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HB 1876

Testimony of Gary Blumenthal Before the Committee on Children, Families and Disabilities

Executive Director
Association of Developmental Disabilities Providers
June 27, 2007

My name is Gary Blumenthal. I am the Executive Director of the Association of Developmental Disabilities Providers, whose 105 members serve thousands of Commonwealth citizens with developmental disabilities in over 250 different settings throughout Massachusetts.

I am here today to urge the Committee's favorable consideration of House Bill 1876, an Act to Change the Title of the Department of Retardation to the Department of Developmental Disabilities.

Changing the name of the Department is consistent with the wishes of many self advocate consumers, family members, and professionals who work in the developmental disabilities field.

Words are important and do convey messages about the people whom we seek to serve. The term mental retardation has long been inadequate and has evolved into a pejorative term often used in a hurtful manner to describe individuals who may have a developmental disability.

Other prominent national organizations have spent many long hours discussing this issue. As a result organizations such as the former American Association on Mental Retardation have changed its name to the American Association on Intellectual and Developmental Disabilities. Similarly the organization I once headed for President Bill Clinton, the President's Committee on Mental Retardation has changed its name to the President's Committee on Intellectual Disabilities.

I do wish to sound one cautionary note with regard to effecting a name change with the Massachusetts Department of Mental Retardation; and I offer this caution as a former Kansas legislator myself.

Please do not simply change our name without also looking at the extensive needs within the developmental disabilities community within the Commonwealth.

The quality of services in the community that Commonwealth citizens have grown to depend upon are at risk for a variety of factors.

People with developmental disabilities live with the highest unemployment rates of any group in the Commonwealth in excess of 70%. Young men women coming out of high school face day services and employment programs that is seriously under-funded and stretched to its limits to deliver opportunities to consumers who seek meaningful employment and day activity.

Direct support professionals who work closely with consumers are finding it increasingly difficult to stay in this field because of the abysmally low salaries. Providers find it difficult to keep community programs stable because of any absence of rate increases for nearly two decades.

Precious limited dollars are poorly invested in operating an obsolete and outdated state institutional system, while community programs struggle to make end meet.

This year the Massachusetts House and Senate both responded to the crisis faced by Direct Support Professionals by increasing the Salary Reserve Line Item. That effort will help, but so much more remains to be done to improve the lives of Commonwealth citizens with developmental disabilities.

Will changing our name solve these problems? Certainly not.

So please keep your attention focused on all of our needs. Don't just change our name with out addressing our systemic needs as well.

Thank you.



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Testimony Presented to
The Joint Committee on Children, Families and Persons with Disabilities
June 27, 2007

I am pleased to be addressing the Joint Committee for the first time in my role as EOHHS Assistant Secretary for Disability Policy and Programs. I will be providing comments on the overall intent of the bills being reviewed here today and discussing related developments within the Secretariat. The bills under review address critical concerns facing people with mental retardation, developmental, traumatic, adult onset, and aging-related disabilities:

- reduction of stigma;
- determination and tracking of needed services;
- provision of community-based services across the lifespan and across disabling condition;
- facilitation of self-determination and choice; and
- assurance of safety and protection.

These are concerns the Administration shares and is actively pursuing through the discreet functions of the disability- and aging- related agencies and through the over-arching responsibilities across the Secretariat that now fall under my jurisdiction. I appreciate the considerable work that this new Committee, members in their previous roles, and the advocates, consumers, and stakeholders here today have done in framing important issues facing people with disabilities and their families. I look forward to our work together.

Stigma: Regarding the reduction of stigma as represented by the words "mental retardation", outgoing Commissioner Gerry Morrissey, in collaboration with the DMR Statewide Advisory Committee and others, has undertaken a substantive review of this issue and of the changes that have been enacted in other states. We are now one of only seven states with MR as the sole agency title and one of only a total of twelve with mental retardation in the title at all. It is time to make a change and the Administration is looking favorably upon this development as an important step forward in affirming the humanity of people living with this disability. Prior concerns regarding potential expansion of the service eligible population through the name change have been addressed substantially in this current bill. The Administration looks forward to completing a final review of the proposal in collaboration with incoming DMR Commissioner Elin Howe in anticipation of a decision in the next few months.

Determination and tracking of need: Disability policy, program and resource planning require access to individual and population level information regarding presenting disabilities, associated acuity, and needed services and other supports. Across EOHHS we are about to begin an inventory of all disability-related data sources, both those that are associated with service utilization and those that are part of public health and other population profiles. Included in the data review will be information from Turning 22, the program which entitles individuals who have received services as children to a continuation of certain services as adults.

The cross-Secretariat data review will provide us with a baseline for future service planning for people across disability and across the lifespan. It will also help highlight where data collection like that proposed in H.135 would be useful and what it will cost. Among the things we are especially concerned about highlighting are issues associated with differential disability and service access across racial and ethnic minorities. We look forward to reviewing the inventory process with the Joint Committee.

Provision of community-based services across the lifespan and across disabling condition: EOHHS has a number of efforts underway intended to address the expansion of community based services for individuals with developmental, traumatic, adult onset, and aging-related disabilities. Many of these have come about because of the leadership of the legislature and have yielded demonstrable progress in recent years:

- Since fiscal year 2001 we have assisted approximately 2624 persons with Mental Retardation to avoid admission to, or leave nursing facilities, and
- Since fiscal year 2005, have assisted approximately 250 persons with major mental illness to move from state psychiatric hospitals to community residences and reduce the number of psychiatric hospital beds.
- In the last two years, over 1400 young adults have been provided day habilitation, family support and other home and community based services through Turning 22;
- Currently, 1200 adults with traumatic brain injury are receiving home and community based services through the Statewide Head Injury Program;
- Three MassHealth home and community based waivers now in place enable us to help individuals with disabilities and frail elders choose from an array of community-based supports to help them remain home.
 - Through expanded PCA access we now have more than 15,000 disabled and elder adults receiving community living support annually; and
 - In the past two years alone, enrollment in the Frail Elder waiver has grown from roughly 6,000 to 8,000.
- For elders, we have continued to increase Assisted Living capacity and have expanded our supportive housing model; for persons with disabilities of all ages, we have successfully launched two Aging and Disability Resource Centers that provide comprehensive information and referral services, and have several more planned.
- Through changes in MassHealth regulations, we continue to foster mechanisms for enabling more people to remain in home settings in the community.
 - In both Adult Foster Care and the PCA program EOHHS changed regulations to allow family caregivers and others to care for elders and persons with disabilities.
- And through efforts administered by MRC, we have expanded our Independent Living Center and Adult Supported Living Program capacity, programs which, since the 1990s, have provided advocacy, peer support, case management, and PCA surrogacy, among other crucial services, to persons with disabilities who want to remain at home or return to home but who have no home agency or HCBS service entitlement.

Additional developments currently underway include: the recently completed Autism Waiver; the newly updated and approved DMR waiver; second year funding of "Community First" initiatives supported by the legislature, including upcoming expansion of services to people with traumatic brain injury; and the new Community First 1115 Waiver program currently under development and anticipated to eventually provide community supports to over 15,000 adults with significant disabilities, including qualified people with adult onset disabling conditions. Ongoing efforts to fully launch the PCA Workforce Council hold promise of improving the recruitment, training, and retention of an improved PCA workforce.

EOHHS is fully aware that many people with similar functional impairments and needs who do not have an entitlement basis to service access do not currently have the supports that would permit them to remain at home or in community settings. Through our multi-year federally funded System Transformation grant, we are producing policy, program, and financing restructuring recommendations to address these populations. The issues addressed in H.2195 / S.429 are broad ranging, have significant service structure and payment considerations and, thus, would best be first entertained by the Special Commission on Long Term Care for Persons with Adult Onset Disabilities that was authorized last year under Chapter 305 of the Acts of 2006. I am committed to accelerating that process in collaboration with this Joint Committee and to facilitating a review of interim restructuring and system change recommendations from the Systems Transformation efforts, at your earliest convenience.

Facilitation of self-determination and choice: Considerable research has documented the efficacy of self-determination and choice models in maximizing consumer satisfaction and facilitating independent living and effective habilitation. EOHHS has a number of developments underway in this arena, including: the service model currently in place throughout the Independent Living Centers; the recently established recovery learning centers at DMH; the individual supports model at DMR through which individuals are able to use budgets to purchase services with the assistance of an Intermediate Service Organization; a self-direction approach within the recently completed Autism Waiver; and the ASAP model of brokering elder-directed support.

Additionally, individuals using family support services at DMR have an option, in some cases, to convert the value of the services they need to an individual budget and area assisted by family support providers who serve as both support brokers and fiscal intermediaries. This option is undergoing further development. Last, there is a *Real Choice Pilot program, currently administered on behalf of EOHHS by UMASS, which is serving 12 adult Mass Health members with disabilities who need ADL assistance but do not qualify for hands-on PCA support. In this pilot, individuals are able to convert the plan of care developed with them to meet their needs to an individual budget. UMASS contracts on EOHHS' behalf with support brokers and fiscal intermediary entities to assist the enrolled individuals with managing their budgets and making their purchases and care plan changes.*

EOHHS seeks to develop a Secretariat-wide approach to developing self-determination and choice models and intends to have the pending recommendations from the federally funded C-PASS (Community-integrated Personal Assistance Services and Supports) inform this process. C-PASS is in its concluding year and has four main objectives: 1. to come up with a continuum of support to target under-served individuals with a consumer directed approach; 2. to use a collaborative model for managing the grant that includes consumers and other stakeholders; 3. to fund mini projects of alternative models for delivery of personal assistance services; and 4. to identify the challenges and barriers to self-determination we face in MA. C-PASS as well as planned new Real Choice initiatives

in disability and aging will help shape future program and resource decision-making. We would welcome reviewing the status of these efforts with the Committee in the fall.

Assurance of safety and protection: EOHHS recognizes the vulnerabilities faced by people with disabilities and is deeply committed to assuring their safety and protection. A review of incident reporting and investigation practices across the Secretariat has just begun and will include Department-based and DPPC-related activities. Additionally, the Governor is re-instating the Governor's Commission on Mental Retardation to facilitate the important oversight activities of this group. Candidates for membership on the Commission are currently under review and recommendations from the Joint Committee would be most welcome.

The EOHHS has embraced a cross-disability approach to developing systematic policies, programs, protections and resources for people living with disabilities across the lifespan. We will be expanding our plans in this arena over the course of the next year and look forward to working closely with you and with consumers and their advocates as together we plan for a more just and supportive future.

14) Department of Mental Retardation Name Change

Requested Action: Outside Section
Department of Mental Retardation

Proposed Language:

SECTION XXX. The name of the department of mental retardation is hereby changed to the department of developmental disability services.

SECTION XXX. The department of developmental disability services shall serve the same population as the department of mental retardation and shall not exclude any said person who is currently receiving services from the department of mental retardation nor shall the department of developmental disability services include any said person who is not currently receiving services from the department of mental retardation. This does not preclude the department of developmental disability services from expanding the population served at a later time.

SECTION XXX. The name change in the department of mental retardation shall take effect on June 30, 2009.

Background:

Massachusetts is one of only six states who still use the title of Department of Mental Retardation (DMR). Most states use a variation of Developmental Disabilities to describe the services offered by the agency.

As Chair of the Committee on Children, Families and Persons with Disabilities I have had the opportunity to see the impact the words 'mental retardation' have on people. During committee hearings during this session and last, I have seen hundreds of people come forward and request the department's name be changed to reflect politically correct language and not the slang term 'retardation'. They have described the feeling of receiving their mail with the return address of DMR as a reminder of people making fun of them.

I have also spoken to both the present and past Commissioner about changing the name of DMR. The main concern they and many advocates have is that the population served would increase. I believe the language presented would require the 2008 population being served to remain the same.

I fully support Senator Berry's language to see the name of the department of mental retardation changed:

SECTION 1. Section 1 of Chapter 19B is hereby amended by striking out the first sentence and inserting in place thereof the following paragraphs:-

“There shall be a department of developmental disability services, in this chapter called the department, and a commissioner of developmental disability services who shall have and shall exercise exclusive supervision and control of the department. All action of said department shall be taken by the commissioner, or under the direction of said commissioner, by such agents or subordinate officers as he shall determine.

The department of developmental disability services shall serve the same population as the former department of mental retardation and shall not exclude any said person who is currently receiving services from the department of mental retardation nor shall the department of developmental disability services include any said person who is not currently receiving services from the department of mental retardation. This does not preclude the department of developmental disability services from expanding the population served at a later time.

The name change in the department of mental retardation shall take effect on June 30, 2009.”

DMR STATEWIDE ADVISORY COUNCIL (SAC)
Seven Hills Foundation – Worcester
April 20, 2007

MINUTES

PARTICIPANTS: Cynthia Levine (Chair), Ron Asbjornson (Vice-Chair), Hank Paszko (Secretary), Rob Cutler, Jr., Amy Robinson, Gary Siperstein (phone), Almada Alexander (phone), Martin Adolphe

GUESTS and STAFF: Maria Damiano (MN Chair), Steve Powell, Maria Freccero (MV Chair), Jane Ricard, Jean-Mark Nortelus, Denise Daley, Barbara Cutler, Ann-Paszko, Ed Bielecki (MASS), Barbara Mazzella (Governor's Commission), Ralph Edwards (OCL)

The meeting was called to order at 9:38 a m

Cynthia Levine, SAC Chair, welcomed everyone to the meeting. She noted that Reggie Clark was vacationing in Arizona. This is the first meeting that he has missed in several years.

DMR Transition

Cynthia announced that the EOHHS Secretary appointed Dr. Jean Flatley McGuire as Under-Secretary and Interim DMR Commissioner. Part of the meeting will be devoted to discussing the implications of this appointment.

Members expressed their disappointment that Gerry Morrissey was not reappointed. His experience, dedication and leadership are a great loss to the Commonwealth. Several shared personal experiences with him that demonstrated his understanding and valuing of families and individuals served by DMR.

Members felt that SAC officers should meet with the Secretary and the Interim Commissioner. The SAC wishes to participate in the selection of the new commissioner and advise on the qualities and characteristics needed to be an effective commissioner. Some of these are:

Effective in legislative advocacy	Experience with the population served
Shared values	Team Player
Expertise on Medicaid	Vision
Support deinstitutionalization	

ACTION: SAC officers will meet with Secretary Bigby and Assistant Secretary McGuire to discuss transition and SAC role.

The SAC wishes to be part of recognition activities regarding the Commissioner.

ACTION: Cynthia will contact Larry Tummino to assure SAC participation.

Commission Conversation

Cynthia updated the SAC on her conversation with Commissioner Morrissey. Topics included:
Fernald – DMR is in compliance
Autism – waiver process proceeding; will work out relationship between SAC and Autism Division
Budget – Commissioner will keep SAC informed of progress

Emergency Management

Hank Paszko updated the SAC on the Mass Emergency Management meeting he attended. The key question was how to prepare for and respond to catastrophic events, particularly regarding special populations. Sub-committees will examine identification of special populations, personal preparedness, evacuation, and other matters related to emergency management. The challenge of transportation is addressed by a review of town evacuation plans to ascertain:
Where will individuals go? How do you get them out? How do you prioritize the order of evacuation?

There was general agreement that this is a matter that warrants the involvement of all CABs.

ACTION: The May SAC/Chair conference call will focus on emergency management. Ralph will contact Assistant Commissioner Diane Enoch and Erin McGaffigan, Senior Project Director of the Emergency Preparedness Project, to present to the CAB Chairs.

Quality Council

Ann Paszko reported on the Quality Council meeting and distributed the National Core Indicators (NCI) Consumer Survey Outcomes report. Massachusetts performance is highly rated. Clarification is helpful regarding responses related to transportation.

ACTION: A copy of the NCI report will be mailed to members. This will be an agenda item at the May SAC meeting.

Change the Name

Ed Bielecki, MASS State Coordinator, joined the meeting by phone to report on Change the Name. He reported that the MASS sponsored bill had been put into the wrong committee; but that has been corrected. Though it is now in the Children and Family Committee as part of the legislative process, MASS seeks to have the name of DMR changed through an Executive Order. An educational conversation with candidate Patrick makes them optimistic concerning his support and a meeting, within the next forty-five days, is being sought with the Governor.

SAC Budget Survey

Ron Asbjornson reported that the annual SAC/CAB Budget Survey was sent to all CAB members. Each should respond individually and contribute to a collective CAB response. The SAC requests that each CAB send the individual responses along with the CAB survey report.

SAC/MASS Collaboration

Barbara Mazzella reported on the SAC / Mass Advocates Standing Strong meeting. The group proposes that the SAC promote Citizen Advisory Board awareness of self-advocacy and MASS as an organization. The following information is needed from CABs:

How many self-advocates are on each CAB?

Do they participate in Family Citizen Monitoring and other CAB activities?

How does the CAB recruit self-advocates?

How does the CAB support self-advocates in participating on the board?

A member suggested that the turning 22 process provides a pool of prospective family and self-advocate members.

ACTION: Information on Turning 22 will be provided to the SAC at the May meeting. Ralph will contact Larry Tummino.

Human Rights Conference

The SAC will have a booth at the June 12th DMR Human Rights conference. Members are asked to attend the conference and to sign up to cover the booth. The conference brochure was distributed.

ACTION: Ralph will send registration information on the conference to SAC members and a sign up schedule.

Regional Reports

Hank Paszko reported that the Central / West Regional legislative breakfast was well attended by both the state legislative delegation and families. Ron reported that the NE regional meeting was rescheduled for May 9th. A report will be given at the next meeting. Arrangements are needed to get information on the SE region activities.

Turning 22 Meetings

Barbara Mazzella reported that a series of meetings on Turning 22 are being held across the state. The Governor's Commission and DMR seek to better understand family perceptions and experiences of the process. The Commission is conducting a survey and a guide for families on Turning 22 is planned.

Review of Minutes

The February 2007 minutes were approved. There was no March meeting in light of the SAC/DMR State House Celebration.

Restraints

In response to member inquiries regarding the letter to the Commission on restraints, Ralph reported that it is being reviewed by Human Rights and Legal Council. A response is forthcoming.

Members agreed to meet in June and July.

Maria Freccero stated that the Merrimack Valley CAB will share with the SAC its findings from tracking Family Citizen Monitoring data.

Cynthia announced that the 2007 Gunnar Dybwad Leadership Award recipients were Craig Smith and Anne Fracht, two self-advocates, along with Representative Angelo M. Sciccia.

The meeting was adjourned at 1:15 p m