

HEALTHY Times

A medical newsletter for health care professionals and caregivers of individuals with intellectual and other developmental disabilities



June 1, 2012, The Arc of New Jersey's 23rd Annual Conference on Medical Care. Pictured LtoR: Walter Bender, President, The Arc of New Jersey; Morning Keynote Speaker, Lauren Charlot, PhD, Director of ID/MH Services at UMass Medical School; Dawn Apgar, PhD, Deputy Commissioner, NJ Department of Human Services; Beverly Roberts, Director, Mainstreaming Medical Care Program, The Arc of New Jersey; Thomas Baffuto, Executive Director, The Arc of New Jersey.

Weight Management 101: Back to Basics

Dawna T. Mughal, PhD, RD, LDN

"The committee envisions a society of healthy children, healthy families, and healthy communities in which all people realize their full potential and develop the competencies required to interact successfully with their surrounding environments."

- Institute of Medicine, 2012, p. 19

Purpose

This article reviews the increased prevalence of obesity in the general population and among individuals with intellectual disabilities (ID) and its implications for health, economics, and overall quality of life. Good nutrition, translated into nutritious foods that look good and taste good, and physical activity are key ingredients of a recipe for disease prevention or treatment/management and health promotion. This article, therefore, will include some practical behaviors that individuals, their families and other caregivers can do to help them achieve and maintain healthy weight as much as possible. Bombarded often by large doses of weight loss messages, some of which are conflicting or are misinformation delivered in catchy words, consumers might lose sight of the basics that they can tailor to their individual needs and resources. The information in these weight loss messages is not intended for clinical management or nutrition therapy for a complex problem of obesity, which requires consultation with health professionals.

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Specialized, Coordinated Multidisciplinary Healthcare Service for Individuals with Intellectual Disabilities and Mental Health Disorders (ID/MH)

Lauren Charlot, PhD

You Can't Always Get what You Want, But if You Try Sometimes...

Our multidisciplinary team evaluated John, a 25-year-old young man with Autistic Spectrum Disorder (ASD) several years ago. He was referred for increasing severe behavioral difficulties, and his life, according to his mother, had been "turned upside down." He was about to lose his day program because of his severe aggression and self-injurious behavior. He had always had some problem behaviors, but the intensity and frequency of these had grown markedly over the past year. He now had 2:1 staffing because he was a tall, strong young man and when he had "melt downs," he was unfortunately very dangerously aggressive. He had several Emergency Department (ED) visits, when even his experienced staff could not manage his behavior. He was also hospitalized for 20 days on an inpatient psychiatric unit. He was now treated with 5 psychoactive medications, including 2 antipsychotic drugs. Our team reviewed his history in detail, interviewed his caregivers and family and observed and directly evaluated John. We looked at a lot of information about the nature of his problem behaviors, the context in which these occurred as well as reviewing all records regarding his health and developmental history. One small detail struck a cord. John occasionally seemed to spit back up some of his food undigested after meals, and he seemed to cough very slightly during and just after eating. After a lot of groundwork and planning, it was arranged for John to have an upper endoscopy under sedation. The test revealed a highly significant degree of esophageal excoriation related to what was likely to have been a long-standing problem with severe gastroesophageal reflux disease or GERD. John had also developed severe constipation. Once these medical conditions were more aggressively treated and began to improve, his mother said he was a "new man." His behavioral crisis was resolved.

John was one of many cases we saw at the UMass Memorial Multidisciplinary ID/MH Consultation and Evaluation Clinic. All patients

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Thomas Baffuto, Executive Director, The Arc of New Jersey

Walter Bender, President, The Arc of NJ

Beverly Roberts, Director, Mainstreaming Medical Care; Editor

Helen Rivera, Administrative Assistant
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Mainstreaming Medical Care
The Arc of New Jersey
985 Livingston Avenue
North Brunswick, NJ 08902
Email: broberts@arcnj.org
Phone: 732-246-2525, ext. 34

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Obesity Epidemic

Obesity is a global epidemic. Its prevalence worldwide has more than doubled between 1980 and 2008 (World Health Organization, 2012). In the U.S., 35.7 % of adults (41 million women and more than 37 million men) aged 20 and over were obese in 2009–2010. Among children and adolescents, aged 2 to 19 years, 17% (or more than 5 million girls and approximately 7 million boys) were obese (Ogden et al, 2012). The recent report of the Institute of Medicine (IOM) (IOM, 2012) emphasizes the need to accelerate the progress in preventing obesity to prevent or reduce its long-term health, social, and economic costs—prevention in children and youth as many obesity-related problems in adulthood begin in childhood. Prevention should include adults because “an obese adult population is an incubator, biologically and environmentally, for childhood obesity” (IOM, 2010, p 19).

Obesity has physical, psychosocial and functional consequences. These include cardiovascular diseases, hypertension, type 2 diabetes, high blood lipid levels (examples, cholesterol and triglycerides), orthopedic, balance and mobility problems, sleep apnea, stigma, and social marginalization among many others (IOM, 2010). The estimated cost of obesity-related illness for 2004-2005 is \$190.3 billion (in 2005 dollars), or 21% of annual medical spending in the United States (IOM, 2012).

The IOM's report (IOM, 2012) highlights the complexity of the problem and the need for a systems approach that can make meaningful impact to curb and reverse obesity during the next decade. This approach involves messages, school, food and beverage, health care and work, and physical activity environments. Although individuals are responsible for their own decisions and actions (for example, what and how much they eat), improving and maintaining desired health-related behaviors can be difficult if these environments are unsupportive. The report points out that “a variety of characteristics historically linked to social exclusion or discrimination, such as race or ethnicity, religion, socioeconomic status, gender, age, mental health, disability, sexual orientation or gender identity, geographic location, and immigration status, are known to influence health status ” (IOM, 2012, p 26). “To change this inequitable resource and risk distribution, robust and long-term community engagement and civic participation among these disadvantaged populations must occur” (IOM, 2012, p 27). This statement is relevant to individuals with ID who may not be able to access and use many of the resources in the different environments. As Rimmer and Hsieh (2011, p.12) pointed out, “current approaches to creating healthier communities for people with ID require greater involvement on the part of direct care staff and family members to facilitate increased access to healthy lifestyles, including more opportunities for regular physical activity and greater access to nutritious and affordable food choices. The environment is far more complex for people with ID who may have limited mobility or must be supervised when traveling in the community.”

Obesity and Intellectual Disabilities

Defining overweight and obesity

Body mass index (BMI), calculated using the height and weight, is used to classify weight status. A BMI of 25 to 29.9 is considered overweight and 30 or higher, obese. By this definition, the percentage of obesity in adults with disability (36%) is 55% higher than for adults without disabilities (23%) (CDC, 2011b).

For children and teens, BMI is age- and sex-specific and is referred to as BMI-for-age. A BMI at the 85th percentile but less than the 95th percentile indicates overweight, and a BMI at the 95th percentile or greater, obesity. By this definition, the prevalence of obesity (22%) among children, 2 to 17 years old, with disabilities is 38% higher than for children without disabilities (16%). The annual health care costs of obesity that are related to disability are estimated at approximately \$44 billion. The CDC and the Academy of Pediatrics recommend that BMI be used to screen for overweight and obesity in children beginning at 2 years old (CDC, 2011a).

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Some issues with BMI and location of fat

BMI does not assess body composition (amount of body fat versus lean body mass), but it has a high correlation with body fat for most people. It has been pointed out that BMI may not be the best measurement for obesity in individuals with disabilities (CDC, 2011b). Height and weight should be measured correctly using proper techniques, as wrong values can misclassify an individual's BMI. Some individuals with ID are unable to stand straight or stay on the standard weight scale or are non-ambulatory. In addition, BMI can overestimate body fat in muscular or edematous individuals and underestimate it in those who have lost muscle mass, such as the frail and older adults (Lee and Neiman, 2010). Although it has limitations, BMI, assessed with the other risk factors that individuals have, is used to guide clinical decisions about obesity management (NHLBI, 2000).

In addition to BMI, waist circumference and waist-to-hip ratio are used to assess risk for chronic diseases in adults. The concept is that central or abdominal obesity (android obesity or apple shape) presents a greater risk for chronic diseases than the pear shape or gynoid obesity where fat placements are in the hips and thighs (Lee and Nieman, 2010). However, given the limited functional and physical abilities of some individuals with ID, their waist and hip circumference measurements cannot be done or will likely be inaccurate.

Rimmer and Hsieh (2011) reported that almost two-thirds of the 995 adults with ID in their survey were overweight and obese.

A Snapshot of some factors related to obesity in individuals with ID

Children and adults with mobility limitations and intellectual or learning disabilities are at greatest risk for obesity. They face challenges including lack of healthy food choices; difficulty with chewing or swallowing food, or with its taste or texture; medications that can contribute to weight gain and changes in appetite; and physical limitations that can reduce their ability to exercise. They may also lack energy that can affect desire to shop or prepare foods or be physically active; accessible environments (sidewalks, parks, and exercise equipment); and resources (money, transportation, and social support from family, friends, neighbors, and community members) (CDC, 2011b). Lack of positive role models for health-promoting lifestyle; cultural factors that affect food preparation, caregiving practices and interpersonal relationships; use of food to pacify disruptive behaviors; and educational training of family members and other caregivers may also be contributing factors.

Obesity prevalence has been shown to vary by gender, disability types, severity of disability and living arrangements. Rimmer and Yamaki (2006) reviewed several studies conducted in the U.S and other countries that reported higher prevalence of obesity in individuals with ID than in individuals without ID. Among adults with ID, the highest obesity prevalence was observed in those with Down syndrome. More recent studies reported similar obesity prevalence (Stedman & Lelland, Jr., 2010; de Winter et al, 2012). High obesity prevalence was observed in younger study participants (12-18 years old). In this group, youths with autism and Down syndrome were likely to be obese and overweight compared to their counterparts without ID. Obese or overweight youths with IDD had a significantly greater number of obesity-related secondary

conditions, such as asthma, high blood pressure, high blood cholesterol, diabetes, depression, fatigue, preoccupation with weight and pressure sores (Rimmer et al, 2010).

Rimmer and Hsieh (2011) reported that almost two-thirds (64%) of the 995 adults with ID (18 years and older) in their survey were overweight and obese, obesity prevalence was higher in females than in males, and highest in the older group (45-64). It was highest in adults living on their own or in a supported living setting and lowest in adults living in group home settings. Overall, the majority of the participants were sedentary; almost one half did not consume the daily recommended amount of fruits and vegetable (5 servings) and ate unhealthy snacks at least once a day. Adults living on their own had the highest number of health risk behaviors related to diet, smoking, alcohol consumption, and oral hygiene.

While certain genetic causes contribute to obesity (such as in Down syndrome and Praeder-Willi syndrome), environmental factors that affect energy balance in the general population also affect individuals with ID and with compounded consequences. In simplistic terms and at the physiological level, it is about positive energy balance: Calorie intake exceeds output. Like their counterparts without ID, overweight and obese individuals with ID can gain health benefits from moderate weight loss. Education and behavioral changes can include health risk behaviors noted previously.

The Committee on Accelerating Progress in Obesity Prevention has presented a set of recommendations with goals, strategies, and different levels of engagement to mobilize change from a systems perspective. These include societal, community and family/household- and-individual level engagement (IOM, 2012). While all parts of the system working together will have bigger synergistic impact, even only one part working to fire change can make a difference. This article emphasizes what we can do at the personal level-- as family/household and individual.

ACTIONS WE CAN DO: TAKING CARE OF OURSELVES AND OUR FAMILIES

Weight loss management is complex because genetic, metabolic, environmental, cultural, and socioeconomic factors affect our body weight (American Dietetic Association, 2009). However, there are certain steps we can do to chip away at the problem.

Remember the Major Parts of Weight-Loss Programs

The basics of a weight-loss program are a healthful diet, regular physical activity, education, and behavioral changes (NHLBI, 2000). Healthy weight is not just a diet, but a lifestyle. Our weight-loss program should be personalized so that it fits our individual needs; long-term so that we can live with it for a lifetime; realistic so that we can achieve our goals; well-rounded by including all food groups; and comprehensive by focusing on healthy eating, physical activity, and behavior modifications (CDC, 2011c; State of Michigan, 2012).

Based on assessment of our individual needs, the calorie level can be estimated to promote a weight loss of no more than 1 to 2 pounds a week. A weight loss of 5 to 10% in six months can already produce health benefits, such as improvements in blood pressure, blood cholesterol and blood sugars. Reducing energy intake by 500 to 1000

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kcalories per day can achieve this weight loss, as 1 pound of body fat is technically equal to 3,500 kcalories (NHLBI, 2000). The next step, however, which is preventing weight regain, is the more challenging part.

Beware of Fad Diets

We have information overload about weight loss some of which are not supported by science or evidence. There is no magic pill for losing weight and keeping it off. A sound weight-loss diet is calorie-reduced but should still be nutritionally balanced. Fad diets can be nutritionally harmful, depending on what they promote and exclude. In general, they promise a quick fix, recommend magical fat-burning effects of foods, promote avoidance or severe limitation of a whole food group, promote eating mainly one type of foods, recommend eating foods only in particular combination, and make claims that sound too good to be true (WebMD, 2010; USDHHS and National Institutes of Health, 2009).

Know our Resources: The Dietary Guidelines and its Messages

In the U.S., several food guides, some culturally-based, exist and can help people plan healthful diets. Many other countries have their own dietary or food guides. The US Department of Agriculture (USDA) and US Department of Health and Human Services (USDHHS) have developed the Dietary Guidelines for Americans, the foundation for Federal dietary guidance promotion and education efforts aimed at improving America's health and reversing obesity and chronic diet-related diseases (USDA/USDHHS, 2011a). The Dietary Guidelines for Americans 2010 describe a healthy diet as one that emphasizes fruits, vegetables, whole grains, and fat-free or low-fat milk and milk products; includes lean meats, poultry, fish, beans, eggs, and nuts; and is low in saturated fats, trans fats, cholesterol, salt (sodium), and added sugars (USDA/USDHHS, 2011a). Dietary guidelines are translated into a food-based guide. **MyPyramid** has been replaced by **ChooseMyPlate**. It should be noted that the recommendations in the Dietary Guidelines and in **MyPlate** are for the general public over 2 years of age. **MyPlate** is not a therapeutic diet for any health condition. Individuals with a chronic health condition should consult with a health care provider to determine the diet that is appropriate for them (USDA/USDHHS, 2011b).

Messages in the guidelines

Selected messages for consumers in the Dietary Guidelines 2010 are about balancing calories; increasing intake of fruits and vegetables, whole grains and (switching to) low-fat and fat-free milk; and reducing foods that are high in salt (sodium) and sugar such as soups and sugary drinks (USDA/USDHHS 2011b). Additional information is available at www.choosemyplate.gov

Selected details from the Consumer Brochure (USDA/USDHHS, 2011b) are as follows:

- ◆ Build a healthy plate: Make half your plate fruits and vegetables. Switch to skim or 1% milk. Make at least half your grains whole. Vary your protein food choices.
- ◆ Keep your food safe to eat. Learn more at www.FoodSafety.gov.
- ◆ Cut back on foods high in solid fats, added sugars, and salt (sodium). Choose foods and drinks with little or no added sugars and foods with lower amount of sodium. Eat fewer foods that are high in solid

fats, such as cakes, ice cream, pizza, cheese, sausages, and hot dogs. Select lean cuts of meats or poultry and fat-free or low-fat milk, yogurt, and cheese.

- ◆ Eat the right amount of calories for you. Enjoy your food, but eat less. Avoid oversized portions. Use a smaller plate, bowl, and glass.
- ◆ Be physically active your way: Pick activities that you like and start by doing what you can, at least 10 minutes at a time.
- ◆ Use food labels to help you make better choices. Use the nutrition facts as a tool for food selection. Details are available in the USDA Consumer Brochure. Resources for African women are also available. Finally, different food patterns and their calorie levels are available at USDA Food Patterns.

So What Now?

Apply the Dietary Guidelines to the Grocery Stores and the Table

The principles of the dietary guidelines are intended to be translated into foods, from the point of purchase to eating, in the context of our preferences and resources. And with proper planning, we can eat a healthful diet on a budget. We CAN do these.

When **buying foods**, we start with a shopping list that includes colorful fruits and vegetables, whole grains; lean meats, poultry, fish, eggs, dried beans, nuts; low-fat dairy; and healthy oils. Read the food label. Foods that are lower in fat are not necessarily low in calories.

In **preparing foods**, we can reduce calories by using low-fat cooking, such as baking, roasting, or grilling. We can reduce the amount of fat and sugar or use low-fat ingredients instead of high-fat ones. A few examples: 1%, 2% or fat-free milk for whole milk; low-fat yogurt for sour cream; egg whites or egg substitutes for whole eggs; Neufchâtel or "light" cream cheese for cream cheese; extra lean ground beef such as ground round or ground turkey (read label) for regular ground beef; jelly, jam, or honey for butter or margarine on toast or bread, and canned broth-based soups for canned cream soups. Many practical tips are available at the CDC's website; and at the National Heart Lung and Blood Institute (NHLBI, 2000).

Control the portion. What we **add (and the amount)** to the basic food increases calories. For example, butter or margarine to the toast/bread, pancakes, and vegetables; gravies and sauces to meats; and salad dressings to salads. Eating a smaller portion than our previous "normal" will help us reduce calories. Selected examples: 3 oz chicken or meat = a deck of cards, 1 Cup = a baseball, 1 1/2 oz of cheese = 3 dices; and 3 oz muffin or biscuit = hockey puck (WebMD, 2008). A serving of rice or pasta is 1/2 cup, and yet we see big plates or bowls filled with this type of starches. Another way of controlling portion is to use a plate (Use a small plate and glasses). We fill half our plate with non-starchy vegetables and fruits and the other half with protein foods and grains (whole grains). Plant foods occupy three-fourths of the plate. We add dairy on the side to complete this meal. We can create a vegetarian plate with the proper food combinations according to our preferences.

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Control calories when eating out, including in fast food restaurants. Examples of obvious differences in calories: Hamburger versus a big sandwich, junior instead of super or deluxe, and kid's meals versus the value and combo meals. Buffets are a dieter's pitfall. The websites in the references section of this article have many practical tips. See the appendices of the Dietary Guidelines for obesity for additional tips; the information on WebMD is user-friendly.

Drink Plenty of Fluid

Fluid is an important part of a healthful diet and is vital to body functions. Sources are the drinking water, beverages, water in the foods, and water from the metabolic breakdown of certain nutrients. Heat and humidity, physical activity, and health conditions such as fever and diarrhea affect fluid needs. The general recommendation for a healthy individual who consumes 2,000 kcalories is 2 to 3 liters of water or 8 to 12 (8-oz) cups (Rolfes et al, 2009). Drinking water instead of sweetened beverages can help reduce calories. Fluid needs of persons with fluid restriction are individually determined. Additional tips on fluid intake are available here.

Practice Food Safety

We should observe safe food handling practices as food-borne illnesses can be life-threatening especially for individuals who are malnourished, or older, or have weak immune system. A simple way is to wash our hands the right way, the utensils after each use, and the kitchen surfaces. We cook foods to the right temperature, refrigerate them promptly and know when to throw them out (USDHHS, 2012). Additional details can be found at <http://www.foodsafety.gov/index.html>.

Let's Move Our Body

The CDC's physical activity guidelines recommend that adults with disabilities should engage in regular physical activity according to their abilities and should avoid inactivity. The benefits include improved cardiovascular and muscle fitness, improved mental health, and better ability to do tasks of daily life. They should consult their health care providers about the amounts and types of physical activity that are appropriate for them (CDC, 2011d). Details for physical activity for adults are available at the CDC's website. And this website has additional information on physical activity for individuals with disability.

Engage Individuals in Food-related Activities

Learning -by -doing is a practical way to teach individuals with ID about healthful food choices. Food is a universal language, a powerful tool for teaching nutrition. Participation in meal planning, food preparation and service promotes ownership of the decision made and the results. Some resources mention gardening which seems to be a current trend, depending on where we live.

Summary of Key Messages: We Can!

Our recipe for achieving and maintaining healthy body weight includes a nutritionally balanced diet that is personalized to our needs, preferences, and resources. This means filling our small plate with colorful vegetables and fruits, whole grains, some lean meat, poultry, fish, dried beans, some nuts and having low-fat dairy near our plate. It also includes food safety; low-fat, low-calorie cooking methods; smaller portions than what we used to eat; and regular physical activities, according to our abilities. We will drink plenty of fluids, and get sufficient rest and sleep. We will do one or two simple actions from our long list and just get going! We

should "focus on positive changes and adapt a problem-solving attitude towards shortfalls. Weight control is a journey, not a destination" (NHLBI, 2000, p. 32).

Commentary

As a group, individuals with ID are at high risk for overweight and obesity. Obesity is a risk factor for chronic diseases such as cardiovascular diseases, diabetes and hypertension. Moderate weight loss through a reduced-calorie but healthful diet, physical activity, education, and behavioral changes can contribute to their overall health and quality of life. With our guidance and support and their engagement in the learning activities, they can make behavioral changes to achieve their personal weight goal. The NHLBI guidelines (NHLBI, 2000) noted that preventing further weight gain is an appropriate goal for individuals who are not able to lose weight or body fat. Changing behavior is difficult even for people without ID. Serving as positive role models, family members and other caregivers can teach simple lessons about healthful, tasty, attractive, and safely prepared foods. Diverse messages come from many directions. Taking a small step and keeping it simple, focusing on a small change at a time can set the stage for success in the long-run.

However, in our desire to help individuals with ID, we are reminded that "they should be involved in decisions about screening and engaged in lifestyle changes that may follow. Potential health gains may need to be balanced against losses in autonomy or rights, and thoughtful decisions respected, whether these have been made by the person alone or with input from family, caregivers or a multidisciplinary team. Communicative and explanatory skills will be essential" (Hasan, McCoubrie and Spicer, 2006, p. 223).

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Dawna T. Mughal, PhD, RD, LDN is associate professor in the Morosky College of Health Professions and Sciences, Gannon University, Erie, PA. She is a registered dietitian, licensed in Pennsylvania and is certified as a Charter Fellow of the American Dietetic Association (now The Academy of Nutrition and Dietetics). She serves on the Steering Committee of the National Task Group on Intellectual Disabilities and Dementia Practices. She can be reached at Mughal@gannon.edu.

An Educational Workshop on Aging, Dementia, and Developmental Disabilities

The National Task Group on Intellectual Disabilities and Dementia (NTG), in cooperation with The Arc of New Jersey, is planning an educational workshop on Aging, Dementia and Developmental Disabilities for Fall 2012, to be located in central New Jersey. The NTG is developing educational, screening and training materials to be distributed at the workshop.

The workshop is designed to provide helpful information to families, direct care workers, clinicians, program staff, and administrators – who are concerned about or involved with adults with intellectual and developmental disabilities affected by dementia.

The NTG is currently seeking to compile a list of individuals and stakeholders interested in this workshop. For more information, or to add your name to the distribution list, please contact: Leslie Diana at ldiana@trinitas.org or 908-272-3606.

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are referred for a “second opinion” because they have severe challenging behaviors (CBs) and/or psychiatric illness in addition to ID, and teams have been unable to determine the causes of their “treatment resistance.” Our multidisciplinary evaluation team has been seeing individuals with ID and challenging problems for several years, initially to help divert patients from inpatient admissions to our specialty ID/MH inpatient unit. In many cases, we found that health problems and medication side effects were a prime cause of agitated behaviors in patients with intellectual and developmental disabilities (IDD). These patients frequently received psychiatric treatment (psychoactive medications, emergency assessments, hospital admissions). If the detection and treatment of these medical problems can be increased using simple and inexpensive models of care, very expensive and disruptive care may be avoided, while improving the patients’ health and quality of life. At UMass Memorial Healthcare and UMass Medical School, pilot projects will examine how multidisciplinary assessment and care for patients with IDD/ASD referred for mental health treatment can help improve quality outcomes and reduce suffering, as well as contain long term costs of care.

It may be that identification of health problems that affect behavioral and mental wellness is more complicated in patients with ID for several reasons:

- Patients with ID are poor reporters of their own health problems; many individuals with ID will express pain or physical distress behaviorally.
- Often, much of the information about what may or may not be wrong health-wise or medically comes from observations of others.
- Problem behaviors like aggression, tantrums, self-injurious behaviors and property destruction may act as a “final common pathway” for distress in individuals who have a limited behavioral repertoire (few ways to express distress, poor functional communication). Even when there is a nonpsychiatric medical cause, on the surface, it looks like a behavioral or mental health problem.
- When people with ID carry psychiatric labels, or have a history of engaging in challenging behaviors, there is even more of a tendency to view problems as due to the psychiatric disorder, and as requiring a psychiatric solution, even when the actual cause is a problem like constipation, dental pain, complications related to seizures or other medical causes.
- Medical providers who do not see a large number of patients with ID may have difficulty recognizing the usual kinds of “occult” medical problems that might be affecting mood and behavior, or give up on completing tests that are hard to accomplish with our patients.
- A person that has very complex needs may be having medication changes made by multiple prescribers, inadvertently leading to increased risk of adverse drug events (ADE), that may, in turn, provoke agitated behaviors, which drive the addition of psychoactive medications to treat presumed exacerbations of mental illness.

The Whole is Greater Than the Sum of the Parts

In the new “UMass ID/MH Multidisciplinary Collaborative Care” program, patients will be followed closely to identify non-psychiatric medical problems and ADEs using a variety of strategies to include a newly developed surveillance tool designed to provide caregivers with very clear behavioral descriptions of frequently missed problems like constipation, sedation, and orthostasis. Patients will be served along a continuum of care with some having an actual “Medical Home” with our

team (all of our team members will be the direct care providers), while others will be helped through comprehensive evaluation followed by consultation, support and training provided to the treatment team and family. We are excited to be able to provide a comprehensive multidisciplinary consultation evaluation remotely, using specialized video equipment.

We will closely follow wellness and positive quality of life outcomes, reduction of psychiatric symptoms and challenging behaviors, but also the cost of care. We believe that our high-risk patients will experience fewer intrusive and expensive care outcomes (fewer ED visits and inpatient hospitalizations), including patients who have a recent history of multiple ED visits for behavioral reasons, recurrent inpatient psychiatric admissions and who are treated with multiple psychoactive medications. If successful, we hope to expand the service and to train others who may wish to use our model to develop similar teams. Ultimately, we hope to improve mental and physical wellness for individuals with ID or ASDs who have mental health disorders and challenging behaviors.

Failure to Identify and Treat Medical Problems in Patients with ID

Why are medical problems that are simple to identify and treat in most people, missed in patients with ID? First, medical causes for agitated behavior may frequently be missed because people with ID are poor reporters of their own health problems. In most cases, the history of the present illness must come from caregivers or family members rather than the patient him or herself (Abend & Silka, 1999; Ryan & Sunada, 1997). Unless caregivers are asked very specific questions, they may not realize what information is most important to share with the doctor.

Another reason medical problems may be missed in patients with ID is that the initial picture can be very confusing. It has been noted by experts that physical distress (caused by non-psychiatric medical problems) can provoke changes in mood, mental status and behavior in people with ID (Carr & Owen- DeSchryer , 2007). In fact people with ID will appear moody, labile, irritable, or tired and engage in more of their usual problem behaviors as a general sign that “something is wrong.” These manifestations of distress may occur for a variety of reasons, because people with ID often have a restricted behavioral repertoire.

Unfortunately, the above described tendencies may mean that an individual with ID who appears agitated will first be brought to see a mental health professional, and may even have multiple psychoactive medication treatment trials, urgent psychiatric care in an ER or an inpatient psychiatric admission, before a medical problem that provoked the initial alterations in mood and behavior is finally detected and treated. Pain or acute physical discomfort may serve to “lower the threshold” or “set the occasion for” problem behaviors (Carr & Owen-DeSchryer, 2007). The pain or discomfort of an unrecognized health problem may be missed not only because patients with ID often fail to clearly describe their internal experiences, but because the outward signs all seem “psychiatric.”

The individual and societal cost of missing medical causes of behavioral distress in people with ID could be very high. In our pilot research (see below), we found over 40% of people admitted to a specialized inpatient psychiatric unit serving only individuals with ID were diagnosed with a non-psychiatric medical cause for the index episode leading to the stay.

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In our pilot research, we found over 40% of people admitted to a specialized inpatient psychiatric unit serving only individuals with ID were diagnosed with a non-psychiatric medical cause for the index episode leading to the stay.

Stays are costly and highly disruptive to the lives of these patients, who frequently have great difficulty coping with alterations in daily routines (Reiss, 1994). Many patients end up on long term, multidrug psychoactive medication treatments that might be avoided if medical problems were detected and treated in a timely way. We conservatively estimated that if half of our patients with medical causes for psychiatric admission had been diverted from inpatient care, savings over a two-year period could reach as much as 1 million dollars. (A bed day costs approximately \$1,600.00 for n = 40 patients who would consume an average of 18 inpatient bed days = approximately \$1,152,000.00. Estimating additional outpatient care to be an average of \$5000.00 per person per year, for n= 40, this total would be \$200,000.00) (Damiano et al., 2006).

What medical problems affect psychiatric patients with ID?

Specific health problems identified as causing or worsening behavioral problems in people with ID include ear infections, premenstrual pain, seizures and GI distress (Bosch et al., 1997; Carr et al., 2003; Gunsett et al., 1989; Molloy & Manning- Courtney, 2003; O'Reilly, 1997). In our research, we found constipation and GI disorders such as gastro-esophageal reflux, skin infections, dental pain, sedation and stiffness from medications were all common causes of distress that, on the surface, looked like "psychiatric" problems.

Recent Trends in Psychoactive Medication Treatment of People with ID

Recent reports suggest that people with ID may increasingly receive treatment with multi-drug regimens (Lott et al., 2004; Stolker et al., 2002). Most people with ID are referred for acute mental health care when they display aggressive behaviors, and their pharmacotherapy is often aimed at its reduction (Tsakanikos et al., 2006). This is unlike most psychiatrically treated individuals for whom pharmacotherapy is overwhelmingly aimed at the amelioration of symptoms of Axis I psychiatric syndromes. Despite expert consensus that all efforts should first be made to identify any acute psychiatric conditions, and that treatment using various modalities in combination is preferred, more and more individuals with ID may be getting medication as the primary approach to their disruptive behaviors (Kroese, Dewhurst, & Holmes, 2001; Rush, & Frances, 2000). Of special concern is the limited investigation of side effects and adverse drug events (ADEs) experienced by people with ID (Valdovinos et al., 2005). This is especially worrisome because people with ID may not accurately complain, or may not complain at all, when suffering from distressing or even dangerous side effects. Individuals with ID rarely control their own pharmacotherapy (Kroese, Dewhurst, & Holmes, 2001). Most often, decisions are made by others to continue medications or add medications, and whether or not any apparent side effects are "well tolerated."

Though pharmacologic interventions may reduce rates of targeted problem behaviors in the short-term, troubling side effects may eventually provoke apparent "relapse" and prompt the introduction of more medications. Recent studies reveal high rates of psychoactive medication treatment of people with ID. The Center for Developmental Disabilities Evaluation and Research (CDDER, 2005) reviewed Medicaid prescriptions to document the prevalence of psychotropic medication use in 16,212 adults with ID who received services paid by the Department of Developmental Services in Massachusetts. Over 60% of consumers were prescribed psychoactive medications; 47% when excluding anti-epilepsy medications. (It was not possible to determine who was treated for epilepsy or other medical conditions alone, and who received these medications for psychiatric indications.)

In our research, we found constipation and GI disorders such as gastro-esophageal reflux, skin infections, dental pain, sedation and stiffness from medications were all common causes of distress that, on the surface, looked like "psychiatric" problems.

Only 27% of consumers did not receive any psychoactive medication during the one month study period. Langworthy-Lam, Aman, and Van Bourgondien (2002) reported that 45.7% of children with autism were taking psychotropic drugs in their sample of over 700 children. They concluded that individuals with autism are a "highly medicated group." Lott and colleagues (2004) examined pharmacy records of 2344 individuals with ID over a 17-month period and reported that 52% of all prescriptions written during the study period were for psychoactive medications, and that 62% of individuals were prescribed two or more such agents.

Several investigators have reported that psychoactive medication use is predicted by disruptive or aggressive behaviors in people with ID (Stolker et al., 2002; Tsakanikos et al., 2006) though few studies discuss rates or risk factors for ADEs. Valdovinos and colleagues (2005) found that the frequency of medication changes correlated with number of possible side effects. They speculated that having frequent medication adjustments might actually provoke more ADEs. Deb and colleagues (2007) conducted a comprehensive review of the literature regarding the effectiveness of antipsychotic medication management of behavior problems in adults with ID. A number of studies have reported improved behavior when these agents are used in patients with ID. However, high rates of ADEs were found including weight gain, sedation, withdrawal dyskinesias, other Parkinsonian symptoms and constipation. A new very promising tool called The MEDs has been developed by John Matson and colleagues, and may be used to help improved side effect detection.

Patients with ID treated with psychoactive medications may experience uncomfortable or distressing side effects, but their altered mood and behavior may then be seen as a worsening of their mental health problem, sometimes prompting the addition of yet more medications. Increased detection of side effects that cause discomfort and distress could potentially improve behavioral outcomes for patients with ID treated with psychoactive medications.

Summary

People with ID are often referred for psychiatric care because of aggressive and disruptive behaviors. We strongly suspect that missed medical problems may be one significant factor contributing to their behavioral decompensations. If we can increase detection rates for medical problems, behavioral outcomes for patients with ID may be improved, unnecessary and costly interventions avoided, and quality of life enhanced.

In our experience with hundreds of psychiatric inpatients with ID, simple interventions used to alleviate medical problems or side effects, were frequently associated with dramatic reductions in irritability, agitation and aggression. The cost of missing these problems in people with ID referred for psychiatric care is likely high, both in human suffering and in terms of health care expenses. When the real source of distress is missed, patients not only continue to suffer, but their problems may inadvertently be compounded by the addition of inappropriate and ineffective treatments (i.e. adding psychoactive medications). Patients with unresolved sources of distress may also receive more costly and disruptive acute care (ER visits and hospital admissions). The solutions are not complex. Multidisciplinary coordinated and collaborative care models include time for doctors to work together with other professionals, a model long supported by the Autism Treatment Network. And, it works!

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Lauren Charlot, PhD is Assistant Professor in the Department of Psychiatry at UMass Medical School/UMass Medical Center in Worcester, MA. She can be reached at charlotl@ummhc.org

SeizureTracker.com

Lisa Moss

Co-Founder, Seizuretracker.com

SeizureTracker.com empowers people living with epilepsy and their caregivers

When the topic is Epilepsy, the math can be daunting; one in 26 people will be diagnosed with Epilepsy at some point in their lifetime. Although having epilepsy can be a challenge, SeizureTracker.com has developed a revolutionary way to keep track of the details surrounding seizures and easily share this information with physicians and care providers. This free online resource allows the individual to log seizures, medications and therapies and at the click of a button, send a detailed report to whomever they choose.

Electronic Seizure Diary empowers consumers and caregivers!

The powerlessness that patients and caregivers felt over not being able to easily share crucial information with their doctors started to ebb in 2007, when SeizureTracker.com was made available as a free global resource to anyone experiencing seizures. This online electronic seizure diary system helps the patient community keep track of their epilepsy, aids in communication and empowers patients. Over the years many upgrades have been added to create a comprehensive diary system and additional features continue to be added. Seizure Tracker can be accessed online on any web-enabled mobile device or by using the newly launched, free iPhone App. In addition to the electronic interfaces, there are also corresponding paper forms available to print out so that seizure logging can be done easily when it's not convenient to be by a computer, smart phone or tablet.

Seizure Tracker allows the individual to log seizure activity and medications or therapies and at the click of a button, create interactive reports with graphs showing treatment effectiveness and time-of-day trends. These reports can be easily shared with physicians and care providers through an email contact manager system, viewed together online or printed out to be shared at office visits. When logging seizures, the user can include when the seizure happened, how long it lasted, the seizure type, possible triggers, seizure event descriptions and post event descriptions. There are text boxes to include specific information if desired and seizures can be "flagged" if they are unique or different so they will be highlighted in the report. Since so many patients are asked to try to catch a video of a seizure, an interface was developed to allow individuals to attach strictly private YouTube videos to seizure event records.

Over the years specific requests have been made from neurologists and patients as well as non-profit organizations focusing on various Epilepsies asking for the development of additional features for SeizureTracker.com. Seizure Tracker has welcomed the opportunities to work closely with these groups and as a result has been able to provide a more comprehensive tool for the Epilepsy community as a whole. At the request of a neurologist, the entire medication history can now be selected to appear on the report to make it easier to see that comprehensive information when making medication or dosage changes. Individuals can also track emergency rescue medications in a way that isolates the emergency medications from daily scheduled medications. Because hormonal fluctuations can be a challenge for female patients, the ability to record menstrual cycle information was added. For patients using the Vagus Nerve Stimulator (VNS), magnet swipes across the VNS to stop the seizure can be recorded along with a rating of its effectiveness. As different Epilepsy diet therapies have shown effectiveness in treating some patients, Seizure Tracker

responded to this need and created a way to track the diets which includes areas for daily ketone and glucose levels. Collecting this detailed information empowers the patient with continued access to their own treatment history and enables them to easily share it with whomever they choose.

First Real Time Mobile Seizure Recorder

Seizure Tracker recently released an iPhone App that has revolutionized the way seizures are recorded. For the first time ever, there is an App that will allow an individual to record a seizure in real-time with the option to also video the seizure as it happens. Once the seizure ends, additional details can be added about the event that corresponds with the website interface. The seizure event and video can then be synced to the website/private YouTube channel and the information will be available in any way the Seizure Tracker user chooses to access their account. The graphs available through the App keep the ability to compare seizure activity and treatment effectiveness at your fingertips.

Improving Clinical Care through Information Sharing

Seizure Tracker aims to improve patient-physician communication and as a result improve clinical care. When a physician is able to view a complete and concise history of seizure activity since the last visit alongside treatment schedules, the appointment is more efficient and more time can be devoted to treatment options and potential solutions. Having an easy interface to enter seizure events improves the reporting process by helping the user capture a more complete seizure history. The ability to produce graphs representing the time of day for seizure activity can show trends and result in modifications of medication dosing schedules. The reports make it easy to access surrounding treatment information, possible triggers, hormonal shifts, diet changes, missed medications, videos of seizures and more.

Necessity is the Mother of Invention

SeizureTracker.com was originally created as one family's solution to their son's seizures. Evan was having multiple daily seizures and the sheet of paper with 365 boxes to record Evan's seizures quickly became a jumble of numbers, notes and highlighted codes. Rob and Lisa Moss knew they needed to find a better way to keep track of the increasing seizures and constantly changing medications. They knew they needed something that would allow them to see even slight improvements and it needed to allow them the ability to enter a lot of seizures in a short period of time. They looked for an online diary system and came up empty. Rob said he would build it himself. After completing a very basic tool and showing it to Evan's neurologist, the question about other people using the site came up. Rob spent the next several months building on what he had already created to make it more inclusive and comprehensive. Evan's seizures increased dramatically and when Evan was 4 years old he had brain surgery in the hope of finally gaining control of his seizures. The website was ready to launch during the same time period and Rob launched it from a quiet waiting room in the hospital while his son slept after surgery. Evan remained seizure-free for almost 2 years and is now having seizures again although much less frequently. The family is once again searching for seizure control for Evan and continues to use Seizure Tracker to manage their son's Epilepsy and remain the users who have used the website the longest.

"SeizureTracker.com enables my patients and their support team in being able to objectively follow the seizure events. This data has helped in many instances with the doctor-patient-caregiver relationship as well as with my being able to accurately assess the effects of my therapies."

- Seth Keller, MD

WHAT IS A D-SNP?

WHAT ARE THE DIFFERENCES BETWEEN A MEDICAID HMO AND A MEDICARE HMO D-SNP?

By Beverly Roberts

There is a new type of health plan for people who are dually eligible for both Medicare and Medicaid. It is called a Dual Eligible Special Needs Plan, or D-SNP. It is important to remember that **enrollment in a D-SNP health plan is voluntary**. The decision on whether or not to voluntarily enroll in a Medicare HMO D-SNP should be made on an individual basis.

Anyone who is considering enrolling in a Medicare HMO D-SNP, should ask ALL current Medicare providers if they have joined that D-SNP's network, including the primary care doctor, specialists, and mental health provider (if applicable). Also, find out whether the preferred hospitals and the company that provides medical equipment and supplies have joined that D-SNP network.

Most people in NJ who are dual eligibles are already enrolled in a Medicaid HMO. But a Medicaid HMO is different from a Medicare HMO D-SNP. See the chart below for the differences that are most important for dual eligibles with disabilities. Please call the State Health Insurance Assistance Program (SHIP) if you have questions about Medicare HMO D-SNPs: **1-800-792-8820**. SHIP offices are located in every county, and the staff provide free counseling on all aspects of Medicare, including helping people who have both Medicare and Medicaid.

	In a Medicaid HMO	In a Medicare HMO D-SNP
Access to Medicare doctors	Dually eligible consumers can go to all doctors and hospitals that accept Medicare, and who are willing to treat a dual eligible.	Dually eligible consumers can only go to doctors and hospitals that have joined the network of that D-SNP HMO.
Access to prescription drugs	Dually eligible consumers will continue to have a separate Medicare drug plan (Part D), and they can switch to another Part D drug plan at any time. The Medicare "extra help" copays will apply of \$1.10 for generics and \$3.30 for each brand name prescription. As of Jan. 1, 2012, dual eligibles with developmental disabilities who are on the Community Care Waiver (CCW) have a \$0 copay for drugs covered by their Medicare Part D drug plan.	Dually eligible consumers will be automatically disenrolled from the Medicare Part D drug plan, and their medications will be provided through the formulary of the D-SNP. Consumers should check to see if their medicines are on the D-SNP's formulary before enrolling to make sure their medicines will still be covered. Medicare drug co-pays will be covered by the D-SNP at \$0 copay. If enrolled in a D-SNP and a drug copay is charged, report the error - and receive reimbursement - via the Medicaid Pharmacy helpline: 609-588-2732 . Any pharmaceutical (Medicare Part B or Part D) balance billing or copays should be considered human or systems error and should be reported for resolution.
Access to health care services that are <u>not</u> covered by <u>Medicare</u>, but are covered by <u>Medicaid</u>	Dual eligibles have access to all of the Medicaid-covered services. Some health services are not covered by the Medicare system, but they are covered by the Medicaid HMO, e.g., dental care, hearing aids, incontinence supplies, adult medical day care, personal care assistance services, etc. These services must be obtained through the network of the Medicaid HMO.	Dual eligibles have access to all of the Medicaid-covered services. Some health services are not covered by the Medicare system, but they are covered by the Medicare HMO D-SNP, e.g., dental care, hearing aids, incontinence supplies, adult medical day care, personal care assistance services, etc. These services must be obtained through the network of the Medicare HMO D-SNP.
Additional benefits	No additional benefits.	There may be some additional benefits (examples: personal emergency response system, monthly allowance to purchase over-the-counter items, gym membership), but the benefits vary from one D-SNP to another. If interested in the additional D-SNP benefits, please check with the individual D-SNP health plans.



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