

What's in a name? Attitudes surrounding the use of the term 'mental retardation'

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Over the past 200 years, there have been periodic shifts in the terminology used to describe what is still most commonly referred to in the medical world as 'mental retardation'. There are differing opinions about the acceptability of the term, but very little existing evidence on which clinicians can base their decisions regarding what terminology to use with patients and families, and with one another. The present survey of parents and professionals used questions based on paper-based clinical scenarios to survey each group's attitudes about terminology usage. The results of both the parent and professional surveys support a move away from the use of the term mental retardation. The majority of parents indicated that they would be upset if a physician used the term mental retardation. Some professionals reported being criticized for using the term. Teaching about terminology has been variable.

Key Words: *Intellectual disability, Mental retardation, Terminology*

During the evolution of a language, terms appear and disappear. In most cases, this is a natural phenomenon; in others, it is the result of a conscious effort to effect a change in usage (1). This has held true in the field of mental retardation. Over the past 200 years, this condition has been described by many different terms, including feeble-mindedness and idiocy (1). The term 'mental retardation' was introduced to replace words such as those because they were believed to be inappropriate. Many now believe that mental retardation has itself become pejorative (2). It has been stated that the term mental retardation is scientifically worthless and socially harmful (3), and there is a push to change the terminology used. In 2007, the American Association on Mental Retardation was renamed the American Association on Intellectual and Developmental Disabilities, and also changed the name of its affiliated journal (4). The draft revisions of the *Diagnostic and Statistical Manual* (5) first indicated a change to 'intellectual disability' and, more recently, to 'intellectual developmental disorder'. However, there is not yet universal consensus about the use of the term mental retardation or about replacing it. The term continues to be used clinically, and commonly appears within textbooks and publications. Meanwhile, public attitudes and usage have been shifting. An American study from 2002 (2) found a sizable number of parents of affected young children who did not identify with the term mental retardation, but rather described their children's conditions by either their specific syndrome or used the term 'developmental delay'. A PubMed search of article titles published in 2010, found that there had been an

Qu'y a-t-il dans un nom? Les attitudes entourant l'utilisation du terme « retard mental »

Depuis 200 ans, on observe des changements périodiques dans la terminologie utilisée pour décrire ce qui est encore surtout désigné dans le monde médical par retard mental. Les opinions divergent quant à l'acceptabilité du terme, mais il existe très peu de données probantes sur lesquelles les cliniciens peuvent justifier leur décision quant au choix de terminologie à utiliser auprès des patients et des familles et les uns avec les autres. Ce sondage auprès des parents et des professionnels faisait appel à des questions fondées sur des scénarios cliniques écrits afin de connaître les attitudes de chaque groupe au sujet de l'utilisation de la terminologie. Les résultats du sondage auprès des parents et des professionnels appuient le rejet du terme retard mental. La majorité des parents seraient vexés si un médecin utilisait ce terme. Certains professionnels ont déclaré avoir été critiqués pour l'avoir employé. L'enseignement au sujet de la terminologie est variable.

increase in the number of titles that included the terms intellectual disability or developmental delay in the past two years, compared with their average usage in the preceding years. However, mental retardation remains the most commonly included term of the three in publications, in spite of the relative decrease in its usage.

The presumed force behind the push to change terminology is the desire to improve attitudes, and ultimately, the experiences of affected individuals. It has been argued, however, that changing labels does not ameliorate the problems facing individuals with mental retardation in our society, and that the successive changes in terminology over the past 200 years have failed to make any difference in the societal stigmatization of affected individuals (6). Regardless, common sense supports the idea that terminology has the power to improve or harm communication, and that health care professionals can best communicate if they know from evidence what others believe and feel about the relevant terms.

Currently, clinicians have surprisingly little such evidence. While there are a number of publications discussing the need to change terminology, there has not been much actual study of community or professionals' perceptions on the subject. One 2005 study of United States Midwesterners, many of whom were university students, found that 'mentally challenged' was the most positively evaluated replacement term for mental retardation (7).

It has been the authors' experience that there is still confusion and concern about what terminology professionals should use in this area. The shift in the United States would appear clearly to be in favour of using intellectual disability in place of mental retardation.

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TABLE 1
Parent survey: Affected family member (n=16)/no affected family member (n=36)

	Strongly disagree or disagree		Undecided		Strongly agree or agree	
	Affected	No Affected	Affected	No Affected	Affected	No Affected
I would understand meaning of the term mental retardation.	31	19	0	8	69	72
I would not care which term the doctor chose to describe Thomas' learning.	81	81	0	17	19	3
I would be upset with the doctor because he/she used the term mental retardation rather than a term such as developmental delay or mentally challenged.	19	11	6	11	75	78
I would prefer that the doctor used the term mental retardation rather than developmental delay or mentally challenged or other similar terms.	75	86	13	11	13	3
The term mental retardation should be used, if it applies, when talking to parents.	*81	*56	6	28	13	17
The term mental retardation should be used, if it applies, when talking to people with mental retardation themselves.	*94	*69	0	25	6	6

Data presented as %. * $P < 0.05$ in comparing responses of affected versus no affected family member at the "strongly disagree or disagree" level

The term 'learning disability' is commonly used to equate with mental retardation in the United Kingdom, while it means something quite different in North America. The authors' observations have been that intellectual disability is not currently a commonly used term in Canada. Our study was designed to identify the perceptions of health professionals and parents about the terminology used in this area, to help professionals make informed decisions about usage. In selecting which terms to include as options, we sampled terms based on our own observations of Canadian and American usage, as well as the existing literature and linguistic trends.

METHODS

Two questionnaires were created, one for health care providers and one for parents. Each questionnaire presented a scenario. In the questionnaire for health care professionals, the scenario presented involved an interaction with the parents of a seven-year-old who was described as having an intelligence quotient >2 SD below the mean, with significant delay in language, self-help, social and adaptive skills. The scenario was followed by a series of questions about what terms the practitioner would use to describe to the family the child's learning profile, as well as what terms would be used when speaking with other professionals and colleagues. Health care professionals were also asked to choose the term, from a series of provided terms, that sounded the most positive. There were also questions that specifically explored opinions about the use of the term mental retardation, whether the answering individual had ever been criticized for using the term, and what term that professional had been taught to use during training.

The questionnaire for parents presented a scenario wherein the person answering the questionnaire was to picture himself/herself in the role of the parent of a seven-year-old who functioned at a level closer to that of a four-year-old child and who had undergone psychoeducational testing that found a learning level far below that expected for a seven-year-old. The parents were asked specifically to consider the terminology that might be used. There were a set of questions based on a scenario in which the doctor with whom they were consulting about the child's developmental concerns used the following statement: "Thomas has mental retardation." The questions included whether parents would understand the meaning of the term mental retardation, whether they believed the term should be used, and whether they preferred that term or other terms. The parents were asked whether they believed a diagnosis of mental retardation was more serious than a diagnosis of developmental delay or mental challenge, and were asked to choose from a set of terms which one was the most positive.

Demographic information about the parents included whether they had a family member with developmental delay/mental retardation.

The majority of health care professionals who completed the survey worked in the Children's Program at the IWK Health Centre in Halifax, Nova Scotia. The IWK provides regional primary and secondary paediatric care, as well as tertiary care for the Maritime provinces, and is strongly linked with Dalhousie University (Halifax). Some of the physicians who responded were family physicians in the Halifax Regional Municipality and some were community paediatricians. The nonphysician professionals who completed the survey included social workers, nurses, physiotherapists, occupational therapists and psychologists, all of whom worked at the IWK Health Centre. The questionnaires were distributed by mail or by hand, and returned via the mail system. All responses were anonymous. Overall, the response rate was approximately 75%.

The parents who completed the survey were approached in a variety of clinic waiting areas at the IWK Health Centre over a several-month period in 2007. To avoid bias, the parents of children seen by any of the authors were not included. Participation was voluntary. More than 90% of parents who were approached agreed to complete the survey.

The project was approved by the Research Ethics Board of the IWK Health Centre.

RESULTS

Parent survey

Tables 1 and 2 summarize the results of the 52 completed parent surveys. Parent demographics indicated that for approximately one-third of participants, the highest level of education completed was high school. Thirty-six parents did not have a relative with developmental delay/mental retardation (69%). Of the parents, 30% did not feel they understood the term mental retardation, including 31% of the group with affected family members. Very few indicated that they did not care what term the doctor in the scenario chose to describe Thomas' learning, and the majority would be upset with the doctor if he/she used the term mental retardation. A small minority of parents indicated that they would prefer the doctor use that term. In general, parents disagreed with the use of the term mental retardation in speaking with parents or affected individuals. The parents who had an affected relative were significantly more likely to disagree with the use of the term.

Approximately 40% of parents indicated that they believed a diagnosis of mental retardation was more serious than a diagnosis of developmental delay or mental challenge, with no significant difference between those with or without affected family members.

When asked to choose the term that sounded most positive, parents overwhelmingly favoured developmentally delayed. Mentally challenged was endorsed by 19% and intellectually

TABLE 2
Parent survey

Which of the following terms do you think sounds the most positive?	Affected family member (n=16)		No affected family member (n=36)	
Mentally retarded	0		0	
Mentally challenged	12		8	
Developmentally delayed	69		72	
Intellectually disabled	19		19	

Data presented as %

TABLE 3
Professional survey (n=101)

If during your work with this family you needed to describe to them Thomas' learning, would you use the term:	Thomas' learning, would you use the term:			
	Never	Rarely	Frequently	Always
Mental retardation (all professionals: n=101)	71	23	6	0
Physicians (n=49) and psychologist (n=8)	53*	37	10	0
Other professionals (n=44)	95*	5	0	0
Developmental delay	2	11	60	27
Mentally challenged	58	33	9	0
Intellectually disabled	60	29	11	0

Data presented as %. *P<0.001

TABLE 4
Professional survey (n=101)

What term are you most likely to use when talking to parents about their child when the child would meet criteria for mental retardation?	
Mental retardation	5
Developmental delay	78
Mentally challenged	3
Intellectual disability	6
Other	8

Data presented as %

TABLE 5
Professional survey (n=101)

If you were discussing this child's condition with other professionals and colleagues, would you use the term:	If you were discussing this child's condition with other professionals and colleagues, would you use the term:			
	Never	Rarely	Frequently	Always
Developmentally delayed	2	13	59	26
Mentally challenged	51	41	8	0
Intellectually disabled	62	25	11	2
Mental retardation	52	32	15	1

Data presented as %

disabled was chosen as the most positive by 10%. No one selected mental retardation (Table 2).

Professional survey

Completed surveys were returned by a total of 101 health care professionals (12 occupational therapists, 13 physiotherapists, 11 social workers, eight psychologists, eight nurses and 49 physicians). All surveyed professionals had practices including children, with 96% reporting that more than one-half of their practice was paediatric. Approximately one-half had been in practice for >15 years, and most had hospital-based practices. Tables 3 to 10 show the responses of the health care professionals who completed the survey.

Overall, there was a low frequency of self-reported use by professionals of the term mental retardation when speaking with families. A more detailed analysis showed that nurses, occupational therapists and physiotherapists universally reported that they would "never" use the term with a family. Twenty per cent of the social workers indicated they would do so "rarely". The physician/psychologist

TABLE 6
Professional survey (n=101)

	Strongly disagree or disagree		Strongly agree or agree	
		Undecided		
The term mental retardation should be used, if it applies, when talking to parents.	72	18	10	
The term mental retardation should be used, if it applies, when talking to people with mental retardation themselves.	81	18	1	
I am not sure what term is best to use to describe the developmental problems of children who meet criteria for mental retardation.	39	18	43	
I believe the benefits of using the term mental retardation outweigh the negatives possibly associated with the use of the word.	75	16	9	

Data presented as %

TABLE 7
Professional survey (n=10)

Which of the following terms do you think sounds the most positive?	
Mentally retarded	1
Developmentally delayed	87
Mentally challenged	5
Intellectually disabled	6

Data presented as %

TABLE 8
Professional survey (n=10)

I have been criticized for using the term mental retardation	
Yes	20
No	80

Data presented as %

TABLE 9
Professional survey (n=10)

If yes, by whom? (multiple responses permitted)	
Parent	8
Colleague	12
Other	7

Data presented as n

TABLE 10
Professional survey (n=101)

During your professional training what were you taught to use for terminology? (multiple responses permitted)	
Mental retardation	48
Developmental delay	68
Mentally challenged	23
Intellectually disabled	10
Other	11
I wasn't taught about this	15

Data presented as n

group was statistically more likely to indicate some use of the term (Table 3). Forty-seven per cent of the physician/psychologist group (ie, the professionals most likely to convey the diagnosis of a developmental disorder), reported some use of the term, with one psychologist and five physicians indicating they "frequently" used the term. All professionals selected developmentally delayed as the term they were most likely to use in the scenario presented. The terms mentally challenged and intellectually disabled did not appear to be frequently used in the health centre surveyed (Table 4).

With respect to terminology, there was a difference in how professionals reported they communicate with families compared with how they communicate with one another (Table 5). There was a higher frequency of use of the term mental retardation with colleagues among psychologists and physicians. The other groups did not report using the term mental retardation in discussion with colleagues. There appeared to be some level of disconnect between the respondents' ideas of what they should do compared with what they were doing (Table 6). Specifically, seven of the eight psychologists (87%) and 15 of the 49 physicians (31%) indicated they were either undecided or agreed that "the term mental retardation should be used, if it applies, when talking to parents", yet a much smaller number actually reported doing so.

This ambivalence was also reflected in the responses to the statement "I am not sure what term is best to use to describe the developmental problems of children who meet criteria for mental retardation". The majority of surveyed professionals in all groups, except social work, indicated they were either "undecided" or "agreed/strongly agreed" with that statement.

Of all the professionals surveyed, 20% indicated they had been criticized for using the term mental retardation (Table 8). This was reported from each discipline. The criticism most commonly came from colleagues (n=12), but also from parents (n=8) and other community members (n=7) (Table 9).

There was considerable variability with respect to what terminology respondents reported having been taught to use (Table 10). Some were taught to use more than one term. Of the 101 professionals, 68 had been taught to use developmental delay and 48 had been taught to use mental retardation. Only 10 had been taught to use intellectual disability, and 15 reported that they had received no training on this.

DISCUSSION

The results of both the parent and professional surveys support a move away from the use of the term mental retardation. Indeed, the majority of parents clearly indicated that they would be upset if a physician used the term mental retardation, and that the term should not be used when speaking with them or with affected individuals. Mental retardation is regarded as a less-positive term and as a more serious diagnosis. The reported preferential use of the term developmentally delayed is noteworthy in this context. This term is perceived to have fewer negative connotations. The authors have heard it argued that the word delay has softness in comparison to retardation, implying the potential for 'catch-up' over time. From a linguistic perspective, this is interesting. The actual meanings of the words delay and retard are identical, with both referring to the slowing of a process. The very common belief that one term is, in effect, more optimistic than the other must, therefore, be grounded in something other than the literal meaning of the words. One hypothesis is that the association of the word retardation with a stigmatized population has progressively shifted its interpretation. A second possibility is that a basic shift in vocabulary has made the use of the word retard less frequent, so that many people do not know its meaning.

Regardless of which hypothesis is correct, it is important for clinicians to understand that parents perceive the term mental retardation to be more serious. This has implications with respect to how best to work toward a shared understanding of prognosis, and may, in and of itself, argue for a move away from using either of the terms developmental delay or mental retardation in

situations where the speaker wishes to convey a significant and lifelong impairment of cognition and adaptive function in a child. Developmental delay, we would suggest, may be best reserved for situations in which the prognosis is unclear.

A considerable number of professionals reported having been criticized for their use of the term mental retardation. The fact that the majority of the professionals were not using the term, despite many having been taught to use it and/or believing they should be using it, is presumed to be evidence of the impact of experience and modelling within the health care culture. There is still more reported use of the term by psychologists and physicians than by the other health care professional groups surveyed.

One area we did not explore in the present study was whether professionals had been criticized for not using the term mental retardation. It is possible that differences in professional groups' usage may create tension, particularly during phases of transition in terminology. We also did not explore the use of the terminology in written reports, such as those by psychologists, nor perceptions regarding common descriptors such as borderline, mild, moderate, severe or profound, as applied to levels of disability. There may be benefit in further research regarding the emotional connotations and communicative clarity of these and other words used by the various groups of involved professionals.

In our region, the term intellectual disability did not, at the time of the survey, appear to be commonly taught or used. In our survey, that term was not generally endorsed by parents or professionals as a positive-sounding choice compared with the alternatives offered. If the reasoning behind the previously described shift in usage, from mental retardation to intellectual disability, was to present a more positive profile of that condition, our results suggest that the anticipated effect may not be seen.

While acknowledging this final point, the authors have nonetheless engaged in a conscious shift in practice, and in teaching, in favour of the increased use of, and recommendation to learners to use the term intellectual disability. It will be important to observe the linguistic trend over the next decade to see whether this shift, also recommended by groups such as the American Association on Intellectual and Developmental Disabilities (previously the American Association on Mental Retardation) 'catch on' in Canada. It will also be important to see whether there will be a correlating shift in the definitions used and accepted by key groups and resources, such as agencies providing support, including federal, provincial and local community resources.

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