



Maine Developmental Disabilities Council

Report of the

Respectful Language Workgroup

Pursuant to Chapter 62, 123rd Maine State Legislature

March 6, 2008

Additional information available from the Maine Developmental Disabilities Council 207-287-4213 or ehowes@maineddc.org

1. Background

As directed in a resolve passed in 2007 by the Maine Legislature¹, the Maine Developmental Disabilities Council (MDDC) formed a working group to identify words which currently appear in Maine statutes that convey negative and/or derogatory perceptions of people with disabilities, and to make recommendations for replacement terminology to be substituted when new statutory language is crafted to replace and/or add to existing laws. A copy of the Resolve is included as Attachment A.

MDDC sent invitations to participate in this work group to representatives of public and private agencies which are involved in advocating, overseeing and/or providing services and supports for persons with disabilities. Individuals with disabilities were also encouraged to participate. The working group met twice as a large group, with participants including representatives of the Maine Departments of Education, Labor, and Health and Human Services, along with a variety of advocacy organizations and self-advocates. Several smaller meetings were held as well, with representatives of specific sub-groups, to discuss terminology of concern to their groups, along with recommendations being circulated via email for additional comment. A listing of the participants in the working group is included with this report as Attachment B.

The impetus for this legislation and the working group's recommendations for new terminology to be used in State statutes and regulations derived in particular from concerns expressed by self-advocates – notably members of the statewide self-advocates' organization, Speaking Up For Us – regarding the usage of the term "retarded" or "mentally retarded." As explained in testimony before the Joint Health and Human Services Committee, individuals with developmental disabilities are very frustrated with the use of these terms in everyday language, given how these words have evolved in common usage to become stigmatizing labels used in cartoons² and by comedians and others to make fun of people.

Many of the terms used in State laws and rules became common usage across the country during earlier periods of time when people with disabilities were regarded as individuals to be pitied, feared or ignored. They were portrayed as helpless victims, repulsive adversaries, heroic individuals overcoming tragedy and charity cases dependent upon others for their care and wellbeing. Individuals with developmental disabilities, whether cognitive or physical in nature, were most

¹ Chapter 62, 123rd Maine State Legislature – Resolve, To Convene a Working Group To Review Statutory Language and Propose Standards To Ensure the Use of Respectful Language.

² For example, the cartoon character Napoleon Dynamite used the term "retard" to make fun of others in the animated movie released in 2004, and the accompanying talking doll available in stores that year include the word "retard" among its limited vocabulary.

often segregated in large state-run institutions with little more than custodial care, and often deplorable living conditions.

Advances in academic and professional understandings of the capacities of individuals with developmental disabilities to learn and increase their levels of intellectual and adaptive functioning have played a critical role in generating efforts toward deinstitutionalization and provision of community supports and opportunities. Maine is notably ahead of many other States in the country, having closed its only state-run institution, and developed a community-based system of services for individuals who would otherwise be served in institutional settings.

Much has changed over the past thirty years in the United States, with disability activism and expanded coverage of disability issues encouraging changes in public awareness and knowledge, and increased opportunities for individuals with disabilities to participate as respected and contributing members of their communities and society in general. People with disabilities continue to focus attention on difficult issues that affect their quality of life, such as accessible transportation, housing, affordable health care, employment opportunities and elimination of discriminatory practices that limit their participation.

To further the goals of full inclusion and equal opportunities for persons with disabilities, there is strong sentiment that new terminology is needed to focus on each person as an individual, and not emphasize a disability. Efforts are being made across the country to have labels which contribute to negative stereotypes and focus on only one aspect of the whole person removed from State laws and rules, and usage in government programs. (See Attachment C)

2. Findings

The working group identified a list of more than 90 words and phrases in Maine Statutes that are used as "labels" to define individuals and groups to whom the pertinent section and/or Title applies.

There was agreement that the basic principle of "people first" language should be used in considering any recommendations for words/phrases to replace existing terminology. In essence, the emphasis should be placed upon the person, and a disability should not become through labeling the primary, defining characteristic of that individual, but be seen as merely one aspect of the whole person.

There was also agreement that no reference should be made to any disability in usage, unless it is relevant to the topic addressed. In the same way that racial identification is eliminated when it is not significant, terminology calling attention to any disability should also be avoided if unneeded.

Through an initial sorting of the list of terms to be discussed, the group chose to set aside and not consider those terms that do not specifically address any disabling condition. However, given the group's agreement that labeling individuals and/or groups based on a single characteristic does not follow the principle of "people first" language, it was agreed that this report would mention (without any recommendation for changes) some of the terms that were initially identified but determined to be outside the purview of this working group. Those words/phrases included: disadvantaged, gifted and talented students, "the poor", physically abused children, needy individuals, needy persons, and indigent client.

There are no recommendations included in the report for any changes in terminology related to individuals who are "deaf, hard-of-hearing, or hearing impaired", or any type of vision impairment. Although input was solicited from those groups, there was not adequate response for the working group to feel comfortable in formulating recommendations. However, there was consensus that the same general recommendation should apply to these groups; i.e. any time terminology referring to a specific disability or group of persons with that disability is going to be used in legislation or draft rule, representative members of the group should be consulted to determine appropriate and respectful wording is used.

The working group also acknowledges that there is a long history of replacing stigmatizing and pejorative terminology for individuals with various types of disabilities with newer terms that in turn become negative and stigmatizing in their own usage. It is therefore highly likely that any new terminology selected to replace phrases such as "mental retardation" may in the future become outdated as well. It will be important for there to be ongoing communication with the disability community to assure that, to the greatest extent possible, terminology is updated when possible to assure that State statutes and rules model the respect and recognition of individual rights and abilities that are due to everyone who lives in Maine.

3. Recommendations

The working group reviewed and made recommendations for replacement terminology for more than 60 words and phrases that currently appear in Maine statutes. Those recommendations are included in Attachment D.

The working group also reached consensus on the following general recommendations:

- No reference should be made to any disabling condition unless it is relevant to the issue being addressed.
- No changes in terminology should be made that might negatively impact individual eligibility for services.

For this reason, the term "mental retardation" will have to be used in some places in State statute and rule when there is a link to the federal Medicaid program, which uses this term.

- No changes should be made in terminology that might have a negative impact on individual rights or otherwise cause unintended harm to any individual or group.
- In all cases, *People First* language should be used, with descriptive terms used as adjectives rather than nouns. Referring to people as "the disabled", "the retarded", etc. should be avoided at all times.
- Avoid negative or sensational descriptions of a person's disability, such as "suffers from," "afflicted with", or "a victim of".
- A process should be established for ongoing communication with representative members of the disability community to review terminology that is included and recommended in this report, to determine if any changes should be made to reflect more current usage.

PLEASE NOTE: Legislative Information *cannot* perform research, provide legal advice, or interpret Maine law. For legal assistance, please contact a qualified attorney.

Resolve, To Convene a Working Group To Review Statutory Language and Propose Standards To Ensure the Use of Respectful Language

Sec. 1 Convene working group. Resolved: That the Maine Developmental Disabilities Council, referred to in this resolve as "the council," shall convene a working group to review the terminology that is currently contained in the Maine Revised Statutes to refer to persons with disabilities. The council may propose standards to be used prospectively by the Revisor of Statutes when preparing bills that enact or amend legislative language referring to persons with disabilities. In convening the working group, the council shall invite the participation of representatives of the Maine Disability Advocacy Coalition and other interested parties. In preparing its recommendations, the working group:

1. May identify terms that it recommends be designated for substitution and may recommend replacement terms;

2. Shall ensure that any proposal for terminology changes reflects a positive approach to persons with disabilities;

3. Shall include in any proposal language that ensures that terminology changes may not be implemented if the change would alter or render ambiguous the substantive meaning of any statutory unit;

4. Shall ensure that any proposed language changes are not in conflict with or prohibited by federal requirements; and

5. May recommend that each department, bureau and agency of State Government, when adopting or amending its rules and policies and when publishing or republishing its publications, incorporate the standards proposed; and be it further

Sec. 2 Report and recommendations. Resolved: That, by November 1, 2007, the council shall report to the Joint Standing Committee on Health and Human Services the findings and recommendations of the working group, including any necessary implementing legislation; and be it further

Sec. 3 Authority for legislation. Resolved: That, after receipt and review of the report and recommendations submitted pursuant to section 2, the Joint Standing Committee on Health and Human Services may submit legislation to the Second Regular Session of the 123rd Legislature.

Attachment B

Workgroup on Respectful Language

Members

Julia Bell Maine Developmental Disabilities Council

Brenda Bennett Learning Disabilities Association of Maine

Jodi Benvie Disability Rights Center

Carol Caruthers NAMI Maine

Marcia Cooper Brain Injury Association

Nancy Cronin Autism Society of Maine

Melinda Davis Advocacy Initiative Network

Eric Dibner Maine Department of Labor

Mary Lou Dyer Maine Association of Community Services Providers

Richard Estabrook Office of Advocacy

Sue Fairfield Maine Parent Federation **Beth Gallie** Maine Center on Deafness

Jaci Holmes Maine Department of Education

Jamie Kaplan Cromwell Center

Irene Mailhot Maine Developmental Disabilities Council

Paul Picard Speaking Up For Us

Christine Robinson Maine Department of Health & Human Services

Lisa Rouelle Alpha One

Valerie Smith Center for Community Inclusion & Disability Studies

Paul Tabor Maine Department of Health & Human Services

Gary Walcott Maine Department of Health & Human Services

People First Language (PFL) Legislation and Policies in the United States as of 2007

State	Vehicle	Key Provisions	
Alaska	State Law passed in 2006	Revises existing state statute to remove outdated terms and replace with respectful language.	
Arkansas	Pending Legislation for 2007	Outlines specific terms to avoid in new legislation and authorizes the Arkansas Code Revision Committee to change any such references in past statute. Outlines appropriate substitute terms. Declares an emergency, a people with disabilities' needs are going unheard.	
Connecticut	Legislation introduced in 2006, but not passed	Legislation required the use of respectful language in the Connecticut General Statutes when referring to persons with disabilities. Although this did not pass, separate legislation did pass to change the name Department of Mental Retardation to Department of Developmental Services.	
District of Columbia	State Law passed in 2006	Removes outdated, offensive terms from the DC Code; requires the use of respectful language in all new laws, regulations, official publications and web sites; requires existing regulations and publications to be updated to use respectful language within 6 months; requests a study recommending options for replacing the term "mental retardation" in local DC laws and documents within 6 months.	
Louisiana	Policy effective 2003	Ensures that persons with disabilities served by the Department of Health and Hospitals (DHH) are referred to in language that is affirmative and respectful. DHH has begun discussions with the Governor's Office of Disability Affairs about an Executive Order to expand PFL to other departments.	
Minnesota	State Law passed 2005	Orders revisions to existing statues and rules to remove objectionable terms and replace them with PFL. Orders replacement of signs and printed materials moving forward.	

Information provided by individual State Developmental Disabilities Councils and report "People First Language (PFP) Legislation: a Review. Prepared by The Arc of the District of Columbia, Inc. May 2006.

Attachment C

Attachment C

State	Vehicle	Key Provisions	
Mississippi	State Law passed 2005	Directs legislative drafting offices and state agencies to use respectful language when referring to individuals with disabilities in the preparation of legislation and rules.	
New York	State law passed in 2007	Outlines general types of language to avoid and authorizes replacement of such terms using "persons first" language in new and revised statutes.	
Ohio	State law passed in 2006	Mandates removal of words "idiot', "lunatic", and "insane" from the criminal code and replacement of those terms with "incompetent person." No consensus was reached on replacement term for "mental retardation."	
Oregon	State Law passed in 2006	Mandates review and revision of state agency rules and policies; requires the use of PFL in all state correspondence and publications; requires education of state employees, officials and general public about the worth and capacity of people with disabilities and use of PFL; and encourages state agencies to foster use of PFL in the media and school texts.	
Pennsylvania	Executive Order issued 1992	Forbids discrimination against any individual with a disability, endorses respectful treatment of people with disabilities and requires all state agencies, boards and commissions to use PFL in publications.	
Utah	House Joint Resolution in 2006	Urges all state agencies to replace the term "mental retardation" in official documents with language that is sensitive to people with disabilities. Encourages state agencies to review and consider alternative references to this term that are used by other states.	
Washington	State Law passed in 2005	Recognizes that language can shape and reflect society attitudes. Clarifies preferred language for new and revised laws by requiring the use of PFL.	

. Information provided by individual State Developmental Disabilities Councils and report "People First Language (PFP) Legislation: a Review. Prepared by The Arc of the District of Columbia, Inc. May 2006

LD 1780 WORKGROUP ON RESPECTFUL LANGUAGE

Terminology to be Avoided/Replaced and Recommendations for Acceptable Words/Phrases

	Terminology to be avoided and/or replaced	# of statue sections in which used*	Recommendations for Replacement Language
1.	Afflicted	6	This term should not be used. In most cases, simply eliminate this word. If substitute word is necessary in specific instance, use <i>affected</i> .
2.	Alcoholic	62	Person dependent upon alcohol, or person with alcohol dependency
3.	Arthritic	1	Person with arthritis
ана на селана на села На селана на селана н На селана на селана н На селана на селана н	Autistic person		Person with pervasive developmental disorder, or person with autism (Current statutory language in Title 34B addressing eligibility for services includes the range of pervasive developmental disorders in the definition of "autism". However, in other usage, "pervasive developmental disorder" (<i>PDD</i>) includes autism and other disorders on the spectrum.)
5.	Children with handicapping conditions	1	Children with disabilities
6.	Consumers of mental health services	4 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	People who use (or employ) mental health services
7.	Crippled children	7	Children with disabilities

^{*} Note: () around number indicates that the number is included in another entry, e.g. the number of sections in which "handicapped person" appears is included in the number of sections indicated for the word "handicapped".

	Terminology to be avoided and/or replaced	# of statue sections in which used*	Recommendations for Replacement Language
8.	Deranged	1	Persons who have mental health diagnoses
9.	Developmentally disabled	26	People with developmental disabilities
10.	Developmentally disabled child/children	2	Children with developmental disabilities
11.	Developmentally disabled person	1	Person with a developmental disability
12.	Developmentally disabled persons	3	People with developmental disabilities
13.		405	This term should not be used as a noun (i.e. "the disabled"). If it is used as an adjective to describe a person, then "person" should be stated first (i.e. "person with a disability" rather than "disabled person")
14.	Disabled person	25 (included in count above)	Person with a disability
15.	Diseased person	1	Person with a disease
16.	Drug addict	9	Person with substance abuse disorder or person with drug use disorder
17.	Drunkard	1	Person with alcoholism

^{*} Note: () around number indicates that the number is included in another entry, e.g. the number of sections in which "handicapped person" appears is included in the number of sections indicated for the word "handicapped".

Attachment D

	Terminology to be avoided and/or replaced	# of statue sections in which used*	Recommendations for Replacement Language
18.	Emotionally handicapped children	(1)	Children with emotional disabilities
19.	Epileptic	1	Person with epilepsy
20.	Handicapped	153	Term should be not be used as a noun (i.e. "the handicapped") – see examples below for appropriate replacement phrases.
21.	Handicapped children	(16)	Children with disabilities
22.	Handicapped housing	(2)	Accessible housing
23.	Handicapped individual	(0)	Person with a disability
24.	Handicapped individuals	(0)	Persons with disabilities
25.	Handicapped or disadvantaged	(170)	Persons with disabilities
26.	Handicapped or disadvantaged Individual	(154)	Person with a disability
27.	Handicapped parking	(2)	Accessible parking
28.	Handicapped people	(10)	People with disabilities

^{*} Note: () around number indicates that the number is included in another entry, e.g. the number of sections in which "handicapped person" appears is included in the number of sections indicated for the word "handicapped".

	Terminology to be avoided and/or replaced	# of statue sections in which used*	Recommendations for Replacement Language
29.	Handicapped persons	(17)	Persons with disabilities
30.	Handicapped workers	(3)	Workers who have disabilities
31.	Handicapped youths	(5)	Youths with disabilities
32.	Incapacitated adults	8	Recommendation dependent upon use in statute
33.	Incapacitated person	31	Leave at this time – used in legal proceedings
34.	Incompetent person	5	Recommendation dependent upon use in statute
35.	Insanity	16	Leave – term used in legal proceedings
36.	Intoxicated person	11	Person who is intoxicated
37.	Invalids	3	Individuals with disabilities (or "with", other appropriate descriptor, depending on context)
38.	Lunatic	2	Person declared legally incompetent
39.	Mental deficiency	13	Cognitive disability
40.	Mental disease or defect	6	Cognitive disability

^{*} Note: () around number indicates that the number is included in another entry, e.g. the number of sections in which "handicapped person" appears is included in the number of sections indicated for the word "handicapped".

Attachment D

	Terminology to be avoided and/or replaced	# of statue sections in which used*	Recommendations for Replacement Language
41.	Mental retardation	165	"Developmental disability" should be substituted, when the context does not refer to eligibility for Medicaid services. This term currently appears in federal Medicaid regulations, as a medical diagnosis.
42.	Mentally defective	4	Has a cognitive disability
43.	Mentally ill	113	Person who uses mental health services
44.	Mentally ill and deficient	(2)	People who use mental health services
45.	Mentally ill patient	(1)	Person (patient) who uses mental health services
46.	Mentally ill people	(1)	People who use mental health services
47.	Mentally ill person	(1)	Person who uses mental health services
48.	Mentally incompetent person	(10)	Leave at this time – used in legal proceedings
49.	Mentally retarded	147	People with developmental disabilities
50.	Mentally retarded person	(8)	Person with a developmental disability
51.	Mentally retarded persons	(98)	People with developmental disabilities
52.	Multiple handicapped blind persons	(1)	People who are blind and have other disabilities

^{*} Note: () around number indicates that the number is included in another entry, e.g. the number of sections in which "handicapped person" appears is included in the number of sections indicated for the word "handicapped".

	Terminology to be avoided and/or replaced	# of statue sections in which used*	Recommendations for Replacement Language
53.	Non-verbal	2	Person without verbal communication ability
54.	Otherwise physically disabled	(1)	Person(s) with physical disabilities
55.	Paraplegics (noun)	2	Persons with paraplegia
56.	Person who is physically disabled	(1)	Person with a physical disability
57.	Physically handicapped people	(8)	People with physical disabilities
58.	Senile	1 1	This term should not be used. "People with dementia" or "People who have dementia" may be appropriate substitutes, depending on usage.
59.	Severely handicapped child/children	1	Child/children with severe disabilities
60.	Suffering from	4	Term should not be used – substitute "who has" (e.g. person who has)
61.	The handicapped	(153)	People with disabilities
62.	The mentally ill	(112)	People who use mental health services

^{*} Note: () around number indicates that the number is included in another entry, e.g. the number of sections in which "handicapped person" appears is included in the number of sections indicated for the word "handicapped".