

MAINE ASSOCIATION FOR COMMUNITY SERVICE PROVIDERS

Testimony to Medicaid Advisory Commission

Atlanta, Georgia

March 14, 2006

Good evening Chairman Governor Sunquist and Vice-Chairman Governor King:

My name is Bonnie-Jean Brooks and I live in Sandy Point, Maine on beautiful Penobscot Bay headed Downeast towards Bar Harbor. I have been CEO of OHI, a nonprofit social service agency providing services to people with mental retardation, autism, and mental illness for 27 years. I am also here representing the Maine Association for Community Service Providers, which is a State organization representing over 60 provider agencies with services from Kittery to Fort Kent, Maine and from the Western mountains to our island communities.

As the fall leaves dropped off the trees; as the branches became loaded with ice and snow; and, now, when the buds of those branches are in a state of becoming and some of us are tapping our maple trees, Maine Medicaid providers and their families and people with disabilities they represent have been hearing about the activities of this Commission.

I am here today to tell you a few stories that I hope you will keep in mind as you make very tough decisions about your further recommendations.

It was ten years ago this month that Maine became the 4th State in the nation to entirely close its large State institutions for people with mental retardation. I remember that moment ten years ago when I released my homing pigeons on the grounds of Pineland Center symbolizing the release to freedom of hundreds of Maine citizens back to their home communities.

Maine is one of the few States that operates a community system of services managed almost entirely by the private sector. Maine has taken the position that the public sector can more appropriately and adequately serve in roles other than direct delivery of services for people with disabilities.

This ten-year journey has resulted in previously institutionalized Mainers getting and keeping jobs, owning homes, becoming participating members of their communities and learning how to advocate for themselves. We continue to witness one of the greatest civil rights movements in the history of America!

Much of this success is directly attributable to the Medicaid program, which has served as a lynch pin in people's lives. Pauline is a 69 years old woman whom I first met curled up in a fetal position behind a sofa at Pineland 25 years ago. Thanks to the ICF/MR and, later, the Waiver programs, Pauline now lives in her own apartment in Bangor with 14 hours of support a week and she has a job at a bakery. Her annual budget is \$21,330. Think of what it would be if she continued to live in the institution but, more importantly, think of what the quality of her life would have been! Then there is Amy, a 43 year-old woman who lives in a mobile home in Bangor without live-in supervision. Her Waiver budget is \$65,380. When I met her 23 years ago, she was at Pineland in full restraints with 1 to 1 staff. She works at Maine Distributors. Then there is Norman a 64-year old man who lives in subsidized housing in Bangor with only 14 hours of support a week. His Waiver budget is less than \$20,000.00. When I first met him 23 years ago, he had been institutionalized for many years in a number of California institutions.

However, in any State that has made a commitment to ensuring that people live free in the community without any State institutions, there is always going to be a small fraction of people who require a high budget in order to ensure their health and safety. Some of these people have extraordinary medical needs and/or behavioral challenges. These people are individuals with such complex needs that even Nursing Homes will not accept them because of the severity and complexity of their needs, particularly in view of their growing workforce crisis.

In 2004, the Maine Legislature directed the Maine Department of Health and Human Services to provide information

about individual budgets exceeding \$200,000. Teams consisting of departmental personnel, including the Director of Mental Retardation Services and the Special Master of the Community Consent Decree, engaged in personal visitations and an extensive study of these identified individuals.

When the study results were presented to the Legislators, ultimately, it was convinced that services were appropriate; that they were not excessively costly given the nature of needs of the individuals; and that, in many cases, there were steady reductions in those budgets as people were stabilized and Treatment Plans were effective.

But the ability of Maine's mental retardation service providers to continue to assure quality is being markedly affected by the flat-funding environment; a freeze on Home and Community Based Waiver Services for over two years unless it is an adult protective situation; legislatively -- mandated cuts to the Waiver program; huge increases in health insurance, gasoline, fuel, and other utilities; and other steadily increasing costs. This is all coupled with a dramatic workforce shortage in a mental retardation field in Maine where the starting pay is \$8.56 an hour. Many of our employees and their families are also eligible for Food Stamps, TANF, and other such benefits.

The ability to recruit quality employees is the worse I have seen in my 27 years. My own organization has 40 vacancies and has experienced a 43% turnover rate in 2005. And believe it or not, this is below the national average.

On top of it all, we have just been informed that our agency's health insurance premium will increase by 38% representing over a \$.5 million increase contrasted to our December Profit and Loss Statement showing that our entire organization was \$ 51,400 in the black. I don't know what we're going to do. Will our State be able to unexpectedly serve over 300 people with life-threatening behavior if we have to close?

I have come before you today in an effort to say that Medicaid has led to lives of freedom and success for many people whose civil rights were denied for years but that it is not being funded at a luxury level and that we were are losing ground dangerously. As you move forward with your deliberations, I hope you will remember that the lives of people with mental retardation funded by Medicaid can be changed forever by the recommendations you make that may result in final action.

Thank you so much for listening to the message that I have brought to you from the providers in Maine. Why don't you all come up to Maine for a meeting but don't come in black fly season or you may not return!

Respectfully,

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Attachment: Report To The Joint Standing Committee On The Review of Certain High Cost Individuals (Maine) – January 2005

DHHS
MENTAL RETARDATION SERVICES

REPORT TO THE JOINT STANDING COMMITTEE ON THE REVIEW OF
CERTAIN HIGH COST INDIVIDUALS

JANUARY 2005

To the honorable Members of the Appropriations and Health and Human Services Committee:

At the request of the Appropriations Committee of the 121st Legislature, a review of certain individuals with mental retardation with costs in excess of \$200,000 were reviewed by the Department. The attached report is the summary of the review and its findings.

MENTAL RETARDATION SERVICES
\$200,000 BUDGET REVIEWS
JANUARY 2005

During the 121st session of the Legislature, questions and concerns were raised about high cost of services provided to certain individuals with mental retardation whose annualized costs exceeded \$200,000. Mental Retardation Services identified 81 individuals with high cost budgets. This represents 3.5% of the total number of individuals funded through the waiver program. MR Services developed a protocol and used it to review each of these individuals. Staff from the Department were selected to conduct the reviews. The selected staff had no direct involvement in the design of the supports and services to the 81 individuals. Assigned cases were reviewed between August and October and each team completed the required forms, made observations and, when appropriate, recommendations.

The teams interviewed individuals, direct support staff, house managers and Individual Support Coordinators (ISC). They reviewed the person- centered plan, residential records, staffing patterns, documentation, medication administration, critical incidents and restraints.

The general observation from the review teams was that the direct support staff and their supervisors were well informed and served as advocates for the individuals they support. The teams supporting the individuals were creative in finding positive ways to support individuals by reducing staffing when appropriate or sharing resources with other individuals in need of services resulting in reduction in costs. Overall the review teams were impressed with the efforts that agency staff made to provide stability, resulting in an improved quality of life. Approximately 75 –80% of the cost associated with providing services to these individuals are for direct support staff. These individuals require intensive staffing for behavioral interventions and/or clinical supports. Overall the review teams found the level of staff to be appropriate. However, some of the recommendations from the teams suggested a review of staffing levels as well as referrals for clinical assessments that might assist the teams in evaluating interventions and supports.

Clarence Sundram, Court Master for the Community Consent Decree, conducted several of the reviews with staff from MR Services central office. In the monthly meeting with the parties involved in the Community Consent Decree, Mr. Sundram reported that he was very impressed with the dedication and knowledge of the direct support staff. He also observed that, given the complexity of the individuals he reviewed, funds, for the most part were well spent, perhaps resulting in an overall savings to the State by the dramatic reduction in costly, lengthy admissions to psychiatric hospitals. Mr. Sundram

also commented that in any community system there will be some individuals who will be at a high cost to the State.

Mental Retardation Services found this to be a very useful and informative exercise. Pineland Center, the State's institution for people with mental retardation was closed in 1996. It is clear that community supports and services are meeting the needs of individuals who would otherwise be living in an institution. Although there are 81 individuals on the waiver program with high costs, they represent only 3.5% of the participants. The remaining 2500 individuals on the Home and Community Based waiver are supported at an average cost of \$73,000 which is well below the costs of institutional services.

The costs of services to some of the 81 individuals were reduced even before the reviews took place. This is due to the commitment and partnership of the MR Services caseworkers and the agency staff. However, it is clear that some individuals will remain with high cost budgets due to their extraordinary needs. A process for reviewing necessary level of supports and services is completed routinely by the planning teams supporting these individuals. Efforts to reduce costs when appropriate are an expected outcome.

Attached are the following documents:

#1: Graph with distribution of the numbers of individuals reviewed by County and DHHS (BDS) Regional office.

#2: Chart with de-identified information for each individual reviewed and a summary of the review team's recommendations for each individual.

#3: Chart with de-identified information for children.