

# **Roadmap for Change**

**Maine's Response to the *Olmstead* Decision**

**Work Group for Community-Based Living**

**October 2003**

*Sponsored by the Maine Department of Human Services, with the participation of consumer groups, advocates, and other state agencies. The State of Maine does not discriminate on the basis of disability, race, color, creed, gender, age, or national origin in admission to, access to, or operations of its programs, services or activities, or its hiring practices.*



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# Preface

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This *Roadmap for Change* was prepared by Maine’s Work Group for Community-Based Living in response to the 1999 *Olmstead* Supreme Court decision. The *Olmstead* decision, holding that unnecessary segregation of persons with disabilities is discrimination under the Americans with Disabilities Act (ADA), requires States to administer their services, programs and activities in the “most integrated setting appropriate to the needs of qualified individuals with disabilities”.<sup>1</sup>

In February 2000, Maine’s Commissioner of the Department of Human Services partnered with fellow commissioners to establish the Work Group for Community-Based Living to develop an interdepartmental approach for ensuring that publicly funded services are provided to people with disabilities in the most integrated setting appropriate to their needs and preferences. The Work Group, first convened in May 2000, consisted of persons with disabilities, parents and advocates, and representatives from the Maine Departments of Human Services, Behavioral and Developmental Services, Labor, Education and Corrections. Meeting monthly over a three-year period, the Work Group defined its procedures and goals, established planning priorities, reviewed Sub-Group reports, devised a public communications strategy to solicit public input, and prepared a final report, *Roadmap for Change*.

Early in the planning process, the Work Group agreed to a set of operating procedures that would provide a basis for moving forward. The Work Group decided, for example, not to limit its vision by lack of resources or to assign a permanent chair. The Work Group also recognized the importance of developing a common vocabulary, developing and adhering to procedures for making decisions (i.e., modified consensus), and building in a process-check for evaluating progress toward its goals. To ensure continuing and diverse participation, the Work Group was provided funds for consumers to attend meetings (i.e., stipends or travel reimbursement) and for various in-meeting accommodations.

To meet its goal of community integration, the Work Group identified core values and principles that would lay the foundation for the *Roadmap*, assessed service and infrastructure needs that would later be used to establish planning priorities, and identified three priority areas on which to focus attention:<sup>1</sup>

*Services*—ensuring that persons with disabilities have access to health, mental health developmental, allied, and other supportive services needed to live in integrated settings.

*Workforce*—improving the quality and capacity of the direct care workforce charged with supporting people in integrated settings.

*Service Coordination*—making sure that State coordinates its services and programs to maximize responsiveness and flexibility.

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These priorities and additional issues of concern (i.e., access to and availability of transportation, housing, and employment for people with disabilities) are addressed in the following reports (Appendices A-H):

- Advocacy, Self Advocacy, and Quality Monitoring
- Flexible Funding to Promote Integrated Services and Choice and Control
- Using Data to Make Sure Needed Services Are Funded
- Coordination of Services
- Improving Quality and Availability of Direct Care Workers
- Affordable, Appropriate, Integrated Housing
- Transportation Issues and Problems
- Barriers and Issues for Employment

Recommendations in the *Roadmap for Change*, derived from this series of reports, reflect the Work Group's conviction that the following themes must underlie any comprehensive, integrated response to the *Olmstead* decision:

- Helping people control and deliver the services and supports they need.
- Supporting individuals in finding their voice and speaking for themselves.
- Organizing services around the person served.
- Creating a single, integrated system of coordinated services.
- Integrating access to services so that there is no wrong door into the system.
- Building standards for quality and accountability of services and evaluating quality on on-going basis.
- Improving access to and availability of transportation, housing, and jobs.

The Work Group for Community-Based Living submits its *Roadmap for Change* as an interdepartmental approach for improving home and community services for people with disabilities, and invites the State to join it in implementing the Work Group's vision:

*All of us together in community with equality in rights and dignity, in pursuit of happiness and fulfillment.*



# The Work Group

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## *Who We Are*

The consumer and state staff representatives who have contributed to Maine's Work Group for Community-Based Living include current and prior members.

<b>Member</b>	<b>Naming Organization or State Agency</b>
Michael Arenstam	NAMI-Maine
Helen Bailey	Disabilities Rights Center
John Baillargeon	Department of Human Services, Bureau of Elder and Adult Services
Tom Bancroft	Department of Human Services, Bureau of Child and Family Services
Christine Bartlett	Department of Education
Shirley Bastien	Long Term Care Steering Committee
Laura Bell	State-wide Independent Living Council
Drew Bolduc	Maine Parent Federation
Tonia Boterf	Maine's Developmental Disabilities Council
Kathleen Brogan	Department of Labor, Bureau of Rehabilitation Services
Myra Champagne	Brain Injury Association of Maine
Jonathan Connick	Maine Center on Deafness
Alice Conway	Maine Developmental Disabilities Council
Peter Driscoll	NAMI-Maine
Margaret Forbes	State-wide Independent Living Council
Jane O'Loughlin French	Rehabilitation Council for the Blind and Visually Impaired
Jane Gallivan	Department of Behavioral and Developmental Services
Cary Gifford	Maine Association of Substance Abuse Programs
Steve Hoad	Rehabilitation Council for the Blind and Visually Impaired
Nathaniel Hussey	Department of Corrections
Linda Jariz	Department of Behavioral and Developmental Services
Kathryn Kazenski	Maine Administrators of Services for Children with Disabilities
Tonya Labbe	Oversight Committee for Children's Mental Health Services
Sawin Millet	Department of Behavioral and Developmental Services
Chandra Murphy	Speaking Up for Us
Lora Perry	Parent

Tracy Piantoni	Maine Advisory Council on the Education of Children with Disabilities
Debbie Rogers	Maine Parent Federation
John Shattuck	Department of Labor
Cynthia Sudheimer	State Rehabilitation Council
Ronald Welch	Maine Association for Mental Health Services
Debbie Williams	Long Term Care Steering Committee
Deb Parker Wolfenden	MaineCITE Project
Stephanie Crystal Wolfstone-Francis	State-wide Independent Living Council
Susan Wygal	Department of Behavioral and Developmental Services
Christine Zukas-Lessard	Department of Human Services, Bureau of Medical Services

## ***Who We Represent***

All people are affected by disability. Whether or not we know it, we all have or know someone who has a disability. According to the 2000 U.S. Census, almost one out of every five persons living in Maine has a disability.<sup>2</sup> In Maine that represents about 224, 400 people<sup>3</sup>. It might be our elderly grandmother who can no longer live on her own or the homeless man we drive by every morning on the way to work. It might be the little girl down the street born with Down Syndrome or a spouse injured on the job. It might be our teen-aged son who was expelled from school because of substance abuse, or a co-worker concealing a mental illness because she's afraid of the stigma others attach to it. Or it might be us, because we have a chronic illness, a hearing or visual impairment, or some other condition that falls within the scope of the Americans with Disabilities Act (ADA).

If we do not have a disability now, there is a good chance that we will in the future. According to one estimate, at birth a person with a life expectancy of 75 years will spend 12.8 of those years with some degree of activity limitation.<sup>4</sup>

Under the ADA, the term "disability" means "a physical or mental impairment that substantially limits one or more of the major life activities of [an] individual; a record of such an impairment; or being regarded as having such an impairment."<sup>5</sup> Within this definition fall an array of different types of disabilities, including addiction disorders, chronic illness, developmental disabilities, mental illness, physical disabilities, sensory impairments, and traumatic brain injury.

Our ability to estimate how many people have a disability or how many people have a particular type of disability is limited. And perhaps that is a good thing, because numbers can prevent us from intimately knowing the uniqueness of each and every person with a disability: each person's needs, hopes, dreams and expectations that are as profoundly worthy as our own, but so much more difficult to hold because of a disability. From the point of view of the individual, disability rights improve lives one person at a time. The most important number, in a sea of numbers, is one.

## ***Our Mission***

*The Work Group was formed to develop a coherent plan, across departments and programs, to make certain that the State is providing services to people with disabilities in the most integrated setting appropriate to the needs and preferences of each individual.*

The Work Group was convened in response to the *Olmstead* decision. *LC. v Olmstead* is a 1999 U.S. Supreme Court decision holding that unnecessary segregation of persons with disabilities is discrimination under the Americans with Disabilities Act (ADA). The Supreme Court said that a state must provide community services to qualified individuals when:

- the treating provider believes it is appropriate;
- the affected client (or authorized representative) does not oppose it; and
- the placement in the community can be reasonably accommodated taking into account the resources available to the state and the needs of others.

A state can show that it is complying with the ADA if it has:

- a comprehensive, effective working plan for placing qualified persons with disabilities in less restrictive settings; and
- a waiting list that moves at a reasonable pace not controlled by the state's endeavors to keep its institutions fully populated.

As discussed in the previous section, the principles underlying *Olmstead* apply to all people with a disability, as defined under the ADA, who are institutionalized or are at risk of institutionalization (including in a nursing facility, treatment facility or other restricted settings). The ADA protects people with any type of impairment that “substantially limits one or more of the major life activities,” including a physical disability, a mental illness, a developmental disability, a chronic illness, an addiction disorder, blindness, and deafness. All state or other publicly funded institutional or home and community-based services offered to people with disabilities are subject to the *Olmstead* decision.

Maine is far ahead of many states in providing community alternatives to institutionalization. Yet we continue to face many challenges in achieving the vision of sustainable, fulfilling participation in community. Seeing the *Olmstead* decision as a catalyst for a comprehensive, thorough evaluation of the State's capacity to maximize community integration, the Work Group was asked to develop a vision for improving home and community services.

Starting in February 2000, state representatives from five departments began working on Maine's response to *Olmstead*. These five departments include the:

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

In May 2000, these five departments joined with consumers, family members, and advocates to form Maine's Work Group for Community-Based Living. Since that time the Work Group has met monthly, with numerous additional Sub-Group meetings in between.

Focusing on community services, we identified and prioritized areas of focus and divided into three Sub-Groups to address those areas. In particular, we focused our energy on:

- access to services;
- inter-departmental coordination; and
- workforce development.

The reports in the later half of this document are the products of those Sub-Groups. In addition, we also developed recommendations for improving access to:

- housing;
- transportation; and
- employment.

## ***What We Believe: Our Vision***

In developing a coherent, inter-departmental plan for home and community-based services, we are guided by our vision of ultimate success:

*All of us together in community with equality in rights and dignity, in pursuit of happiness and fulfillment.*

Central to our ability to achieve our mission is the common understanding of the core values and agreement as to how those values operate in real life situations. Our values are the standard against which we will measure the *Olmstead* plan we develop.

### **We believe in honoring the dignity, equality and value of each individual.**

Honoring individual dignity means listening to and respecting each person's dreams and aspirations and respecting each person's right to make choices. It also means supporting people in finding their voices, speaking for themselves, and attaining their full potential in all aspects of their lives. Every person is unique in personality, abilities, needs and aspirations and is imbued with personal power and responsibility.

Family and friends are the most valuable resource we have in supporting persons with disabilities. The contributions they make should be honored and their needs addressed.

**We believe that true choice can only be exercised if people are given information and opportunities.**

The right to make choices means the right to choose where and how to live, and with whom. We believe that true choice can only be exercised if people are given information and opportunities. Our government has a responsibility to open the door to choice by providing the services and information that make informed choice possible.

**We believe in services that meet people's needs.**

Services must be accessible, affordable, and available. They should be flexible enough to meet the changing needs of each individual as their needs change. Barriers to services should be eliminated. Services should promote equal dignity and rights and equal opportunity for a happy and fulfilling life in the community. Services should be offered in a way that not only permits but encourages people to maintain control over their lives, including maximizing the use of voluntary services. Each person's voice must be heard and all decisions and planning must reflect what is most important to the individual, and, when appropriate, supportive family and friends. Caregivers are an integral part of quality services.

**We believe that people with disabilities have a right and a need to organize as and within groups so that their voice may be heard in the public process.**

Every day there are policy decisions made that have an impact on our lives. Yet people with disabilities have historically been excluded from the political process through architectural and communication barriers, stigma, and other limitations. In addition, they have been unable to leave institutions and their homes to go to the places where voting, debates, educational or other political events occurred. By joining in groups, people with disabilities will gain the information, education, and confidence to assume their rightful place in protecting their rights and these values.

**We believe that community integration for individuals with disabilities is achievable.**

Community integration requires attention not just to services, but to attitudes as well. The responsibility for achieving this goal falls not just on government, but on our society as a whole, indeed, on each one of us.

# Roadmap for Change

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## *Where We Are: Building on Our Strengths*

Like other states, historically, Maine segregated people with disabilities into institutional settings. Services for people with mental illness were offered primarily through two state-operated mental health institutions, the Augusta Mental Health Institute (AMHI) and the Bangor Mental Health Institute (BMHI). Services for persons with mental retardation and developmental disabilities were offered at another state-operated institution, Pineland in Pownal. Many people with physical disabilities had no alternative but to live in nursing facilities because needed services were not available in the community. In addition, many children were denied equal access to an education because schools did not provide the services needed. Children were entering adulthood unprepared to support and take care of themselves, forced to continue a life of dependency.

Over the last several decades, Maine policymakers and public have become more aware of discrimination against people with disabilities. In addition to effective advocacy, public outrage over abuses, class action law suits, sweeping federal legislation, forward looking leadership in Maine government, and budgetary concerns have helped to drive a shift away from institutionalization. Some of the pivotal events influencing Maine's services include:

- The passage of state legislation, in 1973, and subsequent federal legislation, in 1975, and again in 1997, guaranteeing all children a “free appropriate public education” in the “least restrictive environment.”
- Consent decrees in 1975 and 1994 that led to the eventual closing of Pineland in 1996.
- A class action lawsuit filed in 1988 on behalf of individuals who had been or who would be admitted to AMHI. This lawsuit resulted in a judicially enforceable settlement agreement for developing community services.
- A budget crunch in the mid-nineties forcing the state government to strictly limit access to nursing facility services.

As a result of these events, and other pressures, Maine has made significant progress in minimizing segregation and meeting the needs of people with disabilities. For example, Pineland, which at one time could serve 1500 residents, is now closed. Maine is one of only nine states in the country that has closed all state-operated institutions for persons with mental retardation and developmental disability. In 1998, Maine was one of only 19 states providing 70 percent or more of residential services in settings for six or fewer persons.<sup>6</sup> In 1998, Maine served over 1,300 people under the MaineCare program's home- and community-based waiver for persons with mental retardation.

AMHI and BMHI in 1958 had an average daily census of 3,400. Consistent with the deinstitutionalization trend in other states, forty years later, the average daily census is 180.<sup>7</sup> As the inpatient count has decreased, Maine has worked to build the community supports needed.

In 1994, the State tightened the medical eligibility for nursing homes so that only people with the greatest need would be admitted. Over the next several years, Maine reprogrammed state and federal funding to build and support home- and community- services. Between 1995 and 1999, Maine decreased the number of people residing in nursing facilities by 13%, while nearly doubling the number of adults receiving MaineCare and state-funded long-term care services at home. In FY 2001, MaineCare supported 681 adults ages 18 through 64 in nursing facilities.<sup>8</sup>

In addition, inter-departmental cooperation has made it possible for Maine to significantly reduce the rate of out-of-state placements for children and increase the number of children returning to the state. Between January 1999 and September 2002, the number of children funded by BDS and DHS' Bureau of Children and Family Services in out-of-state placements decreased by 62%, from 205 to 78.<sup>9</sup> This progress is expected to continue.

Maine has also increased its vocational rehabilitation services. Over the past ten years, the number of successful case closures has increased, with a shift away from sheltered workshop settings and toward more integrated employment settings. Between 1990 and 1999, the number of successful case closings increased from 350 to over 1,000 per year. In the same period, successful case closings in a sheltered workshop setting dropped from five-percent of all successful closings to less than one percent. The Department of Labor plans to reduce the reliance upon sheltered workshop placements even further.

Thus, as we have noted, Maine has been moving in the direction of community integration for many years. As a result, we are ahead of many states in minimizing reliance on institutions for persons with disabilities. As Maine has transitioned from institutional services, it has built a broad array of community services. (These services are described in WHAT WE HAVE NOW, Appendix J).

Much of Maine's progress can be attributed to strong advocates who have been passionate in their commitment to civil rights and access to services for persons with disabilities. Through numerous organizations and initiatives, we continue to build an advocacy community of strong, articulate consumer and family representatives. We have numerous advisory boards, committees, and councils all working toward addressing the needs of persons with disabilities.

We also give credit to our leaders. Many of our leaders have a personal commitment to community integration. Our state government is small, making access to and collaboration among leaders easier. We have a Legislature that listens to the people it represents and responds to their needs. And we are fortunate to live in a state that cares about people, with a supportive press community that highlights disability issues.

## ***The Road Left to Travel***

While much progress has been made, when one compares the general well-being of persons with disabilities with the well-being of persons without disabilities, it is easy to see that there is a long way to go before our vision of equality and integration is achieved. Persons with disabilities are more likely to live in poverty, more likely to be unemployed, and more likely to feel excluded from our society than persons without disabilities. Below we review some of the national and state data that document our continued need to address the barriers to community integration and equality.

### **Income and Employment**

- Nationally, almost 30% of persons with a severe disability live below poverty, compared to 8% of persons without a disability.<sup>10</sup>
- For working aged adults, persons with disabilities are much less likely to be employed (either full-time or part-time) than people without disabilities (32% versus 81% respectively).<sup>11</sup>
- When people with disabilities are employed, they earn on average only 67% as much as people without disabilities.<sup>12</sup>
- Supplemental Security Income (SSI), an income-support program for persons with disabilities, currently pays \$545 (\$6540 annually) for an eligible individual and \$817 (\$9804 annually) for an eligible couple.<sup>13</sup> The individual SSI benefits (including a state supplement of \$10) total 22.5% of the one-person median income in Maine.<sup>14</sup>
- Social Security Disability Insurance (SSDI) is an income-support program available to persons who have worked and paid into Social Security (or their dependents). Benefits vary with contribution. If a 40-year old earning \$45,000 annually becomes disabled, annual SSDI benefits would be an estimated \$17,300.<sup>15</sup>
- Nationally, 36% of employed people with disabilities say they have encountered some form of discrimination in the workplace due to their disabilities. Of people who have experienced discrimination, 51% say they have been refused a job due to their disabilities. Others say they have been denied a workplace accommodation (40%), given less responsibility than co-workers (32%), paid less than other workers with similar skills in similar jobs (29%), refused a job promotion (28%), and refused a job interview (22%).<sup>16</sup>

### **Housing**

- One study found that over 87 percent of a monthly SSI benefit is required to rent a one-bedroom housing unit in Maine.<sup>17</sup>



- For some communities in Maine, rent for a one-bedroom would consume all or more than all of a person's SSI benefit.<sup>18</sup>
- Thirty-five percent (35%) of subsidized households headed by a non-elderly adult, include a head of household or spouse with a disability. For the elderly, the rate is 17%.<sup>19</sup>
- Forty-five percent of homeless people in Maine have a mental illness; 60% have an addiction disorder.<sup>20</sup>
- Homelessness for persons with addiction disorders has increased since a change in federal law in 1996, denying SSI and SSDI (and with it health coverage) to people whose addiction is considered to be the cause of their disability status. Two-thirds of those who were paying for their own housing and who lost benefits because of this change went on to lose their housing as well.<sup>21</sup>
- Less than 5% of people with disabilities who receive SSI own their own homes.<sup>22</sup>

## Transportation

- Persons with disabilities are three times as likely to have a problem with inadequate transportation, than persons without disabilities (30% versus 10%).<sup>23</sup>
- Twenty-nine percent of non-working adults with disabilities who report difficulty looking for work said that the lack of transportation is a barrier to employment.<sup>24</sup>

## Education

- Nationally, 22% of persons with disabilities fail to complete high school, compared to 9% of those without disabilities.<sup>25</sup> Graduation rates have improved over the last 15 years. In 1986, 39% of people with disabilities failed to complete high school.
- The likelihood of graduating depends on the nature of the disability. National data show that students with sensory impairments are most likely to graduate (73 %), while about two-thirds of students with orthopedic impairments, mental retardation, multiple disabilities, and learning disabilities graduate.<sup>26</sup> Children with serious emotional disabilities are least likely to graduate (35%).
- People with disabilities are less likely to graduate from college than people without disabilities (12% versus 23%).<sup>27</sup> Data also show that persons with disabilities are less likely to enroll in a 4-year college than their counterparts without disabilities (42% versus 62%).<sup>28</sup>
- Students in special education account for 31% of the incidents resulting in removal from school. Of these students, 47% had behavioral impairments and, of those, 51% were referred to alternative placements.<sup>29</sup>

## Isolation and Inclusion

- People with a disability are less likely to socialize with friends, relatives or neighbors and are less likely to go out to a restaurant, go shopping, or go to a movie.<sup>30</sup>
- For elders, social isolation and loneliness, often resulting from living alone, are important contributors to the high rate of suicide.<sup>31</sup>
- People with a disability are also less likely to vote, sometimes prevented by inaccessible polling places.<sup>32</sup>
- A person with a disability is twice as likely to live alone as a person without a disability.<sup>33</sup>
- Children and adolescents with disabilities are much more likely to feel sad, unhappy, or depressed.<sup>34</sup> Adults with disabilities are much more likely to report feelings such as sadness, unhappiness, or depression that prevent them from being active.<sup>35</sup>
- Compared to persons without disabilities, persons with disabilities tend to be less satisfied with their lives and feel excluded. Thirty-three percent are very satisfied with life in general, compared with 61% for persons without disabilities.<sup>36</sup> Forty-eight percent of people with disabilities say they feel left out of things in their communities, compared to 32% for people without disabilities.<sup>37</sup>

## Families

- A needs assessment conducted in Maine suggests that parents caring for a child with a disability experience limited or reduced work because of their caregiving responsibilities. Three-fourths of respondents reported one or more limitations on employment as a result of meeting the needs of a family member, including limited job choice and giving up a paying job.<sup>38</sup>
- A study found that women who provided 100 or more hours of assistance to their elderly parents in the past 12 months cut back on work by about 459 hours per year.<sup>39</sup> This reduction in work translates into approximately \$7,800 in lost wages (using 1994 dollars), which in turn translates into lost retirement savings because fewer credits are earned toward future Social Security and private pension benefits. In addition, some lose health insurance benefits.

## *Opportunity for Change*

Recent events provide hope and an unprecedented opportunity to build upon and improve the services and public awareness we have now.

The *Olmstead* decision is the primary reason the opportunity for change is so great. The *Olmstead* decision has triggered “*Olmstead* planning” in 40 states across the country. In addition, it has triggered a tremendous amount of activity at the federal level. Under the Clinton administration, the federal government spurred states to respond to *Olmstead* and backed up its commitment with \$64 million dollars in grants, including grants under the Real Choices Systems Change grant initiative. (Previously, the federal government had enacted the Ticket-to-Work and Work Incentives Improvement Act (TWWIIA) with its own array of grants.) The Bush administration has also leant its support to “implementing *Olmstead*” through its New Freedom Initiative. To that end, ten federal agencies evaluated their policies, programs, statutes and regulations to determine whether any should be revised or modified to improve the availability of community-based services. Through these federal initiatives, increased attention has been focused on housing, transportation and employment resources, in addition to improving and expanding access to community health, mental health and supportive services.

The *Olmstead* decision provides an opportunity for increasing the level of awareness in the community. Nearly 14 years after the enactment of the ADA, public awareness and support for community integration have grown. Progress toward integration in the schools, which began under state law in 1973 and is now also governed by the Individuals with Disabilities Education Act of 1997, has also helped to increase public understanding and awareness of needed supports and services. The *Olmstead* decision reinforces this trend by providing another vehicle for pressing the “integration imperative” under these civil rights statutes.

Advances in technology also offer new opportunities for change. An expanded array of technologies, including assistive technology and information technology, permits more people to move from restrictive environments into more integrated living arrangements, with more independence. In addition, advances in information systems technology offer the opportunity for data-driven policy development. The potential to integrate information systems offers the opportunity to reduce the cost of collaboration, reducing one of the barriers to integrated information and referral, integrated services, and integrated funding.

As we consider the opportunities before us, we think, too, about what true lasting change would look like. Transforming the lives of persons with disabilities means transforming the political and cultural landscape, which can create or remove barriers to community integration. In our transformed world:

- The leadership in our state and federal government will have a shared understanding of the meaning of community integration that will endure and expand over time and with changing administrations.
- Our leaders will advocate for and implement creative changes responsive to the needs of people with disabilities.
- Our leaders will commit the resources necessary to make community integration a reality.

- Our community will value the lives and respond to the needs of persons with disabilities, advocating for inclusion and equality in dignity and rights.
- We will understand that “disability” is not about somebody else; it is about all of us.
- We will create a single, coherent and accessible approach to serving persons with disabilities, responsive and accountable to the persons served.
- We will provide meaningful choice by opening to each person the world of possibilities and providing the supports to make those possibilities attainable.
- We will make sure that we have the quality providers we need to make community integration possible.
- We will never ask families to give up their children to make sure they have needed services.
- We will have the information we need to make reasoned decisions about allocating resources.
- We will continually monitor our progress toward community integration with consumers playing a meaningful and active role in that process.
- We will protect each individual’s right to privacy, while making sure we open the lines of communication for integrating services.

## ***Recommendations***

While it is ambitious to think about transforming our community’s understanding and responsiveness to the needs of persons with disabilities, we can take some positive steps toward change. With enough political will and commitment from our leaders and community (and united support from advocates), we can begin down the path toward our vision of community integration. We can start with the recommendations below.

### **Consumer Voice**

- Support the recruitment and training of consumers to participate on state and provider boards, including consumer advisory boards, quality improvement boards for mental health and other provider agencies. Require publicly financed providers to support self-advocacy, and to complete training programs for self-advocacy and peer supports.
- Train employers, community leaders, churches and others to be open and receptive to self-advocacy.
- Develop more user-friendly advocacy organizations and materials.
- Provide supports for protecting individual rights, including user-friendly guides and training programs to educate people about their rights, focusing on different topics (*e.g.*, housing, employers, public accommodations, eligibility for services, filing complaints, successfully negotiating with service providers); and expanding legal resources to advise people on how to protect their rights and to pursue alternative dispute resolution options.

- Develop alternative advocacy models to enable participation by people who do not usually have the opportunity, means, or time to do so.
- Create advocacy organizations independent of the State with funding that cannot be jeopardized by taking positions adverse to the State or provider agencies. (For example, the Office of Consumer Affairs, within the Department of Behavioral and Developmental Services (BDS), should be independent of BDS.)

## **Organized Consumer Advocacy**

- Eliminate barriers to participating in public policymaking, including physical and communication barriers.
- Pay for support services necessary for participation, such as readers, notetakers, drivers, and personal care attendants.
- Make available funding to support transportation costs, childcare costs, and other out-of-pocket expenses that make participation a burden.
- Develop and publicize alternative means for giving input into the political process with use of technology and assistive technology.
- Support coalitions of advocacy groups around key issues.
- Support clearinghouse and information exchange between advocacy groups.
- Support leadership training.

## **Choice and Control**

- Expand self-directed services by providing individuals and families with the power to control and direct the services delivered, including the right to recruit and select their own employees and deliver the paycheck.
- Offer individual budgets for the entire range of long term care and home and community based services needed, basing the level of support on health, functional status, and living situation (including housing and transportation needs). Permit the individual or family to determine which services to purchase.
- Allow and promote the use of independent employment management services (*e.g.*, withholding and filing employment taxes, preparing and disbursing payroll checks) and other types of supports for persons directing their own care. Ensure that the Fiscal/Employer Agent (FEA) has no financial interest in the self-directed services purchased by the individual or family.
- Develop intermediate supports so that self-directed care is an option for persons who do not want all the responsibilities of self-direction (*e.g.*, people who do not want to decide who to hire and fire).
- Develop standards for offering the self-directed care option to persons not legally competent to direct their own care by allowing surrogate decision makers to direct care

(including quality-management standards for ensuring that the surrogate is acting in the interests of the individual).

- Define “allowable expenses” while permitting individuals and families to use their budgets to meet individual needs.
- Develop strategies for reducing the reliance on forced medication and involuntary hospitalization.

## **Person-Centered Services**

- Organize services around the person served, not for provider convenience.
- Provide individuals and families with the option of having one comprehensive resource plan incorporating the full range of needs.
- Provide individuals and families with the option of having one independent person facilitate service integration and coordination across providers and programs.
- Create a “circle of accountability” to ensure that all persons who are part of a comprehensive resource plan are accountable for their roles and that gaps are filled when a promised support fails.
- Adopt accountability standards that require individuals and families to actively participate in planning, to register sources of satisfaction and dissatisfaction, to file grievances, to learn and exercise rights, to share relevant information, to make informed choice, to take advantage of opportunities to serve on policy boards, and to complete information on progress toward outcomes and quality of services received.

## **No Wrong Door**

- Create a statewide, integrated information and referral system that covers all disability-related services through an interactive, searchable website and a statewide toll-free hotline.
- Develop integrated service centers to serve as entry points and information sources about services across programs; including an integrated application process for those who choose it.
- Conduct education and outreach to make sure people know where they can obtain services.
- Conduct follow-up surveys to identify opportunities for improvement in information and referrals.

## **Coherent System of Services**

- Develop common vocabulary across systems.
- Develop 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.

- Develop 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.
- Develop standards for measuring and improving community integration.
- Integrate information sources across systems, while protecting individual control over privacy.

### **Responsive Service Coordination<sup>40</sup>**

- Identify gaps in eligibility for service coordination services.
- Explore new ways of providing service coordination, including strategies for ensuring the independence of support and providing service coordination at neutral sites.
- Improve quality through training and quality monitoring.
- Explore the appropriateness of combining counseling and care management services.

### **Funding & Planning**

- Pursue more accurate measures for how many people have a disability and type of disability, counting both people who receive services and those who do not.
- Define “need for services” to include the range of services necessary to support sustained community living and participation.
- Collect data on place of residence, across a range of settings (*e.g.*, institutional, boarding facility, home, street, shelter); the barriers to moving to a more integrated setting, if applicable; and the individual’s preference for where to live.
- Link data across programs so that the State has the information it needs to effectively manage the allocation of its resources.
- Improve measures of the future need for services by enhancing data collection efforts in schools and evaluating trends that influence the need for services.
- Develop other measures of unmet need, using claims data and other resources to identify when people are waiting too long for services.
- Expand the statutory requirement that state budget requests be based on anticipated need for services, by also requiring budget requests to include the current need for services and unmet need for services. Improve state compliance with this statutory requirement.
- Explore other opportunities to leverage federal funding, including possibly using MaineCare to pay for additional services consistent with the home and community-based services model.

- Advocate at the federal level to eliminate cost neutrality requirements in Home and Community-Based Services (HCBS) Medicaid waivers thereby increasing access.
- Advocate at the federal level for people with mental illness to have reasonable access to Medicaid options that support integrated living.

## **Waiting Lists**

- Develop standards for collecting consistent data on waiting lists.
- Develop standards for maintenance of provider waiting lists.
- Develop standards for the fair administration of waiting lists, including how people get on a waiting list, how persons are prioritized, how persons are notified of their status, etc.

## **Direct Care Providers**

- Build respect for direct-care workers by developing a public relations plan for communicating their importance and responsibilities to key constituencies, including potential direct care workers, their employers, consumers, legislators, and the general public; Build respect through exploring models for elevating the status of direct care workers.
- Explore increasing the educational and training requirements for certain direct-care services.
- Improve recruitment and training by defining the competencies the professional direct-care workers should master; creating effective training; providing direct, hands-on experience during training, providing more supervision, transition, and mentoring support, especially during the first year.
- Consider increasing the direct-care educational and training prerequisites for the provision of certain services.
- Define and develop professional growth opportunities along a career track of increasing responsibility, reward and compensation and create multiple levels of state certification to support the career track.
- Encourage employers of direct-care staff to improve wages and benefits.
- Explore whether or not to create a statewide or regional association to support direct-care workers.

## **Quality Services**

- Build standards for quality and accountability into the design of services and evaluate quality on an ongoing basis.
- Develop a consumer-driven approach to quality management, so that the people receiving the service define what is meant by “quality.”



- Develop a comprehensive definition of quality that includes a complete view of a person's life, including home and family, school, work and daily activities, and social and community living.
- Measure the contribution of all supports in a person's life at home, at work, or in daily living activities, and community.
- Measure quality focusing on what the person values as being most important and what enhances the person's experience.
- Require providers to assess and evaluate satisfaction with the services they provide, use findings to improve services, incorporate the consumer and family in quality management and program design and implementation.
- With the input of consumers, develop quality indicators related to the expected results of the services for the individual, how the design of the services meets the identified need, how the services will be delivered, the expected duration of specific services, possible alternatives for services, and how results will be evaluated.

### **Accessible, Available Transportation**

- Support the recruitment and training of consumers to participate in consumer advisory boards for regional transportation organizations.
- Petition for regional transportation boards to develop consumer advisory boards and committees if they do not already exist.
- Improve coordination between the Department of Transportation and other state agencies to maximize the effective and efficient use of resources and to make sure there is a link between the location of services and transportation planning.
- Experiment with more flexible MaineCare policies which would allow use of Medicaid dollars for transportation services beyond medical appointments (*e.g.*, a Medicaid waiver that allows use of fixed monthly transportation allowances for meeting any transportation need).
- Explore the development and operation of rural programs which train, coordinate, and monitor volunteer drivers and ride-share programs that meet transportation needs of rural residents without cars.
- Identify departmental representatives to participate in a cross-system transportation funding development and oversight group that works to identify and then take advantage of creative funding opportunities, particularly discretionary federal and foundation grants (*e.g.*, social service funding application that takes advantage of allowable transportation cost option, or transportation asset application that takes advantage of allowable costs to train people with disabilities to use public transit).
- Undertake an audit of consumer-led cross-departmental transportation policies and programs to identify opportunities and barriers for better transportation services for individuals with disabilities at the community level.

- Hire a director of statewide driver-training to coordinate training programs for all regional providers.

## **Integrated, Accessible and Affordable Housing**

- Expand the Bridging Rental Assistance Program (BRAP) to cover all who need it.
- Educate bankers, realtors, and other housing professional about home ownership options for people with disabilities, available subsidies and assistance programs, and landlord/tenant issues.
- Make sure resources are available to pay for modifying a home or an apartment when necessary; make sure home modification is affordable.
- Support the recruitment and training of consumers to participate on public housing boards and in public housing authority annual or 5-year planning processes.
- Expand legal resources to advise people on how to protect their housing rights.
- Support training programs to educate people about their housing rights and effective ways of educating landlords about rights and accommodations.
- Support training programs for landlords to educate them about disabilities and different accommodations.
- Advocate to remove the federal barrier to housing assistance for persons in recovery who have a conviction for a drug-related offense.
- Identify departmental representatives responsible for ensuring that the relationship between the location of housing, services and access to transportation are taken into account in the planning and development process.
- Give people options about where to live and with whom and develop those options
- Break the link between housing and services so that individuals do not feel they have to give up their choice of providers in order to keep their residence.
- Break the link between a residential setting and the level of services available so that, rather than moving from one setting to another setting a person can stay in one place and receive appropriately adjusted levels of service.
- Review and modify regulations, as appropriate, to ensure that basic needs, such as home modifications, communications systems, transportation, and other transitional services are provided to meet the needs of people in institutions who wish to return home..
- Make sure that service coordination, including case management services and community support services are available to assist in a transition, for up to 180 days before a transition from an institutional setting.
- Define “most integrated setting,” and track whether the people served are receiving services in the most integrated setting appropriate to their needs and preferences.
- Make sure that all people not served in the most integrated setting appropriate to their needs and preferences are provided that option within a reasonable period of time.

- Increase the affordability of homeownership by supporting homeownership loan programs such as Coastal Enterprise Inc.'s now unfunded *Home Assistance Venture II*, which assisted people with disabilities in making down payments and meeting closing costs.<sup>41</sup>
- Examine all MaineCare options that impact on housing to ensure that only those that maximize integration (such as HCBS) are used.

## Jobs

- Expand legal resources to advise people on how to protect their employment rights.
- Support training programs to educate people about their employment rights.
- Explore current personal-assistance service offerings and additional policy options that Maine might take advantage of under federal law.
- Modify personal-assistance services assessment tools to identify what a person specifically needs in the home in order to prepare for work, as well as what personal-assistance services might be needed on the job site to successfully complete job tasks.
- Expand supported employment services to all who need them regardless of diagnosis.
- Eliminate sheltered workshops and enclaves.
- Improve and expand coordination between schools and vocational rehabilitation services.
- Increase awareness and understanding of disability to eliminate stigma and fear of litigation and costs of complying with the ADA.
- Educate providers on their role in protecting an employee's rights under the ADA.
- Increase support within local secondary schools to provide assistance for students with disabilities in seeking and maintaining after-school and weekend jobs, internships, and cooperative education (work-study) arrangements
- Undertake a statewide effort in partnership with the Social Security Administration to make better use of existing Plan for Achieving Self-Support (PASS) and Impairment Related Work Expenses (IWRE) procedures that allow people with disabilities to target earnings to meet specific work support needs in a way that also continues cash support and medical insurance.
- Develop and sustain additional means of involving employers, particularly small businesses, in leadership networks which allow them to both define and oversee employment preparation and support services. Current opportunities for this include the national Business-Leadership Network, employer networks which are forming under the federal Workforce Investment Act (WIA), and Project with Industry models as funded in the federal labor and vocational rehabilitation systems.
- Promote and support alternative and flexible work options that meet the needs, skills and availability of workers with severe disabilities, including telecommuting, job-sharing arrangements, and use of assistive technology.

- Explore and develop strategies to increase employment options for people with disabilities who have criminal records.

# Endnotes

<sup>1</sup> 28 C.F.R. § 35.130(d)

<sup>2</sup> Calculated using summary tables accessed 2.23.02 through the U.S. Census Bureau website at: <http://factfinder.census.gov/>.

<sup>3</sup> Based on a total population of 1.2 million

<sup>4</sup> Institute of Medicine, *Disability in America: Toward a National Agenda for Prevention*, National Academy Press, Washington, D.C., 1991.

<sup>5</sup> <http://www.usdoj.gov/crt/ada/pubs/ada.txt>

<sup>6</sup> *Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators*, National Conference of State Legislatures, January 2000.

<sup>7</sup> Email message dated August 1, 2002 from Leyton Sewell, Maine Department of Behavioral and Developmental Services.

<sup>8</sup> Email message dated August 6, 2002 from John Baillargeon, Maine Department of Human Services, Bureau of Elder and Adult Services.

<sup>9</sup> Count obtained by Linda Jariz on 8/28/02. Children in out-of-state placements funded by DOE or privately funded are not included in the count.

<sup>10</sup> Jack McNeil, *Americans with Disabilities: Household Economic Status*, U.S. Census Bureau (February 2001), based on 1996 Survey of Income and Program Participation.

<sup>11</sup> accessed 2.21.02 from:

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<sup>12</sup> Mitchell P. LaPlante, Jae Kennedy, H. Stephen Kaye, and Barbara L. Wenger, *Disability and Employment*, Disability Statistics Center (January 1996). Accessed 2.23.02 at:

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<sup>13</sup> SSI Payment Amounts on Social Security Administration website accessed 2.23.02 at:

<http://www.ssa.gov/OACT/COLA/SSIamts.html>.

<sup>14</sup> Ann O'Hara, Emily Miller, *Priced Out in 2000: The Crisis Continues*, Technical Assistance Collaborative, Inc. and Consortium for Citizens with Disabilities Housing Task Force (June 2001), accessed 2.23.02 at: <http://www.c-c-d.org/POin2000.html#a>.

<sup>15</sup> Calculated using Social Security Administration's website Benefit Calculator, accessed 2.23.02 at:

<http://www.ssa.gov/retire2/calculator.htm>.

<sup>16</sup> accessed 2.21.02 from:

[http://www.nod.org/cont/dsp\\_cont\\_item\\_view.cfm?viewType=itemView&contentId=134&locationId=18&contentType=7&fromLocHmePg=F&LineNbr=1&StartRow=1&timeStamp=21-Feb-0211:33:55](http://www.nod.org/cont/dsp_cont_item_view.cfm?viewType=itemView&contentId=134&locationId=18&contentType=7&fromLocHmePg=F&LineNbr=1&StartRow=1&timeStamp=21-Feb-0211:33:55)

<sup>17</sup> O'Hara & Miller.

<sup>18</sup> O'Hara & Miller

<sup>19</sup> Data derived from U.S. Department of Housing and Urban Development website, *A Picture of Subsidized Households – 1998* accessed 2.24.02 at: <http://www.huduser.org/datasets/assthsg/statedata98/me.html>. [revise using MSHA data]

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<sup>21</sup> Michael DeVos, *A Proposal to Reduce Homelessness*, Subcabinet on Homelessness (October 2001)

<http://www.mainehousing.org/reports.html>.

<sup>22</sup> Dwyer & Vogt, *Expanding Our Thinking on Housing Choice*, (2001).

<sup>23</sup> [http://www.nod.org/cont/dsp\\_cont\\_loc\\_hme.cfm?locationId=13&locationNm=Transportation](http://www.nod.org/cont/dsp_cont_loc_hme.cfm?locationId=13&locationNm=Transportation)

<sup>24</sup> Pamela Loprest, Elaine Maag, *Barriers to and Supports for Work Among Adults with Disabilities: Results from the NHIS-D*, The Urban Institute, (January 2001) accessed 2.23.02 at:

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