MISSISSIPPI COUNCIL ON DEVELOPMENTAL DISABILITIES

POSITIVE OUTCOMES

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CDD Mission Statement:

"The Mississippi Council on Developmental Disabilities is a body of advocates, appointed by the Governor, who promote quality of life for people with developmental disabilities, their families, and the community at large. Improvement in quality of life is provided through initiatives that have potential for replication, thus creating systemic change."

About this issue...

By: Ed Butler, Executive Director
Mississippi Council on Developmental Disabilities

Change is ever present, even with the words we use to talk about people. Today, people with disabilities and developmental disabilities are talking more about being referred to or about in a more respectful manner. This is referred to as using ***"Person First Language"*** or ***"Person First Terminology."*** Person first language promotes dignity for people with disabilities. This language has its basis in people with disabilities wanting to truly be a part of everyday life. People with disabilities want to be a valued contributing members in life and not a person to be "taken care of." Through my thirty years of participating and associating with people who require the most supports I learned they value individuals who talk to them with dignity and respect, as opposed to being a "client." They want to be included and not just integrated. They want to make choices about participation and not just participate. Our words do speak as loud as our actions. Our words define our philosophy and action toward people with disabilities. This also applies to people with very significant developmental disabilities who require the most support.

I asked a few people to write articles and express their thoughts about person first language. The people in the newsletter were selected because of their own beliefs and use of person first terminology.

The Mission of Educating Others...

By: Eric Clark
Parent and Secretary of State for Mississippi

Those of us who are committed to the full and active participation of every person in our society have made great progress in recent years. Thanks to the tireless efforts of many, people with disabilities are enjoying productive lives in Mississippi, making our state better. Still, it's important to be vigilant and continue our work. Many times this work requires ***educating others*** to see the world in a way they have not seen it before. One of the best ways to change attitudes is to change the words people use to describe those with disabilities. During the first week of the legislative session, I saw this headline in The Wall Street Journal (January 7, 2003): "Parents Devoted to a Disabled Child ..." The parents in this new article are not devoted to a "disabled child;" they are devoted to a child with a disability. As the dad of a daughter with Down's Syndrome and arthritis, I believe it is important to know the difference.

Experts call this "People First Language." It involves a few basic concepts, as expressed by the experts:

✓Speak of the person first, then the disability.
✓Emphasize abilities, not limitations.
✓Do not label people as part of a disability group.
✓Don't patronize.
✓Let each person speak for himself or herself as much as possible.
✓A "disability" is a functional limitation that interferes with a person's ability to walk, talk, hear, learn, etc. ✓A "handicap" is a barrier imposed by society or the environment.

Think about it. If you saw a person in a wheelchair unable to get up the stairs into a building, would you say, "There is a handicapped person unable to find a ramp?" Or would you say, "there is a person with a disability who is handicapped by an inaccessible building?" Don't confuse the limitations of one person with the responsibility of others. Some may say this kind of talk is simply "political correctness." It's not.

Seeing people as people, being sensitive to everyone, is the bedrock of our Christian values.

Jesus said: "Therefore all things whatsoever ye would that men should do to you, do ye so to them; for this is the law and the prophets (Matthew 7:12)."

The Golden Rule teaches us to put ourselves in someone else's place. We can only do that by speaking of every person just as we would want to be spoken of. All of us are made in the image of God. Who among us is not disabled in some way? Of course, using the right words is only a first step. We need to be personally committed to improving the lives of people who have disabilities. We need churches that are involved in reaching out. We need government that is actively committed to help. We need elected officials that will practice what God preaches.

In this New Year, as we begin a new term of state government, let's make service to those with disabilities a very high priority. For additional information, contact David Blount in the Secretary of State's Office at 601/359-6342.

People First Language

By: Edwin C. LeGrand, Deputy Executive Director
Mississippi Department of Mental Health

At the Department of Mental Health we recognize that the individuals we serve are just that- individuals. To further promote people first language The Mississippi Department of Mental Health Minimum Standards for Community Mental Health/Mental Retardation Services were revised in 2002 to incorporate people first language. We believe that as service providers we should set an example to the public to recognize and treat individuals with disabilities with respect. Respect begins by noting that a person's self-esteem is tied closely with how people describe them.

The Mississippi Department of Mental Health is the state agency charged with administering the public system of mental health, mental retardation/developmental disabilities, alcohol/drug abuse services, and Alzheimer's disease and other dementia services. The Minimum Standards were established for the operation of all Department of Mental Health certified facilities. The Department of Mental Health ascertained that the first step toward converting attitudes is to begin by incorporating people first language in the document by which we certify our programs.

The Department of Mental Health recognizes that people with disabilities have needs and with support from our programs/services those needs can be met. Recognizing that needs are as individual as the persons we serve, encourages the use of language that denotes putting people first. Revising the Mississippi Department of Mental Health Minimum Standards for Community Mental Health/Mental Retardation Services is simply the beginning. We are striving in our duties to promote people first language each and every day.

The Standards Don't Say "Client" Any More...

By: Linda Terry , Division Director
BMR Division of Accrediation & Licensure

In the 1950s professionals in the human service fields made a giant leap forward and began using the word "client" to refer to people receiving special services. At the time, it was a dramatic improvement from using words like "patients" or describing people by their disability, such as "epileptic" or "moron."

Now, fifty years later, the Department of Mental Health has made another giant leap and discarded the word "client." Why? Actually, there are several reasons...

To some people, the word "client" implies the person receiving services is in a lower social or educational status. As we all know, this is not always the case. Many people with disabilities are in an equal or higher social or educational level; however, all people are equal as human beings.

To others, the word "client" connotes a professional relationship, such as the relationship between a person and his attorney, or a person and his physician. The relationship between a person receiving services and the person providing services is often on a much more interpersonal level. Furthermore, relationships between a person and an attorney or physician are often a "one time only" or used occasionally. The services provided to people with disabilities are often on a regular, even daily, basis and are ongoing for long periods of time, even lifelong. The relationship is much different.

And finally, why should people be referred to by any other words just because they require assistance? We refer to mainstream society as people" or "individuals," so why not just use the same words when referring to ALL people?

When revising the Community Mental Health/Mental Retardation Minimum Standards, the Bureau of Mental Retardation staff felt strongly that the language in the standards reflect our belief that the people who receive services are valued and respected and should be treated with the same respect and dignity as any citizen. We concluded the only way to do this was to discard the use of the word "client" and just refer to people as PEOPLE.

Calling Things by the Right Name...

By: Dan and Emmagene McGaughy, Council Member and Persons with Developmental Disabilities

The beginning of wisdom is to call things by their right names. Throughout history people with disabilities have been labeled with such descriptive names as afflicted, unfortunate, misfortunate, victim, invalid, etc. These phrases tend to imply a person with a handicap is in some way inferior to the "normal" individual. We both have a disability and have both worked as Vocational Rehabilitation counselors with people with disabilities, but we have never seen a definition of a "normal person."

These terms do not reflect the distinct characteristics of people with disabilities. People are now recognizing the need for emphasis to be placed on the individual rather than on the individual's disability. For example, a disabled child or adult could be more appropriately referred to as a child with a disability or an adult with a disability. The primary focus should be on the individual, not the disability.

Some people may question the need to place the emphasis on the person instead of the disability. As far back as biblical days we are reminded "As a man thinketh in his heart, so is he." If a person hears terminology as handicapped person, blind person, deaf person, invalid or crippled, he may see himself as the condition and not the person first, and never fully develop his skills or abilities. By focusing on the person instead of the disability, people with disabilities will focus on their abilities.

For example, Ray Charles is nationally known as a great pianist. He just happens to be blind. His inability to see did not prevent him from developing his musical skills. The millions of people who visit Disneyland and Disney World probably do not know Walt Disney had a Learning Disability. In spite of her inability to see or hear, Helen Keller wrote eight books and is known as a great achiever in American History. Although Franklin D. Roosevelt had polio and was a wheelchair user, he was elected to serve four terms as President of the United States.

The stereotypes that people have of people with disabilities are sometimes rather amusing. My wife and I both have Cerebral Palsy. One day we went to a local restaurant. As we were waiting to be seated, we noted that the waiter commented to the hostess that "here comes two retards." The hostess seated us. Since my wife is rather short and walks with a noticeable limp, the waiter asked me what did my wife want to eat. I did not say anything. I acted as if I were deaf. I signed in Sign Language, "hungry." He then turned to my wife and she ordered for both of us. Throughout the meal, we did not talk with each other. As we left the restaurant, I told the waiter "Good By." He was shocked that I could talk!

In reflecting on the terminology to use for people, I sometimes wonder how we decide who needs the labels we give to different people. For example, if a person is a wheelchair user it seems natural to refer to that person as disabled. However, if a person has a heart problem or high blood pressure, should he be referred to as Cardiac Clovis? Furthermore, if we have a friend who happens to have red hair, should we refer to him as Red-Headed Rufus? And since he does have red hair, can we naturally assume that he has a bad temper?

As persons with disabilities, we have received services through the Department of Rehabilitation. Our vocational rehabilitation counselors referred to us as a "client", in some way implying that we had to be "fixed." Many disabilities are the results of conditions which cannot be fixed. The objective of rehabilitation is to provide the services needed that will allow the person with a disability to optimize her/his potential.

As we begin a new year we may need to think about our own attitudes toward people with disabilities and the way in which we communicate our own feelings to them. Will we use language that focuses on people as individuals first who happen to have a disability? Will we be instrumental in helping them focus on their individual skills instead of stereotyping them into a disability? Can we begin today by ***calling things by the right name***?

I Can't Believe What I Just Heard...

By: Shirley J. Miller, MPPA, CMRT, CPM, & MOM

Sometimes when you hear something for the first time your initial reaction is to stop and say, ***"Did I just hear that?"*** You pause and if you are like me you shake your head in disbelief. You would think in the 21st Century people with disabilities would not be referred to in archaic terms such as deaf/mute, sped kids, retarded or as a group "the disabled" the "the retarded." Every day I see, hear and read terms that discount people with disabilities as anything but people.

People with disabilities make up the country's largest and most diverse minority group. According, to Kathie Snow, of Disability is Natural.com, it is the only minority group which anyone can join, at any time. Think about it one can join at birth or through growing older or through an accident.

The power of words is unmistakable. Words can move people to fight, to fall in love, to vote, to make purchases and the misuse of words is equally as powerful. When someone uses terms like "handicapped," "disabled," "defective," they conjure up visions of helplessness, and sympathy. The old nursery rhyme that states, "sticks and stones can break my bones, but words can never harm me," is not true. The misuse of words can lower self esteem, and plant stereotypes that are difficult to overcome.

I saw a headline about six months ago that read, "Deaf/Mute Injured in Fight." I could not believe my eyes then about two weeks later, another headline read "Sped Kids Play Ball." I am sure the authors of the articles were trying to evoke emotion but the emotion I felt was disbelief and anger. No one would have written "red headed man injured in fight" or "kids with glasses play ball". Why, was it necessary to use such demeaning terms to describe two events?

People with disabilities have been described in terms that have harmful to them and paint a portrait of them defines them as their disability. They are not their disability they are people first. Therefore, whether you are submitting articles for your company newsletter, or church bulletin, or broadcasting the news use people first language to convey your message. If that person's disability is not germane to the story don't mention it. It takes a little more effort to put the person first but it gets easier the more times you do it. Let's put people first in all that we write, say or do.

Get to know the person...

By: Matt Nalker, Parent and Executive Director of ARC/MS

Recently I was reminded of how important it is for some of us to have a label or diagnosis for our sons and daughters with disabilities. I have known folks to drive for hours, fly for days, or sit in doctors' offices for what seems like months, to hear that, "Johnny has Cerebral Palsy or that Susie has ADD with ADHD." It seems to put some sort of closure or acceptance of the fact that there really is a known/substantiated disability, and that if there is a name for it or someone else has experienced it - it may soften the blow. After time the name or diagnosis almost replaces the individual it is intended to describe. How many times have you heard the expression, "Those little DOWNS kids are soooo sweet." As if they are all the same just because of their disability label.

I challenge all of you to ***get to know the person*** first, who happens to have a disability. Learn their likes and dislikes, their ways of communicating, and then begin focusing on the lifelong services and supports they will need to be a productive member of their community. I am not advocating that it will be easy, but I am advocating that all people need an opportunity and a chance to be all they can be. Yes, labels maybe needed to access services, but after that we need names, like Matt, Fred and Joe. These individual names are of people not of conditions. I dare say you if you know two people with a specific disability you will definitely find as many differences as you would similarities in their individual personalities. ***Get to know people, not their disabilities.***

These are just a few thoughts of a Dad, who happens to be named Matt Nalker.

I Challenge All Committees, Boards and Advocacy Groups...

By: Shirley Miller, Chairperson Special Education Advisory Panel

I challenge all task forces, committees, boards, and advisory groups to use people first language when referring to persons with disabilities. I sit on numerous committees, advisory boards, task forces, and work groups that shape public policy on persons with disabilities.

People with disabilities compromise the country's largest and most diverse minority group. As public policy makers we owe it to the community that we represent to use language that is empowering and not demeaning. To state that a person is "autistic," "schizophrenic" or "manic" promotes others to think of the person as their disability, rather than "a person who has autism," or "a person with schizophrenia," or "an individual with bipolar disorder." People first language denotes that people are referred to as individuals like everyone else but through circumstances have challenges in their lives.

I have a commitment from two groups of which I am a member, The Special Education Advisory Panel and the Mississippi Interagency

Coordinating Council for Children Birth to Three with Disabilities, to promote people first language. I also have a commitment from members of these groups to further this cause by using people first language in their work and to seek a commitment from their colleagues. So I challenge all members of boards, commissions, task forces, work groups, committees, subcommittees, advisory groups to join me in 2004 in using people first language.

As Professionals We Ought to Know Better...

By: Linda Terry, Division Director
BMR Division of Accrediation & Licensure

Recently, I have had two eye-opening experiences, each of which showed how professional people can be insensitive and demeaning - probably without even realizing it.

The first experience was in a session at a conference where the presenter, a professional, repeatedly differentiated between people with disabilities and people without disabilities as “the typicals” and “the handicapped!” The second instance was shortly after that in a hospital where my mother had a leg amputated due to a medical issue. While in the hospital, one nurse came in to get her up to be weighed. As she pulled back the covers, she saw the amputated leg and exclaimed rather indignantly, “Why didn’t someone tell me I was dealing with an amputee!” My mother’s face showed indescribable hurt. As far as she was concerned she was still a mother, a friend, a neighbor, a gardener, a Christian. Why did either situation have to happen?

My first thought was that ***we, as “professionals,” just ought to know better*** (I used the term professionals to reference all who work in a chosen profession of service to others). I then realized that obviously we don’t know better, and all too often we still use generic headings such as “the mentally retarded,” “the SPED kids,” “the disabled,” or “the amputee.” Or we describe people by using demeaning phrases such as, “He is bound to a wheelchair,” “He suffers from deaf/blindness,” or “She is a victim of a birth defect.”

The use of such terminology evokes negative feelings and creates a perception that all people with disabilities are alike and that any abilities they may have are secondary. Quite the contrary is true. A person’s disability does not define the person; rather, it is only one aspect of the person. Many people have mental retardation, but each one is different from the other, and each one has unique abilities. One may be able to read a book, while another may be able to sew a straight line or jog four miles a day. To say a person is “bound to a wheelchair” implies the person somehow cannot be part of the community. The person may not be able to walk about the community, but, with the assistance of the chair, he can move about the community. He may also be able to read a story to a child or give someone directions to the Post Office. To say, “She suffers from a hearing loss” also degrades. She may have a hearing impairment, but that does not stop her from riding the bus to work each day, going to church, paying her own bills, living a fulfilling life.

The words we choose are powerful - they can inspire and they can degrade. When we, as professionals, begin to recognize ALL people are valued, participating members of the community, we will begin to put aside using these words that hurt, these words that build invisible barriers. We ALL have unique talents as well as unique needs. We all ought to know better and strive to use person first terminology that is now recognized as professional language.

> “The difference between the right word and the almost right word is the difference between lightning and the lightning bug.”
> Mark Twain

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