



# What About Use of the Term Mental Retardation?

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"FAS is the leading cause of mental retardation in western civilization. But most individuals with FAS have intelligence in the normal range." - FAS fact sheet.

My son John, 25 with FAS, is quite aware that he has mental retardation (IQ = 68). There is no shame or embarrassment. It is merely a condition, like having diabetes or a heart murmur. When he was a young boy, he came in from playing with the neighbors and asked me "What's a retard?" And so began my ongoing discussion with him about his mental condition. It was also the beginning of my efforts to educate the neighborhood children and others about FAS and how it affects John's behavior. Once I became upfront and open, the children no longer snickered or whispered behind his back, they felt free to ask questions about it. John can speak about his mental retardation and his FAS disability with comfort and ease. It is others who experience discomfort because they have ambiguous feelings about lower intelligence.

Every once in awhile, someone questions my use of the term mental retardation. The term is used by the federal government and agencies like the March of Dimes, the Centers for Disease Control and Prevention, the American Academy of Pediatrics, etc. Mental retardation is a legal term, a condition that is a valid diagnosis listed in the DSM-IV. The term is embedded in federal law, and there is no getting away from accepting its use. Most school districts in most states continue to have MR as a special ed label, because of criteria spelled out in state laws.

The Final Report, Usage of the Term "Mental Retardation:" Language, Image and Public Education is a government publication that explains why this term is still used. Some people do not like to use the term because they claim it has negative connotations or is a label that carries a stigma. Yes, there is a stigma attached to having a mental disability, whether it is mental illness or developmental delays. A change in terms will eventually result in stigma attached to the new term. Discontinuation of the term could endanger services for people with this class of developmental disabilities. While there is a movement away from use of the term, there doesn't seem to be a suitable substitute.

Some people do not like to use IQ numbers, saying they are irrelevant. But an IQ score is very relevant to the individual who is in need of services for persons with developmental disabilities. In most states, DD services are only delivered to those who legally qualify in certain groups of developmental disabilities, usually these four: Autism, Cerebral Palsy, Epilepsy, and Mental Retardation. In most states, mental retardation is defined as having an IQ under 70, which is two standard deviations below normal.

Some people do not like to refer to their child as having brain damage. I do not refer to "brain damaged child" or "retarded child" or even "FAS child." I always refer to the "child with FAS" or the "individual with mental retardation" or to the brain damage as a condition but not as an adjective. The child or adult is identified first as a person, then as a person with a disability.

The people most likely to dislike use of the term mental retardation or brain damage or reference to IQ scores are parents who have not come to terms of acceptance of the reality of their child's disability or individuals who have been discriminated against because of their mental disability. They may be at a place in their grieving process where they are still fighting the idea that life will not be normal for them. They may be uncomfortable with discussing the diagnosis of FAS, and may shun labels in an attempt to avoid social rejection that goes with being different in this way. It is not the term or the label that causes the negative feelings, but other people's attitude toward the person to whom the label is applied.

I believe that parents may occasionally need help, either from a knowledgeable professional or from peer support groups, in coming to terms with a child's disability and the loss of the dreams they might have had for the child. I believe that society should not be condescending toward or have pity for people with mental disabilities. There is a great deal of ignorance and therefore there is a need for heightened awareness about mental retardation and other

forms of developmental disabilities. Individuals in society would be wise to examine their judgment of people who are not as smart, not as handsome, not as cool as they think they are themselves. We all laugh about the Darwin Awards, but really this is making fun of people who have poor judgment and lower intelligence than you and I have. In fact, the individuals who are the butt of these jokes are very likely struggling with undiagnosed FASD.

People who do "stupid" things or who make "dumb" mistakes over and over should not be viewed as "bad" or "dumb" or "stupid." They should not be judged as having character defects. Most likely it is due to neurological dysfunction (a fancy term that means the same thing as brain damage), often caused by prenatal alcohol exposure and not at all in their control, and certainly not a reason to be put down or degraded. Impaired mental function is not a reason to be thought of as anything less than worthy of respect.

So I repeat, perhaps what needs to change is not our use of the term "mental retardation" but our attitude toward individuals with impaired cognitive function.

In support groups of families raising children with FASD, there is a clear division of the "haves" and the "have nots." That is, some of the children have IQ scores under 70 and some have IQ scores in the normal range. The 25% who qualify as having mental retardation are considered the lucky ones, because they are able to get special ed services and qualify for DD services, and later can get SSI benefits. The 75% whose children have IQ scores over 70 are left high and dry with no services whatsoever. Their functional abilities are often 20 or more points lower than their IQ, as is evidenced by tests like the Vineland Adaptive Behavior Scales. The parents of the children who test in normal IQ range would give anything for their children to have mental retardation, because they know this would provide the safety of support systems that offer special services, assistants, mentors, respite, etc.

Some friends have expressed pity (disguised as compassion) for John for the simple reason that he has mental retardation. "Poor guy," they say as they shake their heads. But I tell them to look and see how happy he is in his life, how accepting he is of all his qualities however they may be perceived by others, how he is afforded so much help to succeed in his life, how much joy he finds in work and friendships and hobbies. He has positive self esteem, because he has not been led to think there is anything wrong with being a "slow learner" - which is the meaning of the term mental retardation. He has a rich life and is appreciated for his gift of music and his sense of humor. When I share this, those full-of-pity friends have to admit that John is indeed blessed. He is one of the happiest people I know. Heck, he even has a romantic relationship! I tell the same people who feel sorry for John to feel sorry for me instead. I'm the one who is deprived of social interaction, intellectually stimulating conversation, a career. So, how's that for a paradigm shift?

I think it is healthy to question our use of terms and be aware of how we refer to people with disabilities. I also think it is important to examine our attitude about people who do not fit into that nice box that society calls "normal." Do we value intelligence above kindness? Do we value common sense above respect? Do we refer to the children in special ed classes as "those kids"? Do we see good judgment as a matter of character? Or do we see it as a natural gift that some have more of than others, that some are robbed of before they are even born? If we want to honor inclusion and bring those with mental retardation and mental illness and cognitive disorders and traumatic brain injury into the circle of "regular" folks, then we need to help eradicate the stigma that is attached to those conditions, however they may be labeled. And we need to empower them to fulfill their potential, however compromised that may be by a damaged brain, and we need to afford them the services and supports that will enable them to succeed in life.

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*February 2002, Surgeon General's Report on Health Disparities and Mental Retardation: The Office of the Surgeon General is aware that there is a controversy around the use of the term "mental retardation" and that self-advocacy groups and professional associations are currently discussing various alternatives such as "cognitive developmental disabilities" and "intellectual disabilities." Until a consensus is reached, and with the goal of drawing attention to the great health disparities faced by people with what has been traditionally known as mental retardation in mind, the term "mental retardation" will be used in official media information on the Surgeon General's initiative.*

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