive housing when persons with mental retardation are not? A fragmentary, rather than comprehensive, approach to meeting needs may open a state to unfortunate and divisive battles between different population groups (and across agencies).

Allocation of Resources across Population Groups. In *Olmstead*, the fundamental-alteration defense would allow a state to show that "in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the state has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities." The Court said Georgia could weigh the needs of individual plaintiffs against its responsibilities to the larger group. Under this view, a state can defend against a request for services if the state can show that honoring the request would involve a harmful reduction in services to other persons with disabilities who need institutional care and who would lose services as a result. For a fair allocation of resources, a state would have an interest in developing standards for defining and measuring the impact of resource allocations across broad population groups.

A "Comprehensive, Effectively Working Plan." The ADA, a political compromise between the vision of community integration and the reality of what states are willing and able to do, only goes so far. The barriers to full participation in the community are vast and complex, and only partially within the control of a state.[1] The ADA does not attempt to set a "standard of care" for the services a state has to offer. The ADA prohibits states from creating barriers to integration, but the ADA does not hold states responsible for eliminating barriers it did not create.

The legal parameters of a comprehensive "*Olmstead* plan" have not been the driving force behind Maine's response to the *Olmstead* decision. In its very early days, the Steering Committee expressed its wish that Maine go beyond the do-no-harm non-discrimination proscription of the ADA. Without committing to the outer boundaries of limitless resources, the Steering Committee asked the Work Group to develop, in essence, a comprehensive, effectively working plan for supporting community integration and participation, rather than a comprehensive, effectively working plan to eliminate segregation.

Working toward a comprehensive, effectively working plan means the state will have to tackle problems that cross agency boundaries and affect people served by multiple agencies. Minimizing the risk of unnecessary institutionalization and reinstitutionalization means Maine has to comprehensively address the complex needs of

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[1] For example, through focus groups, community attitudes were identified as a major barrier to community integration. A state can influence but not dictate community acceptance of persons with disabilities.

persons requiring a range of services. Supporting community integration means increasing access to housing, transportation, and jobs, in addition to providing other home and community supports. Tackling service integration, comprehensive planning, and boundary spanning issues of housing, transportation, and employment requires an investment of interdepartmental resources and commitment. No one agency can address these problems in isolation.

Specialization and Fragmentation in Maine

The Division of Labor

The bureaucracies making up state government were created in response to the real world demands of carrying out a multitude of complex functions. Across departments, and across the multiple agencies within those departments, a bureaucratic division of labor permits the state to carry out its business. The delineation of responsibilities, or jurisdiction, permits state agencies to achieve a certain degree of specialization necessary for carrying out its tasks. The need for specialization is driven by the complexity of each department's responsibilities.

In Maine, responsibility for serving persons with disabilities has been divided across multiple agencies and departments. Several agencies were created with the core mission of serving persons with disabilities:

- BDS administers programs serving persons with mental illness or emotional disability, mental retardation or autism, or addiction disorders.
- Bureau of Elder and Adult Services (BEAS, within DHS) administers long-term care services to elders and adults with disabilities and provides protective services to adults at risk of neglect and abuse.
- Bureau of Rehabilitation Services (BRS, within DOL) administers programs providing vocational rehabilitation services, independent living services, and now the self-directed personal care services to adults with disabilities.
- Special Services Team (within DOE) oversees special education services.

Other agencies have more general missions but still have responsibilities that directly affect services for persons with disabilities:

- Bureau of Child and Family Services (BCFS) serves children who are abused or neglected, many of whom also have special needs.
- Bureau of Family Independence (BFI) administers income support programs and determines eligibility for MaineCare, Maine's Medicaid program; many persons with disabilities access income support programs or MaineCare.

- Bureau of Health (BOH) administers a number of public health programs, including the Children with Special Health Needs Program, which serves children with certain disabilities.
- Bureau of Medical Services (BMS) administers MaineCare services, serving all people meeting income eligibility criteria, including persons with disabilities.
- Department of Transportation (DOT) oversees paratransit and other transportation services that serve persons with disabilities, in addition to the rest of the State's transportation programs.
- Maine State Housing Authority (MSHA)[2] provides funding for affordable housing for low-income groups and supportive housing for persons with disabilities, in addition to its other responsibilities for promoting housing stock in Maine.

Other agencies have missions that only indirectly affect persons with disabilities, although in very meaningful ways. For example, the Department of Corrections' (DOC) mission is to carry out judicially imposed sentences, either through imprisonment or probation. Persons with disabilities are affected because persons with mental illness, addiction disorders, learning disabilities, and mental retardation frequently are encountered in the correctional system.

Cross System Breakdowns

While the division of labor across agencies can be explained by the need for specialization, the needs of the people served do not fall neatly within the jurisdiction of just one agency. Findings from focus groups,[3] case studies, and interviews[4] confirm that there are breakdowns in the collaboration between various departments, programs, and services when needs cross agency boundaries. Some of these breakdowns are described below.

Lack of Access to Information. Focus group participants said they had no central place to get information about services, and that the delivery systems are fragmented with different vocabularies, entry points and applications, services gaps, and conflicting requirements. Said a parent, "I don't think they're keeping [information] from me – I think it's so complicated that they don't even know themselves and so they just tell you as little as possible." An adult participant said access to services is so difficult that "Having a disability is a full-time job."

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[2] MSHA is a quasi-independent agency created by statute and given some of the authority and responsibility of a state agency. 30-A MRSA § 4722.
[3] Ormond C., Ziller E., and Richards M., *Living in the Community: Voices of Maine Consumers.* Edmund S. Muskie School of Public Service, July 2001.
[4] Ormond C. and Ziller E., *Living in the Community: Stakeholders Speak.* Edmund S. Muskie School of Public Service, November 2001.

No Comprehensive Planning. According to providers, "There's no one looking at the big picture." Key informants said that the lack of coordinated services means services work independently to address crises rather than together as an integrated approach to develop long-term systemic solutions. To address the needs of adults with mental illness in the correctional system, key informants recommended increased linkages between corrections and community-based organizations and better discharge planning from correctional facilities. Advocates encouraged better coordination between AIDS service organizations and mental health and substance abuse providers.

Conflicting Regulations. Providers said that departments do not make sure their programs work together. "One department may make a recommendation to change a regulation and they don't realize the effect it has on services provided by another agency." Regulations can be contradictory and they have to be creative when obtaining services for people with more than one diagnosis. "[T]he system is diagnosis driven; consumers with dual or triple diagnoses bounce from one agency to another."

Cross-Disciplinary Conflicts. The lack of cross-disciplinary training and coordination creates further complications when multiple providers offer conflicting treatment plans or excessive services to persons with multiple diagnoses. For example, key informants identified the conflict between abstinence-based and "harm reduction" models of treatment for people with addiction disorders co-occurring with mental illness. Key informants recommended cross training for police officers and jail staff to identify mental illness.

Fragmented Services. Services are fragmented across so many providers that "[c]lients feel they are really screwed up when there are 10 people around the room at a case meeting." For children with complex needs, the narrow specialization of each provider prohibits any one provider from giving comprehensive care.

A Single Coherent Vision

At the inception of this effort, the Steering Committee recognized the need for a "single coherent vision" for serving people with disabilities. The Work Group responded to the Steering Committee's charge and the voices of focus group and case study participants by developing a series of recommendations that provide that vision, across population groups and departments. The Work Group's recommendations call upon Maine to bring together the state's disparate services and programs into a coherent, comprehensive system. They are asking the state to integrate information, access, and services, as well as the infrastructure for supporting and monitoring the success of those efforts. The Work Group's single coherent vision for serving people with disabilities is described in this section.

Collaborative Policy Development

The Work Group identified multiple opportunities for collaborative policy development. In most cases, the policies developed are simply first steps in the process of implementing ongoing interdepartmental operations or in developing infrastructure that will require ongoing interdepartmental maintenance. For that reason, there is some overlap between areas discussed as opportunities for collaborative policy development and as opportunities for ongoing operations and maintenance.

Develop Integrated Information and Referral. The Work Group recommends that Maine develop an integrated information and referral (I&R) system. The integrated I&R system would cover all disability-related services through an interactive, searchable website and a statewide toll-free hotline. To implement, the state would need to integrate information across programs; develop a strategy for the ongoing maintenance and financing of the I&R system; and develop quality measures for assessing and improving performance.

Develop Integrated Access to Services. The Work Group recommends that the state develop integrated access to services with "no wrong door" for entering the service system. Cross-disciplinary training would permit providers to identify the potential need for services and offer information. Maine would explore the feasibility of integrating the application form so that, at an individual's option, application information might be shared with other appropriate agencies or providers. To implement this recommendation, the state would need to create and maintain the cross-disciplinary expertise among service providers, explore the feasibility of and possibly develop an integrated eligibility application form, and develop quality measures for assessing and improving performance.

Integrate Services. The Work Group has developed a series of recommendations around integrating services through a comprehensive resource planning process. Maine's Integrated Case Management (ICM) pilot project was identified as a potential model. To implement this recommendation, the state would need to determine the appropriateness and feasibility of exporting the ICM pilot to other communities; the appropriateness and feasibility of developing alternative mechanisms for creating integrated, comprehensive resource plans; and the appropriateness and feasibility of applying the comprehensive resource planning process to the adult service system. Interdepartmental collaboration would be required to enable cross-system collaboration at the service delivery level.

Integrate Data across Departments. The Work Group recommends that the state develop the capacity to integrate data across departments. Not an end in itself, integrated data could be a tool able to support a series of other Work Group recommendations including integrated services, integrated information and referral, integrated service centers, and collaborative planning and performance monitoring. To take data integration along an incremental path from design, to pilot, to implementation, the state would need to

develop and adopt protocols and standards for contributing data; an administrative infrastructure for maintaining the integrated data; standards and agreements governing confidentiality and security; and a strategy for financing the development and maintenance of the integrated data application. To facilitate the development and use of integrated data, the state would need to invest in creating a shared understanding of the value of integrated data and how it can be used and analyzed to support program objectives.

Fill Gaps and Create Consistency across Programs. The Work Group has identified the need for consistency in several areas. First, emerging recommendations include expanding eligibility for service coordination services and job supports, moving away from diagnosis-driven eligibility criteria and toward a measure of need. The Work Group also recommends a consistent level of inclusion of consumers in the design and delivery of services, as well as in the quality monitoring process.

Maximize Self-Direction and Flexible Funding across Services. The Work Group recommends that Maine expand self-direction and flexible funding by cashing out services based on a level of need. Each individual would choose which services to purchase. In the ideal world, the budget would include the range of long term and community services available, including housing and transportation. Implementing these recommendations would entail the state's commitment to overcoming a multitude of barriers, not the least of which would be the varying restrictions on how funds can be spent imposed by both state and federal government, as well as mechanisms for documenting the appropriate use of individual budgets.

Develop Standards for Collecting Waiting List Data. In the context of the *Olmstead* decision, the Work Group has identified the types of waiting list information that should be collected and the kinds of policies for administering waiting lists that are needed. To respond to these recommendations, the state would need to develop standard waiting list practices, and cooperatively collect and share the information.

Housing, Transportation, and Employment. The Work Group has identified the lack of accessible, adequate, and affordable housing and transportation, and the lack of access to meaningful employment as major barriers to community integration. The need to address these issues crosses all five departments. Finding a way to meaningfully tackle the complexity and cost of these barriers requires a unified commitment across all five departments.

Operations

Integrated Access to Services. Providers and state agencies will need to collaborate consistently in order to ensure that a person is linked to needed services no matter how they enter the system.

Integrated Service Delivery. Once designed, implementation of the integrated service delivery would require ongoing interdepartmental collaboration across direct service staff, mid-level management, and department leaders. To make this happen, Maine would need to support staff by providing the time and resources (including training) needed to sustain ongoing collaboration, as well as mechanisms for cultivating and sustaining collaboration.

Collaborative Performance Monitoring

The Work Group has recommended that Maine collaboratively evaluate and improve performance on an ongoing basis. The focus is on ensuring that the state uses consistent and reliable information to build budgets and that the state measures its success at serving people in the most integrated setting according to preference and need.

Establish a Common Vocabulary. As a first step of ensuring that the state is achieving community integration, the Work Group recommends that the five departments develop a common vocabulary for defining key terms. As examples, the Work Group suggests the state develop common definitions for what is meant by "disability," "least restrictive," "most integrated," types of settings, types of services, and other key terms for measuring and evaluating the state's success at achieving community integration.

Develop Cross-System Performance Measures of Community Integration. The Work Group has identified some key measures for assessing Maine's compliance with *Olmstead.* These measures relate to the type of setting in which a person receiving state-funded services resides (e.g., institutional or other licensed setting, private home, shelter, street, etc.), the number of people residing in a restricted, institutional, or otherwise non-integrated settings who could receive the same type or level of services in a more integrated setting; and the number of people preferring to live in another setting. To comprehensively produce these counts, the state would need to develop common definitions for types of setting (discussed above); develop standards for collecting data on the type of setting, whether or not a person could be served in a more integrated setting and preference for setting; cooperatively implement the data collection effort; and link data across programs to eliminate duplication.

Develop Cross System Measures of Quality. As identified through the Real Choice grant application, the Work Group wants cross systems measures of quality. These measures are to be defined in collaboration with consumers and state agencies. Once developed, the ongoing value of these measures would be determined by the use they are put to by interdepartmental leadership.

Conduct Cross Systems Efforts to Improve Quality. The Work Group identified interdepartmental quality improvement projects as another priority under its Real Choice grant proposal. Under that grant, the feasibility of collaborative quality improvement projects will be explored.

Maintenance of Infrastructure and Supports

As the result of several of the activities discussed above, new initiatives would be created to support either integrated access to services or integrated data. Once jointly created, these initiatives or entities would require ongoing maintenance and financing.

Integrated Information and Referral. For the integrated I&R to remain useful, state agencies and private providers would need to continually provide up-to-date information. In addition, staff would be necessary to coordinate maintenance of the I&R system. Across departments, Maine would need to support the ongoing contribution of current information. The state also would need to provide ongoing funding for the I&R system.

Integrated Access. The state would need to sustain cross-disciplinary training to ensure providers are trained to link people to the appropriate services. If the state does create an integrated application form, it would have to coordinate across programs to ensure that eligibility criteria, etc., are up-to-date.

Integrated Delivery of Services. If Maine implements integrated service delivery through a comprehensive resource planning process, it would have to support and maintain the cross system collaboration at the service delivery level, as well as at the management level.

Integrated Data. As currently envisioned, the integrated data application to be designed under the Real Choice Systems Change grant would support a "virtual database" to the degree possible. That means the integrated data application to be developed would largely consist of a series of data roadmaps, mapping back from an end-user's query to the data sources that respond to that query. State staff would be responsible for contributing updates to those roadmaps, including the location of data, proper use of data, and permitted access to data. Coordination of the maintenance of integrated data infrastructure – the roadmaps – would also need to be provided. Thus, like the two previous items, each department would have an ongoing role in maintaining the currency of the integrated resource and the state would have a separate need to fund coordination of the maintenance effort.

Putting the Parts Together

The Work Group will soon give the Steering Committee a vision for achieving a single, coherent interdepartmental approach to serving persons with disabilities. The Work Group is asking the state to "assemble" the services it delivers into a comprehensive, coherent system of services. Necessarily, implementation of the Work Group's recommendations exceeds the authority and responsibility of any one department. How can Maine turn these recommendations into meaningful change? This section identifies some of the required features of any effort to address the Work Group's recommendations, reviews existing collaborative efforts, and makes recommendations for

building ongoing and sustainable interdepartmental governance of disability related issues.

Required Elements of Implementation

Maine's effort to implement the Work Group's recommendations must incorporate a number of features explicit or implicit to the Work Group's recommendations. Some of these features are specific to the Work Group's vision and others are the necessary elements of successful collaboration.

Interdepartmental. The Work Group's recommendations challenge the state to comprehensively address the needs of persons with disabilities. Collaborative policymaking and performance measurement, integrating data, and access to services, etc., all require a heavy investment from participating departments. Maine's response to that challenge has to include the departments most directly involved in serving people with disabilities. These departments include the five participating on the Steering Committee (BDS, DOC, DOE, DHS, and DOL). In addition, the Department of Public Safety, which oversees local police departments and jails, plays a role in serving many people with disabilities and could also be appropriately added. The Department of Transportation and the Maine State Housing Authority, and others also would need to be involved to address the fundamental barriers to community integration.

Cross-Disability Focus. One of the Work Group's successes has been the ability to maintain a cross-disability, cross-age group focus. Each department already has avenues for addressing the particular needs of certain population groups. A cross-disability focus permits the state to address the needs common across groups and to maintain an interdepartmental focus on coordination.

Consumer Involvement. The Work Group has recommended that the state incorporate the consumer voice in service design, delivery, and quality improvement. Consumer participation is process and time intensive, requiring an investment in educating consumers, being educated by consumers, and building relationships. Some resist consumer involvement because they believe some consumers have an unrealistic expectation about what the state can or is willing to do, and fear "setting people up" or conflict. In the end, however, it makes no sense to attempt to create and maintain a system intended to be responsive to consumer needs in the absence of meaningful consumer input.

Local and Regional Reach. Integrating information and referral, access (i.e., the application process) and the delivery of services will affect regional offices, schools, and local providers. The collaborative effort must have the ability to influence the practices and policies at all levels of the system. The collaborative should be constructed to incorporate the participation and input of regional and local workers and providers. Commitment of resources needs to include a commitment of time to participate in the process.

Resources. Through CMS' Real Choice Systems Change grant initiative, Maine has been fortunate to receive a $2.3 million grant, Quality Choices for Maine, which permits Maine to respond to a number of the Work Group's recommendations. However, the scope of the Work Group's recommendations well exceeds the scope of Quality Choices. For example, Quality Choices does not systematically address the integration of information and referral, the application process, or service integration. Quality Choices only funds the design of the integrated data application, not implementation. It does not begin to address some of the Work Group's major recommendations relating to housing, transportation or employment. The grant will not respond to the recommendation for developing a common vocabulary and measures for community integration. Resources are needed for funding an investment in improved services, the state staff necessary for developing coordinated policy and tools, funds for developing the capacity to integrate data, training regional and local staff and providers, and sustaining and improving coordinated tools and functions on an ongoing basis.

Dedicated Staff for Collaboration. Most efforts at interdepartmental collaboration are not funded. For the most part, the success of these efforts has relied upon the ability of staff to find time within their existing workload and pockets of money in their budgets. The ability to sustain that kind of commitment decreases over time, as competing priorities crowd in. A true commitment to interdepartmental collaboration requires a commitment of dedicated staff and resources. Without the resources to produce results, participating departments will quickly see that their efforts are wasted and they will quickly lose interest.

Authority. In addition to having the ability to marshal resources and influence local delivery, members of the collaborative effort also must be able to effect changes in policies and practices; enable and promote collaborative attitudes and actions within the state bureaucracies and in the regional and local offices; and convene needed parties outside departments, including those who can influence access to housing, transportation, and jobs. Ultimately, this capacity rests at the commissioner level.

Commitment and Leadership. Commitment from both the executive and legislative branches is essential. If the governor is committed to the process, his or her appointed commissioners will be as well. The commissioners can bring needed leadership to the process in the form of setting the agenda, monitoring implementation, and demonstrating shared successes. The effort will require on-going staff support within the governor's office. Staff must have the ability to assure that interdepartmental priorities are considered for inclusion in the Governor's budget and legislative programs.

Formal Mission. To increase the likelihood that the initiative will survive political shifts, the collaborative body needs to be established in law. Its mission must include ongoing responsibility for policy development and implementation of interdepartmental initiatives.

Strategies for Implementing the Work Group's Vision

Existing Interdepartmental Initiatives. Many of the Work Group's recommendations are not new. Many before have recognized the need to coordinate services, fill gaps in service needs, and develop coherent and consistent policies and programs. Nor are the Steering Committee and the Work Group the first or only efforts Maine has made at interdepartmental collaboration. Through numerous formal and informal initiatives, the state has attempted to coordinate policy development and operations. While many of these initiatives have some of the necessary features, none have all of the requirements.

A review of existing initiatives begins with the Steering Committee. Steering Committee membership crosses five key departments. Its members offer staff level leadership. They have charted the Work Group's course, worked collaboratively with each other and consumer members, and provided direction and guidance to staff. The Steering Committee, through the Work Group, also has a mechanism in place for hearing and responding to consumer input and guidance, crossing multiple disability and age groups. In spite of these advantages, Steering Committee members do not have the commissioner-level authority required to effect the needed change in policies and practices, or to identify and allocate the needed resources. The Steering Committee has no formal charter. None of the participating departments have staff dedicated to the Steering Committee's efforts.

A survey of Maine's other collaborative initiatives reveals numerous efforts that have some, but not all, of the required features. Many of these initiatives are formal initiatives, either created by the legislature, the governor, or by memoranda of understanding between departments. Others are the informal product of staff initiative upon identifying a system breakdown or opportunity for improvement. Many are short-term, created to address a specific problem or to produce findings and a report. Few include five departments. None have as comprehensive a mission as is needed here; other than the Steering Committee, no initiative is addressing the broad service needs of persons across types of disability or age groups. Very few include commissioner-level membership. While not a perfect fit, Maine's Children's Cabinet stands out as an interdepartmental effort having most of the elements required for implementing the Work Group's recommendations. With departmental representation overlapping with the Steering Committee and a broad mission, much of its work is disability related.

Reorganization. Rather than collaborating across departments, some might be tempted to think about ways of reorganizing state agencies so that a single "super-agency" is responsible for overseeing the state's services for persons with disabilities. This idea has attracted attention in recent months as gubernatorial candidates responded to press coverage about fragmented mental health services for children by proposing to reorganize government and creating a "Child and Family Department." For a number of reasons, any attempt to reorganize government would have limited success at minimizing the need for coordination:

- Federal funding streams drive many divisions of labor; no amount of reorganization can eliminate those divisions when the state is held accountable for spending money in compliance with federal requirements.

- Even within one large agency, there would still be a division of labor and specialization requiring intra-agency coordination, if not inter-agency coordination.

- Without creating duplicative capacity, the state could never put within one agency all the expertise necessary to fully address the barriers to community integration (e.g., housing and transportation). Medicaid, the Bureau of Child and Family Services, and others would have to be outside the super-agency. Similarly, Maine State Housing Authority and the Department of Transportation, for example, could never subsume their broader missions within a department serving only persons with disabilities. Duplicating expertise and functions within an agency is likely to be wasteful, and possibly unsuccessful. (A reorganization around children's services faces similar challenges. A department fully addressing children's needs necessarily must address adult issues, including access to services, housing, and employment. Similarly, a department fully addressing children's needs have to address the transition to adulthood and adult services.)

With or without a reorganization, Maine will still need to significantly invest in collaboration and the infrastructure to support collaboration to have a meaningful impact on interdepartmental coordination. Given that a reorganization would impose some costs, the state's money might be better spent investing in the infrastructure needed to minimize the cost of coordination (e.g., integrating information systems) and maximizing staff collaboration (e.g., dedicated staff with the time to achieve meaningful results).

Recommendations for Sustaining Interdepartmental Collaboration

Based on the above analysis, the following recommendations are made for creating an environment and infrastructure for sustaining interdepartmental collaboration.

1. *Recognize the need for investing in collaboration*. Many would like to think of interdepartmental coordination and collaboration as a way to improve the state's efficiency and save money. In the long run, there very well may be cost-savings resulting from improved, more effective services or from reduced duplication of effort. However, in the short-term, it is highly unlikely that interdepartmental collaboration will save money. To the contrary, in the short-term, Maine needs to invest in developing its capacity to coordinate across systems.

   Comparing the assembly of an automobile to coordinating the interdepartmental delivery and management of human services helps to illustrate the need for investment. An automobile manufacturer sees bringing the parts of a car together

and assembling them into an automobile as part of the series of steps required to produce a car. No one expects it to happen for free and no one expects it to happen without a plan for what the car should look like or how it should work. Someone at Ford Motor Company is paid to know how the different parts are related and to have a plan for how they should come together. There are people paid to assemble the car; assembly is not something they try to find time for, in between their other responsibilities. In addition to quality control for the individual parts, someone at Ford Motor Company is responsible for monitoring the quality of the car, making sure that once assembled the car performs as intended.

In contrast, we often see the assembly of a comprehensive human service system as either an unnecessary step or something that should happen automatically, without additional resources. Interdepartmental coordination and collaboration might be a stated goal, but departments typically are not given or do not make available the necessary resources to make it happen. As evidence, the Children's Cabinet, the state's most ambitious interdepartmental effort to date, has no dedicated staff and no budget appropriation. If Maine wants to coordinate services, the executive branch, the legislature, and consumers have to see collaboration as a necessary step in the process, requiring dedicated resources and investment.

2. *Charge interdepartmental cabinet with responsibility for addressing needs of persons with disabilities*. This cabinet would build on the foundation laid by Maine's Children's Cabinet. It would be composed of at least six member departments: BDS, DOC, DOE, DHS, DOL, and the Department of Public Safety. In addition, the Department of Transportation and the Maine State Housing Authority could participate as full or adjunct members. The mission of this cabinet could comprehend the needs of both adults and children with disabilities, the original Children Cabinet agenda, and possibly other collaborative interests of the participating departments. In addition to the mission already given the Children's Cabinet, this cabinet would promote community integration for persons with disabilities by ensuring that home and community services support living in the community and participating in community life. Specific tasks for the cabinet could include many of the Work Group's recommendations, including:

   - Integrating information and referral.
   - Integrating access to services.
   - Integrating data across departments.
   - Filling gaps and creating consistency in services across departments.
   - Increasing the flexibility of funding to maximize individual control over services.

- Developing a shared vocabulary, common standards for waiting lists, cross-system measures for quality, community integration, etc.
- Comprehensively addressing the housing, transportation, and employment needs of persons with disabilities.

To preserve the focus on children already established in the Children's Cabinet, this cabinet would have two senior staff sub-committees, one focusing on children's issues and the second focusing on adult issues. The commissioners would play a coordinating role across the two sub-committees.

The cabinet would maintain its relationship with the judicial and legislative branches, as currently provided through the Council on Children and Families.

To increase its chances of survival, the cabinet would be formed by statute. To reinforce its broad mission, its name would have to be inclusive as well, encompassing children, their families, and other adults.

3. *Establish a dedicated staff position in the governor's office responsible for serving as liaison to cross-systems collaborative*. Ideally this dedicated staff position would be statutorily required. This staff person would be responsible for assuring that interdepartmental initiatives are recognized as priorities in the governor's budget and legislative programs.

4. *Partner with legislative committees to foster cross-systems coordination*. The division of labor across departments is paralleled by specialization among legislative committees. Each of these committees focuses on individual departments and is not responsible for addressing interdepartmental needs across departments. Making sure that legislators can cross committee and departmental boundaries will help to minimize the pull against interdepartmental collaboration.

5. *Designate a consortium of consumer advisors*. A consumer advisory group provides Maine with a window into the real world experience of the people they serve, in the same way an automobile manufacturer would look to a focus group to find out how they can better meet their customers' needs. Like other aspects of collaboration, cultivating consumer participation requires an investment of time and resources. For consumers to know they are valued, staff support should be available so that consumer input is recorded and consumers can see their impact on policy. A facilitator should be available to assist in developing open communication and healthy relationships among state representatives and consumers. Engaging in dialogue over disagreements honors the consumer's role and serves as an opportunity to educate and be educated. To maximize the participation of persons with disabilities, the state will want to pay for accommodations eliminating other barriers to participation. To encourage consumer participation, consumers should be reimbursed for their out-of-pocket

expenses, including transportation and childcare, and paid a stipend for participation.

The Work Group serves as one model of a consortium. It comprised consumer advisors, each representing their own council or association, and representing consumers across types of disability and age group.

6. *Cultivate an assembly of cross-disability consumer advocates*. It would be in the state's interest to provide start-up funds to form an assembly of advocates, crossing all types of disabilities and age groups. While the state still needs advocates who understand the needs of particular population groups, it also needs to have advocates who can speak for a broader range of needs. Fragmented advocacy weakens the consumer voice and can tug the individual departments in different directions. An assembly of advocates crossing disability groups could join forces to speak to the broader needs of persons with disabilities, especially as they relate to the larger, more challenging problems of community supports, housing, transportation, and employment. In addition, this assembly could speak for persons wanting more choice and control over services, bringing together the principles shared by the independent living movement for persons with physical disabilities, the self-determination movement for persons with developmental disabilities, and the recovery movement for persons with psychiatric disorders.[5] This body also could serve as a vehicle for public education, addressing public attitudes as one of the primary barriers to community integration. Cultivating stronger consumer advocacy with a cross-disability focus also could help to balance the influence of other political pressures on the state.

7. *Establish staff positions within departments dedicated to interdepartmental collaborative efforts*. Each department should have at least one staff person whose sole responsibility is to further interdepartmental collaboration. These staff positions could be created legislatively and ideally would be located in each commissioner's office. These staff persons would have to have enough authority and support from their commissioner to command the participation and cooperation of others within their department; they would need to be able to span departmental boundaries, understanding how the departments interrelate and how the departmental functions should come together.

8. *Develop interdepartmental standards for community integration*. One of the cabinet's first missions could be developing a common vocabulary and measures of community integration, including: measures of compliance with *Olmstead* (e.g., "most integrated setting," preference for setting, etc.); measures of unmet need and waiting lists; and other measures of quality of care and successful community integration. Beginning with these measures will provide an appropriate cross-

[5] See, e.g., Deegan P. "The Independent Living Movement and People with Psychiatric Disabilities: Taking Back Control over Our Own Lives." *Psychosocial Rehabilitation Journal*, 13(3) 1992.

systems focus to the disability agenda as well as instill community integration into the cabinet's agenda.

9. *Invest in integrating information systems*. Integrating information systems serves as another equally important priority for this cabinet. Data integration is the lynchpin for both integrating and coordinating services and for cost-effective cross-systems management of services. Of all the identified needs for collaboration, data integration could be one of the most attainable and concrete opportunities for improvement. Finally, providing access to integrated information can help the state and providers transform their roles.[6] By increasing the ability to communicate across departments, the cost of coordinating is reduced, making it easier for departmental staff to rethink their relationship with other departments. By improving each department's understanding of which other departments touch the lives of their customers, the departments may find more cost-effective strategies for serving people and achieving better outcomes.

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[6] Fountain J. *Building the Virtual State: Information Technology and Institutional Change.* Brookings Institution Press. Washington, DC 2001.