

THE MICHAEL DUNN CENTER STAFF BULLETIN

NOW YOU KNOW

Volume 1 Issue 6

April, May 2004

edited by Roger Richmond

FROM THE DIRECTOR'S DESK...

Kyle Hauth

A FIGHT WORTH FIGHTING

The Michael Dunn Center belongs to an association known as Tennessee Network of Community Organizations. This association exists to support and advocate for community providers like the Michael Dunn Center. I am proud to say that this organization has been working diligently to pass legislation this year which will ensure that we can provide salary increases to direct support professionals (DSP's). I am somewhat despondent to re-

port that the Tennessee Division of Mental Retardation (DMRS) has chosen not to support our efforts. However, our association and the lobbyist that support us inexorably push on with this fight.

I attended the budget hearing which was recently held at legislative plaza. It was very encouraging to hear several of our state representatives speak up and remind DMRS representatives that our agencies have had no increases in funding in spite of numerous increases in state



funding, state administrative services, unfunded mandates, gasoline costs, insurance costs and other costs of living. Our association had superbly informed the state of the huge inequities in state employee DSP wages and the contradictions that are often espoused

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TRAINER'S MOMENT

Roger Richmond

Trading Places

Have you ever thought what your life would be like if you woke up one day to find that you had magically traded places with the person you support? You were woken up at 5:30 AM because your

house mate had to be at work by 7:00, even though you don't have to be there until 8:30. You really didn't get a very good night's sleep because the overnight staff kept the television on at a loud volume all night long and talked loudly outside your room. When

you were being fed your breakfast, you were given bigger bites than you are comfortable with and the staff person didn't really give you time to chew and swallow before pushing another bite into your mouth. You really

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Do you remember...

- You may never leave individuals who are being supported unattended unless their ISP specifically states they may be unsupervised.
- You must assure that a staff person is present to supervise before leaving an individual at a house.
- You must always check your vehicle before leaving it to assure that everyone has exited.

THE VALUES THAT SUPPORT LIFE IN THE COMMUNITY

The following article comes from the Virginia Department of Mental Retardation Staff Guide

Part III of a series

Respect

Adults with mental retardation, just like the rest of us, are thought of favorably when they are in a position to contribute to the community. Lack of exposure to persons with disabilities and mistaken ideas which follow, often restrict the opportunities people with disabilities' have to take on roles that are valued in the community. People with disabilities, when given individual assistance, can achieve the respect of others by getting the chance to perform useful and meaningful activities.

There is a general tendency to underestimate people with disabilities. Non-disabled persons, even professionals in human services, often focus on the limitations rather than the talents and abilities of people with disabilities. Low expectations can limit people's opportunities to try new things and interfere with their achievements.

Respect requires seeing the individual as a person first. The disability is only one aspect of his life. It is important to remember that people with disabilities want and need the same things others do _ love, security, the satisfaction of personal accomplishment, the opportunity to exercise some control over one's days, environment, and experience, to laugh, and to communicate with others. The way a person experiences these things is different for each, but the desire to have them is the same for everyone.

What's Your Role?

- When supporting a person who is blind, announce your presence,

inform the person prior to touching her if necessary, and don't rearrange her belongings without telling her.

- Don't talk about the individuals you support in their presence or talk to another staff member or person in the community as if they weren't present.
- If you are staff in a group home, you should join the people you support for meals by sitting with them, and eating the same food from the same dishes they routinely use.
- Don't watch TV, read the newspaper or call your friends while on duty. It's not your home, it's the individual's home! It's your workplace.
- Every six months, honestly ask yourself, would you like to live in this home or work in this day program?
- Assist the individuals you support to help out in community endeavors. Help them to join neighborhood and civic groups, to be volunteers with other people around town, to vote and to contribute to regular community living.

Individual Rights

People with mental retardation and other disabilities have the same human rights as non-disabled people. Like you, they are entitled to enjoy the right to privacy, to marry, to free speech, to live in neighborhoods, to vote. Some people with disabilities may have had a few of their legal rights limited through the appointment of a guardian or another legal process. Due to a lack of understanding about people with mental retardation, it is not unusual for an individual to have had certain limitations placed on him such as managing his own money, voting for his governor, even picking out his own clothes-things which he is

perfectly capable of handling with individual supports. As an employee of a community agency providing services to people with mental retardation, you should be aware of these basic human rights, as well as any specific human rights policies followed by your agency. Ask your supervisor to give you a copy and explain your agency's policy to you.

What's Your Role?

- You should carefully read the human rights policy of the agency for which you work. List any questions and discuss them with your supervisor.
- At least once a year, sit down with the people you support one at a time and explain their rights to them in a way that is meaningful to each person- sign language, simple spoken language, or even using pictures to illustrate each right.
- You speak up when you feel other staff are routinely violating a person's right to privacy or other rights.

Zero Reject

Zero reject is the concept that all people with developmental disabilities belong in the community. No matter how severe an individual's disability or challenging her behavior may be, it is possible to develop flexible, individualized supports to help meet her needs. It is the responsibility of the program and staff to devise plans to meet an individual's needs and to help her gain or keep skills or change her behaviors. Community programs used to have very strict entrance requirements, as well as high expectations for allowing people to continue to stay in their program. People who failed to adapt or to meet these criteria went unserved or lost their place in the program.

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A Fight Worth Fighting, continued

(Continued from page 1)

through rhetoric which indicates that the problems with our system are not directly linked to the low wages that people are forced to survive on.

I do not know if we will succeed with this bill this year. There is speculation that our legislators will succumb to the recommendations from DMRS, which is basically wait

and see if the new rates will help providers. Although the new rates have not been finalized, I have been privy to the drafted amounts and have found that at best we will experience a neutral change in our finances and at worst a significant loss to several services. Therefore, I am very hopeful that our legislative body can see through the smoke and mirrors, which are occasionally pulled out when we begin to ask for

real change in the community system, and vote to place funds where they undeniably belong.

You can help join this fight. Call, write and/or email Representative Dennis Ferguson and Senator Tommy Kilby and tell them you desperately want them to passionately support house bill 0791 and senate bill 0502.

Trading Places, continued

(Continued from page 1)

wanted a cup of coffee, but no one asked you, even though the staff all had coffee. The staff person really didn't pay very good attention to what she was doing, because she was having a very excited conversation with the other staff person about the date she had the night before. The things she was saying really made you kind of uncomfortable- some of the words she used weren't very nice.

When you got to the center, the staff person who was responsible for you really didn't pay very much attention to you. He talked a lot to other people about things that you don't like to hear, and sort of acted as if you weren't even there. In the afternoon he complained to another staff person, in front of other people, that he had to take you to the restroom again to change your "nasty pants". He used some more bad language that made you uncomfortable. You really didn't mean to have an accident- you couldn't help it, but you weren't able to speak to apologize for it. At lunch, one of the staff took orders and went out for food for the other staff. You really wanted to try that new Mexican restaurant that they ordered from, but no one asked you what you wanted to eat, so you

had a sack lunch. You really didn't enjoy any of the things that you did all afternoon, but the staff seemed to have fun.

The next day you magically awoke in a different place. In this place, you were allowed to sleep until 7:00 AM and had a good breakfast with staff who talked with you and gave you plenty of time to enjoy your food. When you got to the day program, you were greeted by a staff person who squatted down beside your wheelchair, looked you in the eye, and introduced herself. She then asked you what you

you found interesting. You had a very good day and looked forward to spending time with her again the next day. When you got home, you had a relaxing afternoon and a good supper (they served Mexican, your favorite!), and then watched a movie that you had been wanting to see. At 10:30 you went to bed; even though staff were awake all night, no one disturbed you, and you had a good, quiet night of rest, remembering the things you had done that day.

So ask yourself this: if *you* woke up tomorrow and found yourself living in a group home, unable to speak or communicate your needs and desires, with no use of your arms and legs, which reality would you rather find yourself in? Which reality do *you* provide for the person that you support? Are *you* being the kind of support person that you would like to have taking care of yourself or your family member? Think about your average day and all the things you do and all the small decisions with which you are presented. How would you feel if you lost control over all of those things and had to depend on other people to care for you. Would your day be the way you would want it to be, if you traded places with the person that you support?

How would you feel if you lost control over all of those things and had to depend on other people to care for you.

would like to do for the day. She suggested maybe going to the mall, but you didn't feel like going there, so you shook your head to say "no". When she asked if you would like to go to the antique store and look at their bottle collection, you became very excited (how did *she* know you collected bottles?). While you were together, this staff person talked with you about things that

DDI RECYCLES!

Melanie Harmon

As part of its recycling program, Dunn Diversified Industries provides services to Oak Ridge Associated Universities in Oak Ridge, Tennessee. DDI picks up mixed office paper and cardboard weekly at nine separate ORAU facilities and delivers it to the Roane County Recycling Center.

Oak Ridge Associated Universities is a not for profit corporation and consists of a consortium of 87 doctoral granting colleges and universities. Established in 1946, ORAU holds the distinction of being the first multi-university consortium created in the United States for the purpose of operating scientific and educational programs under government contract. Fifty years later, ORAU continues to use its unique position to link the academic community with government agencies and private industry to create beneficial

partnerships and discover innovative solutions in the areas of education, training, health, and the environment. ORAU manages and operates the Oak Ridge Institute for Science and Education for the United States Department of Energy.

The paper recycling partnership between DDI and ORAU was initiated in April 1998 by ORAU Safety Technician, Becky Williford. She had read an article in the Pollution Prevention Advisor, a DOE Defense Programs quarterly newsletter about the recycling program between Lockheed Martin Energy System's Y-12 plant and DDI involving 27,000 pounds of old books and journals and 19,500 pounds of surplus clothing. Becky says, "By using DDI for our waste paper collection, service is more timely, costs are reduced, and, best of all, we are part of a great community effort. It just doesn't get any

better than this."

The contract is a good one for DDI because it places DDI employees in integrated community settings resulting in increased public visibility of individuals with disabilities. "Our recycling program is our fastest growing area of contracts" says Melanie Harmon, DDI General Manager. "Our recycling program is good for the customers, good for our employees and good for the environment." The work for ORAU is performed by DDI supervisor Roger Edwards and employee John L. Smith. Roger says, "If we didn't pick up the paper, it would probably end up in the landfill somewhere." John L. adds, "We look for paper and we find it." DDI has picked up over 189 tons of paper and cardboard for ORAU since April 1998.

Values that Support Life In The Community

(Continued from page 2)

Our understanding of the varied ways in which people with disabilities communicate has grown, and we now know about the lasting negative affects of living in an institution for a long time. At the same time, the profession has become aware that many of our early methods, especially behavior management, didn't really work and even "dehumanized" people with mental retardation. As we begin to truly recognize the people we support as individuals, our ability to do a good job of teaching and supporting them in community settings grows. Individuals with severe disabilities, who were not considered for the

first wave of deinstitutionalization, are now living productive and fulfilling lives in the community. Zero reject recognizes that it is the responsibility of the community provider agency to develop the supports a person needs to succeed in the community, rather than expect the person to change before she can get those services.

What's Your Role?

- The day program in which you work is admitting a young woman with a history of yelling and sometimes, hurting others. Additional staff have been hired, and training has been provided in "positive behavioral supports." You commit mentally to working

with your team in supporting this individual instead of complaining, "She doesn't belong here."

- You work in a supported living program that is screening individuals for placement. Following a long bout with the flu, one individual has lost many of the self-help skills he once had. Other provider agency staff feel he'll be motivated to learn to care for himself again based on their history with him. You feel it's worth the effort to assist in this and recommend he be admitted.
- The members of your team adjust your work schedules to offer more staff support to a person who has been acting more aggressively following the loss of a

KEEPING MDC BEAUTIFUL

Anita Richmond

Earlier this week I was talking with Robert Gallaher, a friend and supporter of MDC, as we walked down the hall of the school building. As we strolled along he pointed out the room where he attended first grade and as we passed each door he shared a memory of his days as a student in our building when it was an elementary school within the county system. Robert recalled teachers that he had and classmates long forgotten. This conversation started me thinking about all of the students whose lives we have touched since we started our School Program and took over the building, in 1979. I hope that they can all recount happy memories from their

time spent here and hopefully we were able to play a part in helping them achieve their dreams in life, whatever they may have been.

Our school building was built in 1953 and like most buildings over 50 years old it has begun to show its age. We have done our best to keep it in good repair and looking good over the past 25 years but with limited money and man power it is not always easy. With Karin Woody and her husband John's help as contact people we were very fortunate to have a group of about 12 men from OMI volunteer their services to help us maintain our building. These

gentlemen gave up most of a recent Saturday to come and paint the long hallway in our school and rebuild a frame for a swing on one of our playgrounds. All we had to do was provide the materials and throw in some sandwiches for lunch. These guys worked non-stop until the jobs were done and I was extremely impressed with their skill and professionalism.

It may be just a building but we love it and all the "ghosts" of students past. The support that we get from our community is just amazing and I hope everyone realizes how lucky we are to be in Roane County.



UNDERSTANDING AUTISM

reprinted from Autism Society of America

What is Autism?

Autism is a complex developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects the functioning of the brain, autism impacts the normal development of the brain in the areas of social interaction and communication skills. Children and adults with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities.

Autism is the most common of the Pervasive Developmental Disorders, a category of neurological disorders characterized by "severe and pervasive impairment in several areas of development," including social interaction and communications skills, affecting an estimated 2 to 6 per 1,000 individuals (Centers for Disease Control and Prevention, 2001). This means that as many as 1.5 million Americans today are believed to have some form of autism.

And that number is on the rise. Based on statistics from the U.S. Department of Education and other governmental agencies, autism is growing at a rate of 10-17 percent per year. At these rates, prevalence of autism could reach 4 million Americans in the next decade.

The overall incidence of autism is consistent around the globe, but is four times more prevalent in boys than girls. Autism knows no racial, ethnic, or social boundaries, and family income, lifestyle, and educational levels do not affect the chance of autism's occurrence.

Common Characteristics of Autism

While understanding of autism has grown tremendously since it was first described by Dr. Leo Kanner in 1943, most of the public, including many professionals in the medical, educational, and vocational fields, are still unaware of how autism affects people and how they can effectively work with individuals with autism. Contrary to popular understanding, many children and adults with autism may make eye contact, show affection, smile and laugh, and demonstrate a variety of other emotions, although in varying degrees. Like other children, they respond to their environment in both positive and negative ways.

Autism is a *spectrum disorder*. The symptoms and characteristics of autism can present themselves in a wide variety of combinations, from mild to severe. Although autism is defined by a certain set of behaviors, children and adults can exhibit *any combination* of the behaviors in *any degree of severity*. Two children, both with the same diagnosis, can act very differently from one another and have varying skills.

Every person with autism is an individual, and like all individuals, has a unique personality and combination of characteristics. Some individuals mildly affected may exhibit only slight delays in language and greater challenges with social interactions. The person may have difficulty initiating and/or maintaining a conversation. Communication is often described as talking at others (for example, monologue on a favorite sub

ject that continues despite attempts by others to interject comments).

People with autism process and respond to information in unique ways. In some cases, aggressive and/or self-injurious behavior may be present. Persons with autism may also exhibit some of the following traits.

- Insistence on sameness; resistance to change
- Difficulty in expressing needs; uses gestures or pointing instead of words
- Repeating words or phrases in place of normal, responsive language
- Laughing, crying, showing distress for reasons not apparent to others
- Prefers to be alone; aloof manner
- Tantrums
- Difficulty in mixing with others
- Little or no eye contact
- Unresponsive to normal teaching methods
- Spins objects
- Inappropriate attachments to objects
- Apparent over-sensitivity or under-sensitivity to pain
- No real fears of danger

People prefer to follow those who help them, not those who intimidate them. --C. Gene Wilkes

UNDERSTANDING AUTISM

reprinted from Autism Society of America

- Noticeable physical over-activity or extreme under-activity
- Uneven gross/fine motor skills
- Not responsive to verbal cues; acts as if deaf although hearing tests in normal range.

For most of us, the integration of our senses helps us to understand what we are experiencing. For example, our senses of touch, smell and taste work together in the experience of eating a ripe peach: the feel of the peach fuzz as we pick it up, its sweet smell as we bring it to our mouth, and the juices running down our face as we take a bite. For people with autism, sensory integration problems are common. Their senses may be over-or under-active. The fuzz on the peach may actually be experienced as painful; the smell may make the person gag. Some people with autism are particularly sensitive to sound, finding even the most ordinary daily noises painful. Many professionals feel that some of the typical autism behaviors are actually a result of sensory integration difficulties.

There are many myths and misconceptions about autism. Contrary to popular belief, many people with autism do make eye contact; it just may be less or different from a non-autistic individual. Many people with autism can develop good functional language and others can develop some type of communication skills, such as sign language or use of pictures. Children do not "outgrow" autism but symptoms may lessen as the child develops and receives treatment.

One of the most devastating myths about autistic people is that they

cannot show affection. While sensory stimulation is processed differently in some people with autism, they can and do give affection. But it may require patience on a parent's part to accept and give love in the individual's terms.

What Causes Autism?

There is no known single cause for autism, but it is generally accepted that it is caused by abnormalities in brain structure or function. Brain scans show differences in the shape and structure of the brain in autistic versus non-autistic children. Researchers are investigating a number of theories, including the link between heredity, genetics and medical problems. In many families, there appears to be a pattern of autism or related disabilities, further supporting a genetic basis to the disorder. While no one gene has been identified as causing autism, researchers are searching for irregular segments of genetic code that autistic children may have inherited. It also appears that some children are born with a susceptibility to autism, but researchers have not yet identified a single "trigger" that causes autism to develop.

Other researchers are investigating the possibility that under certain conditions, a cluster of unstable genes may interfere with brain development resulting in autism. Still other researchers are investigating problems during pregnancy or delivery as well as environmental factors such as viral infections, metabolic imbalances, and exposure to environmental chemicals.

Autism tends to occur more frequently than expected among individuals who have certain medical

conditions, including Fragile X syndrome, tuberous sclerosis, congenital rubella syndrome, and untreated phenylketonuria (PKU). Some harmful substances ingested during pregnancy also have been associated with an increased risk of autism. Early in 2002, The Agency for Toxic Substances and Disease Registry (ATSDR) prepared a literature review of hazardous chemical exposures and autism and found no compelling evidence for an association; however, there was very limited research and more needs to be done.

The question of a relationship between vaccines and autism continues to be debated. In a 2001 investigation by the Institute of Medicine, a committee concluded that the "evidence favors rejection of a causal relationship.... between MMR vaccines and autistic spectrum disorders (ASD)." The committee acknowledged, however, that "they could not rule out" the possibility that the MMR vaccine could contribute to ASD in a small number of children. While other researchers agree the data does not support a link between the MMR and autism, more research is clearly needed.

Whatever the cause, it is clear that children with autism and PDD are born with the disorder or born with the potential to develop it. It is not caused by bad parenting. Autism is not a mental illness. Children with autism are not unruly kids who choose not to behave. Furthermore, no known psychological factors in the development of the child have been shown to cause autism.



Phone Numbers:

BIT Crisis Beeper..... 909-5593
Poison Control.....1-800-222-1222
Kyle Hauth pager.....602-9611
Abuse Investigator.....1-800-579-0023

Our Mission:

Empowering individuals with disabilities to pursue their choice of livelihood by providing them with opportunities to increase their contribution to the community in which they live.

Write Your Congressmen!

Senate

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When it comes to practicing good ethics, saying no to a vice is not good enough. A quality life is never achieved by focusing on the elimination of what is wrong. True success requires you to focus your mental, emotional, and spiritual energies on pursuing that which is right and good. Trying to become virtuous merely by excluding vice is as unrealistic as trying to cultivate roses simply by eliminating weeds.

-Gary Ryan Blair (*Mind Munchies : A Delicious Assortment of Brain Snacks!*)

Holiday Schedule

Monday, May 31 Memorial Day
Monday, July 5 Independence Day
Monday, September 6 Labor Day