

**Should the
DMR
change its name?**

**Commissioner O'Meara's report to
Governor M. Jodi Rell, the Office of Policy and
Management and the Legislative Public Health Committee
pursuant to Public Act 06-92**

January 2007

Public Act 06-92:

Public Act 06-92 (HB 5478), An Act Concerning the Department of Mental Retardation (DMR) passed the Connecticut General Assembly during the 2006 legislative session. The act required DMR to solicit input regarding a name change for the Department from clients and families receiving services provided by the department, advocates of person with mental retardation and other interested parties.

Pursuant to Public Act 06-92, DMR is required to submit a report of findings and recommendations, including the cost of any recommended name change, to the Governor, the Office of Policy and Management and the Public Health Committee not later than January 1, 2007.

Background of Mental Retardation Services in Connecticut:

Mental Retardation services in Connecticut were provided largely through the Mansfield Training School (opened 1917) and the Southbury Training School (opened 1941). Eventually, these facilities, along with “Regional Centers” established in the 1960s, were overseen by the Office of Mental Retardation (OMR), a division of the State Department of Health.

In 1975, the Connecticut General Assembly established an independent Department of Mental Retardation (Public Act 75-638). The Department has been in the executive branch, headed by a Commissioner appointed by the Governor, since that time. Although DMR continues to directly operate both campus and community-based services and supports, since the early 1980s, and driven by the *CARC v. Thorne* Consent Decree, the focus has largely become community-based relying on a public/private partnership.

The result is a statewide system that provides support and services to persons with mental retardation who reside in family homes, independently, in state-operated facilities, in licensed “community training homes” and in over 830 licensed/certified “community living arrangements.” Since 1987, most services and support provided by DMR have been subject to federal reimbursement under Home and Community Based Waivers, which are approved by the Center for Medicaid and Medicare Services (CMS). In this context, the term “mental retardation” continues in use in terms of federal legislation and entitlements.

At a point in time, the terminology “mental retardation” was considered progress as citizens of Connecticut had become accustomed to the words “idiot,” “imbecile” and “moron” to describe levels of impairment for individuals with an IQ of 69 and below. The “Connecticut School for Imbeciles at Lakeville” was established in 1860, and in 1915 was renamed the “Connecticut Training School for Feebleminded at Lakeville.” In 1917, the Training School merged with the Connecticut Colony for Epileptics at Mansfield and was renamed the Mansfield Training School and Hospital. In 1959, administratively, Mansfield was transferred to the new Office of Mental Retardation in the Department of Public Health until the independent Department of Mental Retardation was established in 1975, acknowledging that there were individuals in Connecticut who needed supports to help them achieve a certain quality of life as described by the DMR’s mission.

“Names and terminologies change over time. However, this must not be allowed to distract professionals and families from what should be the paramount concern. Individuals with mental retardation must be provided the types and levels of supports in school, work, and residential environments that will enable them to enjoy the same quality of life that is available to others in society.” (www.ericdigests.org/2003-4/mental-retardation.html)

The Debate:

There are two distinct schools of thought on this issue. The first is that the use of the word “retard” has become pejorative or derogatory through the years. There are individuals that receive support from DMR who are offended by the very terminology used to describe the Department. On the other hand, there are many individuals who have advocated strongly for many years to attain the level of recognition that the clinical diagnosis “mental retardation” brings to many in the state. Mental Retardation is a definable condition in the medical community and nationally.

Why now?

As referenced above, names and terminologies change over time. There has been a national movement among self-advocates and others to use more respectful language when referring to individuals with disabilities. For example, the President’s Committee on Mental Retardation was renamed the President’s Committee for People with Intellectual Disabilities. It is important to note that the President’s Committee is still addressing the same population as in the past under what they consider to be a more acceptable name.

A member of the New York State Partners in Policymaking class of 2004, a group that helped write New York’s “People First Language” legislation, said that “Words set the tone for attitudes and can change perceptions. Certain terms perpetuate negative attitudes towards people with disabilities and exclude them as being viewed as equal citizens.”

The challenge throughout this debate has been to contemplate how a suggested new name will withstand time in regards to evolving perspectives and perceptions that are constantly changing.

There has been increasing interest from advocates, families, and consumers nationally and specifically in Connecticut, in response to the term “mental retardation” because it is sometimes thought to be stigmatizing and offensive to people. However, the primary concern that has been raised in changing the name of the Department is that it might create an expectation of services for persons that DMR does not currently have the statutory authority or funding to serve.

The American Association on Mental Retardation’s (AAMR’s) Board of Directors voted to change the Association’s name to the American Association on Intellectual and Developmental Disabilities (AAIDD) effective in January 2007. It also voted unanimously to encourage the use of alternate terms for “mental retardation” while acknowledging that this term will continue to

have relevance in the diagnostic, legal and public policy arenas. AAMR's mission is "to promote progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities."

DMR's Mission:

The mission of the Department of Mental Retardation is to join with others to create the conditions under which all people with mental retardation experience:

- Presence and participation in Connecticut town life
- Opportunities to develop and exercise competence
- Opportunities to make choices in the pursuit of a personal future
- Good relationships with family members and friends
- **Respect and dignity**

As an agency whose mission is to promote respect and dignity for people with mental retardation, it is imperative that those who are supported by us feel respected, starting with the name of the agency that provides support to them.

Eligibility:

There has been much discussion about the implications, both real and perceived, that changing the name of DMR might have on eligibility or perceived eligibility for services. DMR's current name is based on the Connecticut General Statute 1-1g statutory definition of eligibility for DMR services that uses the term "mental retardation."

Here is the statute:

"Sec. **1-1g**. "Mental retardation", defined. (a) For the purposes of sections 4a-60, 17a-274, 17a-281, 38a-816, 45a-669 to 45a-684, inclusive, 46a-51, 53a-59a, 53a-60b, 53a-60c and 53a-61a, mental retardation means a significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.

(b) As used in subsection (a) of this section, "general intellectual functioning" means the results obtained by assessment with one or more of the individually administered general intelligence tests developed for that purpose and standardized on a significantly adequate population and administered by a person or persons formally trained in test administration; "significantly subaverage" means an intelligence quotient more than two standard deviations below the mean for the test; "adaptive behavior" means the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected for the individual's age and cultural group; and "developmental period" means the period of time between birth and the eighteenth birthday."

In order to be eligible for supports or services from the Department of Mental Retardation, a person must:

1. Be a resident of the State of Connecticut
2. Have mental retardation as defined in Connecticut General Statutes 1-1g

OR

3. Provide a medical diagnosis of Prader-Willi Syndrome.

Section 1-1g - Definition of Mental Retardation

Mental retardation means a significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.

- **"General Intellectual Functioning"** means the results obtained by assessment with one or more of the individually administered general intelligence tests developed for that purpose and standardized on a significantly adequate population and administered by a person or persons formally trained in test administration;
- **"significantly subaverage"** means an intelligence quotient more than two standard deviations below the mean for the test (usually this means an IQ score of 69 or lower);
- **"adaptive behavior"** means the effectiveness or degree to which an individual meets the standards of personal independence and social responsibility expected for the individual's age and cultural group; (usually this is determined by a test such as the Vineland Adaptive Behavior Scale, Behavior Assessment System for Children or Adaptive Service Scales);
- **"concurrently"** means that both deficits in intellectual functioning and deficits in adaptive behavior have to exist at the same time.
- **"developmental period"** means the period of time between birth and the eighteenth birthday.

WHAT DOES THIS MEAN?

1. You will need copies of all intelligence tests that have been done.
2. Typical IQ tests that can be considered include the Stanford-Binet Test of Intelligence, and the Wechsler Intelligence Scales (Children and Adult versions are available) and if necessary the Test of Non-Verbal Intelligence (TONI).

3. The scores on the IQ tests need to be 69 IQ points or lower.
4. Adaptive testing is also required. This measures any special assistance in activities of daily living such as handling money, cooking, dressing, grooming, and in your social activities and relationships.
5. On these tests the amount of assistance required is much more than other individuals at the same age.
6. Both the cognitive/intellectual and the adaptive difficulties must be present.
7. Both must have occurred before the individual was 18 years of age.

Once eligibility is determined, a DMR Region is assigned to help an individual access services and supports. However, eligibility for services does not assure that requests for services can be met immediately. Services of the Department of Mental Retardation are provided on a priority basis and within available appropriations.

A common concern that has been expressed throughout this process of exploring a name change for DMR is that currently in Connecticut, the agency only provides funding and services to individuals who have mental retardation as defined in state statute. In order to access services, individuals have to meet a specific eligibility requirement and even then services are provided within available appropriations. Services are not an entitlement.

There has been a push to expand services to individuals with developmental disabilities, including autism, which would require significant resources. There is a legitimate concern that services should not be expanded without the appropriate level of required funding. There are also people who fear that any new expansion of services could jeopardize funding for those who are currently eligible for DMR services under the current statute, but have been waiting for funding. Some families expressed a concern that a new name might be confusing to legislators and policy makers, especially in the context of the state budget and organizations and individuals who donate money to support groups and services.

In 2002, a report was issued by the Advisory Commission on Services and Supports for Persons with Developmental Disabilities to advise the Commissioner of Mental Retardation concerning the need for services and supports for individuals with developmental disabilities who do not have a condition defined as mental retardation pursuant to section 1-1g of the general statutes, as amended. (Required pursuant to PA 00-135)

There is a concern that changing the agency's name might create an expectation of services for people who are not currently being served. DMR decided that with passage of Public Act 06-92, it was important to clarify that the solicitation of input was specifically in regards to changing the name of the Department and was in no way meant to change the current mission of the Department, including the eligibility criteria of people served.

Outreach:

Gathering input from many interested individuals has been an important step in this process of pursuing a statutory name change for the department. DMR took many steps to ensure that outreach on this issue was widespread throughout the state. The Department set up a page on its website dedicated to this issue. A questionnaire was designed and widely distributed to gather input and allow DMR to make an educated and informed recommendation on this issue. The questionnaire was an opportunity to present thoughts, concerns, ideas and implications of any potential name change. It was available online as well as distributed by mail, handed out at various family forums, advocacy and advisory meetings. A public forum was organized at the Legislative Office Building as an opportunity for statewide public input. Members of the Public Health Committee were invited to join Commissioner O'Meara and DMR staff to listen to public comment. The forum was open to the public and invited participants included consumers and families receiving services provided by the Department, advocates of persons with mental retardation, DMR employees, private providers, advocacy groups, councils, advisory committees and other interested parties. In addition, the Connecticut Council on Developmental Disabilities hosted a Web log where comments were posted.

It was important to get a sense of where the families receiving services from DMR stand on the name change issue. The questionnaire was mailed to approximately 14,000 DMR families in the agency's Fall 2006 edition of Direct to Families, a DMR publication.

Targeted outreach also included the Council on Mental Retardation, the Council on Developmental Disabilities, the Family Support Council members and list serve of families; Regional Advisory Councils, Private Providers, DMR employees, Public Health Committee members and all state legislators, other state agencies, Southbury Training School (STS) Board of Trustees, STS Home & School Association, STS Foundation Inc., and self advocates.

Information on the name change forum was sent out to all the state cable access outlets and daily and non-daily newspapers to run on community calendars. The forum was broadcast and taped by CT-N and then a link was made available on the DMR website. Commissioner O'Meara was on the radio with WDRC 1360's Brad Davis as well as the WTIC 1080 Ray and Diane radio show and the forum details were also listed in a Hartford Courant article by Penny Overton. Spanish versions of the questionnaire were made available online and for publication in Direct to Families. A Spanish translator and a sign language interpreter were made available at the forum.

The Department allowed approximately four months for input (mid July through mid November) and responses totaled over 400 from consumers, families and guardians of consumers, advocates, DMR employees, private providers, legislators and other interested Connecticut citizens. The variety of input received included: 71 web blog entries, 73 emails (an email account was set up to receive input specific to the name change), 139 questionnaires, 5 phone calls, 6 personal letters (not questionnaires), 4 letters from advocacy organizations, a petition from People First of Connecticut (100 signatures) and 17 people testified at the public forum on September 7, 2006.

Input/Outreach Results:	Change Name	Do Not Change Name	Not Sure	Totals
Web Log	46	22	3	71
Public Forum testimony	17			17
People First petition signatures	100			100
Email	60	12	1	73
Questionnaires	90	48	1	139
General letters	4	1	1	6
Letters from advocacy organizations	3	1		4
Phone calls	2	3		5
Other	6			6
Totals	328	87	6	421

Here is a sampling of the responses that have been received on both sides of the issue (These are actual responses received and do not necessarily reflect the views of DMR’s administrators):

“I believe that a name change will blur the line of those who are serviced by the department. I feel many doors are opened to those serviced by the department that may not otherwise be opened.”

“I’m not sure what the name should be, but, whatever it is, should focus on the services the department provides, not on the people to whom it provides them. Thus the question should not be does 'mental retardation' get replaced by "intellectual disability".”

“I don’t see how a name change is going to better serve the Mentally Retarded citizens of our state. As a parent of one of those individuals, I think the name is a better fit than disabled. He is very able to do a lot of things, but is very slow at some of these functions.”

“I agree that there should be a name change to drop the word retardation out of the title. The "R" word is very offensive, and DMR not only provides services for people w/MR but other labels/diagnosis of people who have fallen through the cracks. Which is okay, but not truly fair to all the families whose kids do not qualify because they don't have the MR label.”

“I believe that being "politically correct" to satisfy the masses would be a mistake. Those of us with mentally retarded family members do not want them lumped in with "developmentally disabled"- I think that would lessen the sympathetic response of the general public if the name was changed from "retarded" to something else. I think many people feel that "developmentally disabled" could mean anything from medical problems from drug use to schizophrenia. I do not want my brother lumped into that category! He is a unique wonderful individual who has thrived despite his retardation!”

“DMR serves more than mentally retarded children. DMR can be construed as offensive to parents of children in Birth to Three who are not mentally retarded.”

“Physicians are not going to change the name of their diagnosis and neither are any other professionals or organizations that offer services to individuals with mental retardation. Mental retardation is a medical condition and should be treated as such. Changing the name won’t change the facts.”

“From time to time, we need to update the language of the business - and in human services, we are always making changes to the nature of the descriptions. Just look at the history, from the days of the "Idiot" & "Imbeciles", to current times - another change is due, particularly since the push is also being demanded by the consumers themselves.”

“The Spanish translation of the word “disability” is “incapacidad.” Translated, it means “disability” but also means “incapacity” and “incompetence” and therefore does not affirm the value of the person who is mentally challenged. This is a step backwards.”

“In the light of the Autism Pilot Program and its probable continuation, the name "Dept of Mental Retardation" is incorrect, since it will also provide services to disabled people who are NOT retarded. I highly recommended that its name be changed as soon as possible, to reflect its expanded mission.”

“So, if the name of DMR is changed and the schools no longer call our children MR, does that mean they are no longer retarded? It is what it is people. My son is retarded and no matter how many labels you care to use and change, until there is a miracle, he will remain retarded.”

"Idiot" used to be a clinical term. Then it became pejorative, and was replaced with "Retarded." Been near kids lately? "You're so retarded" is the popular insult. Can't you hear it 15 years from now? "You're so delayed"; "you're so disabled." What will we call it then? Perhaps the names needs no changing, perhaps it's the attitude that does...

“I am the parent of two children with developmental disabilities who do NOT also have intellectual disabilities (or mental retardation, or whatever the pc correct term is). I am strongly against DMR changing the name to Dept. of Developmental Disabilities unless you are also going to change your mission to serve clients who have developmental disabilities without cognitive impairments.”

As you can see, the responses have been varied, thoughtful and oftentimes passionate.

Recommendation:

After careful and thoughtful consideration of all input, my recommendation is that the agency change its name. Once the decision was made to change the name, the obvious next step was to determine *what* the new name of the Department should be. There have been many suggestions for an agency name change and several themes emerged.

- There are many terms that received some support including but not limited to cognitive impairment or disability, developmental disability, mental disability, mentally challenged, intellectual disability, and intellectual impairment.
- A common suggestion that emerged was to focus on the services provided by the agency, not the disabilities of those receiving services and supports. A new name should describe the type of services provided and not necessarily focus on the disability.
- One commonly suggested name has been the Department of Developmental or Intellectual Disabilities. However, the word “disability” in and of itself can have negative connotations. Synonyms include incompetence and incapability.
- Retarded is defined as occurring or developing later than desired or expected or delayed (slow to learn), slow or limited in intellectual or emotional development. In some responses, the word “retarded” meaning slow, was preferred to the word “disability” meaning unable.
- Input received from Spanish speaking families who receive services from DMR informed us that the Spanish word for disability is “incapacidad” which when translated can also mean incapable or incompetence. There has been a concern expressed by individuals who speak Spanish that having the word “disability” in the agency name could be as offensive as “retarded.”
- The definition of “development” is the act or process of developing; growth or progress.
- Currently, DMR technically serves individuals who do not have mental retardation as defined by 1-1g including some individuals in the Birth to Three Program as well as those individuals most recently served under the new autism pilot. (PA 06-288)
- There are those who strongly believe that a clinical diagnosis should NOT be included in the name of a state agency. The challenge then becomes choosing a name that is clear enough so as not to create confusion regarding who is eligible for services from a department. Ex: Department of Special Services. To the general public, this name would give no indication as to who is eligible for services.
- Another argument is that by using the diagnosis in the name of the department, it might imply that privacy is not an issue to be adhered to.

Although there was no clear consensus as to what the name should be changed to, there were more respondents who recommended a name change vs. remaining the DMR. We certainly do not want to offend the people we serve and we also do not want to be the last state in the country left still using the term “mental retardation” as part of the agency title.

There were numerous suggestions, and based on much research and consideration, the recommendation is to change the name to:

The DEPARTMENT OF DEVELOPMENTAL SERVICES (DDS)

FISCAL Impact:

The Department contacted facilities staff in each of our three regional offices to solicit information on potential cost implications involved in a name change. The questionnaire also included a question regarding any potential implications of a change. Based on the results, we would put an estimate of *approximately \$50,000* on a name change. Some of this cost could be spread out over a period of time or potentially avoided depending on the timeframe for implementation.

This list is not exhaustive, however, some items of consideration include:

- Signage. Generally, group homes do not have signage present and it appears that most of the Department of Transportation (DOT) signage leading to regional centers does not specifically mention DMR (although a handful may). For example the sign reads “Hartford Regional Center” not “DMR Regional Center.” Our administrative regional and central office signage does generally include “DMR.”
- Stationary and envelopes. Some of the regional offices do their letterhead electronically (in-house) which would be easy to change, however, some offices do still order stationary. Generally the envelopes are customized to the location of the regional office. A way to minimize this replacement cost would be to order new envelopes and stationary only as the old stock is running out.
- A new website address to reflect the new name. Also, notification to other organizations that currently have links on their websites to DMR and making the change on our current website to reflect the new name. It would make sense to have a redirection set up so that the public has time to get used to the new name and web address.
- Business cards. Again, a decision could be made to minimize the replacement cost by using the cards with the old name until they run out and then replacing them with the new name at that point.
- Employee ID cards.
- Some time and resources would have to be spent for public and community notification and education. Any public announcement of a new name should include education and clarification about who is eligible for services. This may include public buildings, educational venues, hospitals, schools, universities, doctors’ offices, and specifically pediatricians’ offices or other locations where potential consumers might be preliminarily identified such as psychiatrist, psychologist or neurologist offices.
- Employee manuals, training materials etc.
- Telephone listings/ blue pages.
- Notifying vendors for billing issues
- Stickers to inventory equipment.
- DMR prefixed chart fields/combo codes in CORE-CT.
- Payroll & timesheet materials (notification for IRS & DRS tax forms).
- Notification to other state agencies and organizations that DMR does business with.
- Tax ID number for contracted services, vendors, supplies etc.
- Updated forms related to contracts.

Attached is an estimate by DMR's North Region of its associated costs of a name change (\$10,155). We believe this to be a good estimate because the North Region recently moved office space from Farmington to East Hartford. Therefore, based on a review of invoices from the move, they have valuable information regarding the true costs of changing a piece of identifying information (their address).

Facility Location	Interior Exterior	Size	Replacement Type	Estimated Cost	Comment/Notes
John Dempsey Center	Exterior	96" x 48"	Metal - Double-sided	\$800.00	Front of Administration Building
Willimantic Satellite Office	Exterior	7" X 30"	Plastic - Double-sided	\$100.00	Building directory
Willimantic Satellite Office	Exterior	24" X 32"	Painted on glass door	\$250.00	Entry door
East Hartford Office	Interior	N/A	Directories - Each Floor	\$100.00	Extra letters (4 Sets)
			Subtotal	\$1,250.00	
Description	Unit	Unit Cost	# Needed	Total Cost	
Letterhead (4 Office sites)	Case	\$200	5 Cases	\$1,000.00	
Envelopes (4 Office sites)	Case	\$105	5 Cases	\$525.00	
Business Cards (100/bx)	Box	\$12	400 Support Employees	\$4,800.00	
Self-Inking Dater (Received stamp)	Each	\$45	24 Minimum	\$1,080.00	
Self-Inking Stamp (Address)	Each	\$25	48 Minimum	\$1,200.00	
Simplex Date Stamp (4 Office sites)	Each	\$75	4 Office sites	\$300.00	
			Subtotal	\$8,905.00	
			Grand Total	\$10,155.00	

DMR's best estimate would be to multiply these costs by DMR's three (3) regions and then add miscellaneous costs associated with DMR's Central Office changes plus more general overall administrative costs. Again, some costs can be spread out over time. In talking with some of DMR's self advocates, they would rather see the name changed slowly and the costs spread out rather than not at all due to budget constraints.

Connecticut trends:

Connecticut's State Department of Education (SDE) uses the term "intellectual disability (ID)" in lieu of mental retardation, as they believe ID is a term that more fully captures the essential feature of intellectual functioning. The SDE defines intellectual disability (ID) as: "Significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social and practical adaptive skills." SDE has been using the term intellectual disability since 2000. For SDE purposes, it does not include children who have autism, although they state that there are some children with autism who may also have other disabilities such as an intellectual disability. It also does not include developmental disabilities.

"This revision of the *Guidelines for Identifying Children with Intellectual Disability/Mental Retardation* (2000) is intended to clarify and improve special education identification, as well as placement policies and practices for professionals serving children with intellectual disability (ID) or children suspected of having an intellectual disability in Connecticut schools." (SDE, Executive Summary, *Guidelines for Identifying Children with Intellectual Disability* 2006). In the Executive Summary, one of the purposes of the original guidelines remains and is to "promote intellectual disability" as the nationally accepted nomenclature for thinking about and providing service to students with mental retardation." *Guidelines for Identifying Children with Intellectual Disability* (2006), is a revision to an earlier State Department of Education document, titled *Guidelines for Identifying Children with Intellectual Disability/Mental Retardation* (2000).

A question exists as to whether SDE's use of the term "ID" is actually a parallel term to DMR's use of "mental retardation" as defined by Connecticut General Statute 1-1g for DMR eligibility purposes. This issue remains the subject of continuing discussion at the time of printing this report.

By changing the name to the Department of Developmental Services, the Department's name will reflect being more inclusive of those currently receiving services by the agency who do not have a diagnosis of mental retardation. For example, the Connecticut Birth to Three Program (within DMR) defines their eligibility as "Children under the age of three who live in Connecticut and are experiencing a significant developmental delay, or have a diagnosed physical or mental condition with a high probability of resulting in a developmental delay." A child does not need to have a mental retardation diagnosis to be eligible for the Birth to Three Program, nor do children who go through the Birth to Three system end the program with a diagnosis of mental retardation since that diagnosis is not made until age 5-7. Of the 2,666 children who left Birth to Three at age three in FY05, 70% were eligible for preschool education. Therefore, 794 did not receive preschool education. 550 children (on average about 15% per year) exited the Birth to Three Program because they no longer needed early intervention.

Birth to Three is a system of supports for families to help them meet the needs of their infants and toddlers who have delays in their development or disabilities. In the majority of Birth to Three publications, you will not find a reference to the Department of Mental Retardation, other than to explain that DMR is the lead agency (the state agency responsible for Part C of the IDEA, assures quality, and conducts audits in order to maintain compliance with all applicable

laws.) The main reason you will not find a reference to “DMR” other than for this purpose, is because of the stigma perceived by families entering the program. IDEA entitles every child with mental retardation from age 3 through 21 to a free appropriate public education through an individualized education program (IEP).

In addition, individuals in Connecticut with a medical diagnosis of Prader-Willi Syndrome (a neurobehavioral genetic disorder that is not mental retardation, although many people with this Syndrome do have mental retardation) are currently eligible for DMR services.

There is a concern among some that the name “Department of Developmental Services” may potentially be confusing in that not all developmental disabilities are currently covered by DMR. However, all current eligibility criteria do fall into the classification of having occurred during the developmental period (before the age of 18) including mental retardation, prader-willi syndrome, autism and Birth to Three’s criteria of a significant developmental delay or a diagnosed physical or mental condition with a high probability of resulting in a developmental delay. In addition, the agency considers it a benefit that the name “Department of Developmental Services,” not only more accurately reflects current eligibility requirements, but also allows for the possibility that in the future, more developmental disabilities could be added to the list without having to change the name of the Department again.

One of the most important benefits to changing the name of DMR is how people who receive services and supports from the agency will feel about themselves and about how they are perceived by others. Yes, terminology does change over time. What is at one time acceptable can easily end up on a “no longer politically correct” list. As previously mentioned, the terms “idiot, imbecile and moron” were at one time all considered diagnostic categories. As the terms took on a pejorative meaning over time, they were cycled out of the vocabulary used to describe individuals with disabilities and new terminology emerged. At one time the term “mental retardation” emerged as a step in the right direction and brought attention to a diagnosis that society had chosen to attach a negative stigma to. It opened doors for families by spreading an awareness and in turn provided funding opportunities, and brought attention to the need for equality in areas of life including, education, housing and community inclusion.

Another concern that has been raised is that the cost of changing the name of the agency could be better spent on providing actual services to individuals. Taking this concern into account, it may make sense to spread out implementation of some aspects of the name change so as to lessen the actual fiscal implications. For example, stationary and business cards could continue to be used with the current name until they run out and would then be reordered to reflect a new name. However, it is important to realize that the primary reason for a name change is because there are people who find the current name offensive. This could potentially outweigh the argument of fiscal implications. However, the cost should not be the reason that the name does not get changed. DMR is not living up to its mission of creating the conditions under which all persons with mental retardation experience respect and dignity as long as individuals are insulted by the very name of the agency they are receiving supports and services from.

It is important to note that the term “mental retardation” is still used in the medical field as a diagnosis that is clearly defined. As long as this is the case, it does not make sense to completely

strike the word from our vocabulary. As a diagnosis, “Mental Retardation” will continue to be used in Connecticut as a tool for eligibility. Through the process of receiving input on the name change, many individuals pointed out the access to funding that the term has provided. Funding under the federal ICF/MR (intermediate care facilities/mental retardation) waiver is accessed by Connecticut’s DMR based on a clinical diagnosis of mental retardation.

Special Olympics:

Special Olympics now uses “people with intellectual disabilities” instead of “mental disabilities.” The following information is found on the Special Olympics website. (www.specialolympics.org):

Special Olympics provides year round sports training and athletic competition to more than 2.25 million people with intellectual disabilities in more than 150 countries. The organization has done what they call “Attitude Research.” The following describes their findings:

“According to the latest in attitude studies of the general public and the media, the world has a misperception problem. It thinks that people with intellectual disabilities are not capable and competent individuals. Misperceptions are the biggest barrier to inclusion, and while the world has tried to rectify the wrongs of discrimination for many other minority groups, people with intellectual disabilities stand alone as the silent and forgotten minority. By showcasing the above and similar studies, Special Olympics hopes to inform the public about the competence, value and contributions of the world’s most forgotten and discriminated-against minority group. Through its research and its 36-year history, Special Olympics has found that improved knowledge and perceptions of competence lead to greater willingness to interact with people with intellectual disabilities which, in turn, leads to greater overall inclusion of this population in society.”

Based on a Special Olympics “Multinational Study of Attitudes toward Individuals with Intellectual Disabilities”:

"One of the greatest challenges persons with intellectual disabilities face is overcoming the barriers to inclusion in society," said Shriver. "For many years, the athletes, volunteers and family members of the Special Olympics movement have known that the attitudes and expectations of the public determine the degree to which children, adolescents and adults with intellectual disabilities are able to learn, work and live alongside their peers without intellectual disabilities. Through this study, we now have conclusive and scientific confirmation of this long-held belief. The study uncovered a definite presence of negative attitudes — both within and across the countries surveyed — toward persons with intellectual disabilities. It also demonstrates the relationship

between public attitudes toward intellectual disabilities and the practices within countries that impact the quality of life of these individuals. Attitudes, beliefs and expectations are, in part, influenced by the distinct cultural norms, values and variety of resources and services that are available.”

It is interesting to note that the cover of the above report from 2003 has an asterisk after the title which reads that “various terminology is used throughout the world for intellectual disabilities, including learning disability, developmental disability, intellectual handicaps, mental handicaps and mental retardation.”

An interesting concept explored in this report is that “While the theme of diversity (e.g., racial, ethnic, cultural, gender) has emerged so strongly around the world, intellectual disabilities have been largely excluded. Therefore, Special Olympics organizers around the world are calling on young people, volunteers and community leaders to renew their efforts to promote acceptance through Special Olympics Get Into It™, promote understanding through Special Olympics Unified Sports® and promote a culture of welcome in all aspects of community life.”

The Special Olympics website has a notation “* Intellectual disabilities is synonymous with mental retardation; please see the Special Olympics [Language Guide](#) for more information.”

The following information is from the Special Olympics Language Guide:

- “Words matter. Words can open doors to cultivate the understanding and respect that enable people with disabilities to lead fuller, more independent lives. Words also can create barriers or stereotypes that are not only demeaning to people with disabilities, but also rob them of their individuality. The following language guidelines have been developed by experts for use by anyone writing or speaking about people with intellectual disabilities to ensure that all people are portrayed with individuality and dignity.”
- “Why did Special Olympics update its terminology from “mental retardation” to “intellectual disabilities”? In response to a call from our athletes and the growing social unacceptability of the term “mental retardation” around the world, Special Olympics has adopted the term “intellectual disabilities” when referring to the people with whom we serve. The word “mental” can be confused with the term “mental illness” and the word “retardation” is associated with offensive terms such as “retard” or “retarded.”
- “Why is language and specific terminology important? Special Olympics prefers to focus on people and their gifts and accomplishments, and to dispel negative attitudes and stereotypes. In an ideal world, labels would not exist, but unfortunately they do and language choices can have a powerful impact on impressions and attitudes. As language has evolved, Special Olympics has updated its official terminology to use more widely accepted terminology that is more acceptable to our athletes.”

National Landscape/ National trends:

According to Robert Gettings, the Executive Director of the National Association of State Directors of Developmental Disabilities Services (NASDDDS), over the past couple of decades, there has been significant evolution in the terminology used to describe state services to persons with lifelong disabilities such as mental retardation, epilepsy, cerebral palsy, autism and other developmental disabilities. These changes are evident in the names given to the state agencies with primary responsibility for overseeing services to these populations.

Currently, mental retardation is used as a stand-alone term in the agency titles of eight (8) states (AL, CT, KY, MA, MS, PA, TN, and VA), and in combination with developmental disabilities in five (5) additional jurisdictions (DC, MO, NY, OH and RI). In contrast, twenty-three (23) states now use the term developmental disabilities as a stand-alone term in their agency titles (AK, AZ, AR, CO, DE, IA, ID, IL, IN, GA, HI, LA, MD, NC, NE, NJ, NM, OK, SD, WA, WI, WV and WY).

Many states serving individuals with mental retardation have removed the diagnosis from human service department names. Some use terms that refer to the service being provided rather than the population being served. Thus, a number have adopted the term “developmental services” to refer to the office, division or department responsible for serving individuals with developmental disabilities (e.g., NH, CA and NV). Still other states have consolidated responsibility for serving individuals with developmental AND physical disabilities within the same executive branch unit and assigned the agency a title that includes the word “disability” or “disabilities.”

Examples of recent state changes:

Two years ago, Vermont’s Division of Developmental Services was shifted from the Department of Developmental and Health Services to a newly created Department of Aging and Independent Living. As part of this reorganization, the DDMH’s Division of Developmental Disabilities was consolidated into a new Division of Aging and Disabilities Services. However, this was part of a major human services reorganization.

Last year, the Maine Adult with Mental Retardation Program was shifted to a newly created Dept. of Health and Human Services and combined with programs for people with physical disabilities to form the DHHS Office of Adults with Cognitive and Physical Disabilities Services.

About 5 years ago, Developmental Disabilities Services in Oregon were shifted from the Division of Mental Health and Developmental Disabilities Services to a Division for Seniors and People with Disabilities as part of a major realignment of the state Department of Human Services.

In 2005, Minnesota changed from Mental Retardation to Developmental Disabilities in statutes but there was no change to the agency's mission or to the clients served by the agency.

An important note in this discussion is that the majority of changes in agency titles that have occurred came about as the result of an administrative, rather than legislative, action and frequently for reasons other than dissatisfaction with the agency's existing title. This is unlike in Connecticut, where the driving force for a name change has been a growing discontent with the term "mental retardation" among consumers and advocates.

Next Steps:

As previously mentioned, it is possible that there will be legislation proposed not only to change the name of DMR, but also to expand the population of individuals eligible to receive services. While DMR recognizes that this is an important issue, it is not the charge of Public Act 06-92 to address.

As this is not our current intention without commensurate funding, DMR strongly recommends that legislation be as clear as possible, especially in reference to associated eligibility. Also, it is essential to the success of a name change that educating the public is addressed so that misconceptions are minimal and it is apparent as to who is eligible for support from the Department of Developmental Services. In addition, it might make sense to pursue the possibility of an annual public awareness campaign regarding respectful language in conjunction with the SDE so that new terminology does not become outdated in the near future, due to misuse and misunderstanding.

The name "Department of Developmental Services" is respectful of individuals who are currently served by DMR, is inclusive of individuals in the Birth to Three program and the Autism Pilot who do not have a diagnosis of mental retardation, and allows for some future flexibility if and when the state decides to change its scope of services to additional developmental disabilities. In addition, it is consistent with other human service agencies in Connecticut that use a service related name rather than a disability related name.

Although eligibility criteria will not change, an evaluation of current state statutes will need to be undertaken. References to the old name of the Department should be replaced with the new name however; it is not the intention to replace the words "mental retardation" throughout the statutes. The Diagnostic and Statistical Manual of Mental Disorders "DSM-IV" (published by the American Psychiatric Association), still includes a diagnosis of "mental retardation." The DSM-IV is the standard for medical diagnosis in the United States. In addition, the DSM-IV diagnosis of mental retardation is the same as used in the International Classification of Diseases (ICD-9). As the terminology still continues to have a purpose in terms of a clinical diagnosis and in reference to eligibility, it will continue to be used in some places. As the Director of the Office of Protection and Advocacy has pointed out, eliminating all references to "mental retardation" could inadvertently affect the current legal standards for protective services. A majority of states, even the ones who have taken "mental retardation" out of their agency title, still use the term and define it. In addition, the terminology "mental retardation" is still applicable in regards to bigotry and bias statutes, the Commission on Human Rights and Opportunities' discrimination

statutes, federal waiver classifications, certification for Intermediate Care Facilities and the Americans with Disabilities Act.

There needs to be limitations and constraints in any legislation regarding the timeframe for implementation and eligibility not changing so that the scope of the Department is clearly defined.

Draft Legislation:

An Act Concerning Changing the Name of the Department of Mental Retardation to the Department of Developmental Services

Be it enacted by the Senate and House of Representatives in the General Assembly Convened:

Section 1. (NEW) The Department of Mental Retardation shall henceforth be known as and referred to as the Department of Developmental Services. The name “Department of Mental Retardation” in state statutes shall be replaced with “Department of Developmental Services”. Any related changes, including but not limited to business cards, stationary, brochures, websites and signage shall be done in a manner and timeframe prescribed by the Commissioner. Pursuant to this legislation, there is no change to eligibility of the Department as currently defined by Section 1-1g of the Connecticut General Statutes.

In Summary:

DMR would like to thank everyone who took the time to share their thoughts and opinions with us and we look forward to working with the legislature to assure that the name of our state agency is one that Connecticut residents feel comfortable approaching when services and supports are sought.