



Healthy lives and informed choices. You can have both!

by Joan Guthrie Medlen

Jared is 27 years old and lives in a group home. The management and staff believe strongly in letting the people they support make choices. However, over the past 10 months Jared has gained weight at an amazing rate. When Jared's parents talk to their son about his weight, he says he is getting too big and that he would like to stop getting bigger. His parents have spoken with the group home manager about encouraging their son to go for a walk and drink less soda, or to choose diet soda.

At a recent team meeting everyone, including Jared, agreed to build in the opportunity for a walk or some other exercise each day. They also agreed to make other drink options available. Yet Jared continues to gain weight. They discovered 48 soda cans in his closet. When they ask him about his daily walk, he says, "That's a good idea. I don't go on a walk every day." When his parents ask about the plan to encourage Jared to make healthier choices they are told, "We give him the choice to exercise every day, but he says 'no.' When we offer diet soda or water, he chooses other things to drink." Jared's parents want him to make his own choices about his life, but his long-term health is in jeopardy if he continues this pattern.

Jared's parents decided to take a no-nonsense approach to his continued weight gain. He moved back in with his parents and siblings. They began a family-oriented weight management program, which has been successful, though "success" has also been redefined. He has lost some weight. More importantly, he now better understands his choices and their consequences to his health. He is learning how to manage his weight better and live more healthily. Jared is planning to move out again in the next few months. Jared's story is not unique. It is also not limited to living in a group home or to adults. Self determination and weight management are, however, not incompatible. The greatest challenge appears to be the clash between boundless self-determined freedom and teaching the concepts that lay the foundation for making informed choices. In the zeal to provide appropriate support, another key element is often forgotten: What does the person with Down syndrome want? When asked, most people with Down syndrome clearly want to be healthy. In countless workshops, I hear young adults talk about wanting to be healthy. Rarely do they say they do not care.

This means the difficulty in getting there is our problem, the parents, professionals, and support people. The problem is in the design of education and support for weight management, not the ability to make choices

What is weight management?

Weight management is not losing weight. It is not implementing a strict diet. It is a process through which you learn to manage time, food, activity, and everything else in a way that you are comfortable with and meets your personal goal for your weight and health. It takes time, tenacity, and training, especially in the beginning or when making changes. Clashes between support staff and families regarding weight gain are usually because everyone assumes a "diet" is the answer.

Diets are punitive by nature, establishing "good" and "bad" foods based on a specific eating plan. For example, carbohydrates are "bad" when following the Atkins diet. Weight management, on the other hand, is a simultaneous effort to provide education regarding food choices that promote health and creating the structure to be successful in changing habits through goal setting. This includes choosing how others, including parents, professionals, and friends provide support.

Self-determination is the heart of successful weight management

All that is ethically needed to begin a weight management program in any living environment is for the person with Down syndrome to express an interest in weight management. I've yet to hear someone with or without Down syndrome tell me, "I think it would be fun to be the fattest person in the world." I have, however, been told by some that they are too busy or overwhelmed to think about their weight right now, a perfectly appropriate answer. A good weight management program for your child with Down syndrome is designed so your child is making decisions that drive the program based on what he is learning about nutrition, activity, time management, and so on. Making choices is the center of self-determination. In other words, successful weight management requires self-determination. It also requires commitment to the process by everyone.

The process of weight management

The process of weight management is the same for everyone. It involves learning how to balance the number of calories eaten with the number of calories used over the course of time. Sounds simple, but it's not. When you are looking at a weight management program, such as Weight Watchers, look for the following elements to the program:

- **FUN**
- **Social component:** Is the atmosphere one of acceptance and support? Your child wants to be greeted warmly when he arrives.
- **Variety:** Are there a variety of activities to choose from in the physical activity component of the program?
- **Challenging, but not competitive:** Most people prefer programs in which they can try new things, but without the fear of failure.
- **Appropriate goals:** Goal setting is a key component to a good weight management program. Goals should be set by your child, not the program.
- **Rewards:** Your child should choose non-food rewards for certain benchmarks. CDs, workout clothes, a special trip are some examples.
- **Individually competitive:** By setting goals, your child competes with himself. For example, continually increasing the amount of time spent exercising or drinking water rather than soda.
- **Support of family, friends, and medical community.**

Having your support is essential for your child to be successful. This may mean not having trigger foods in the house or modifying your own behaviour if it supports your child's goals. Focus on successes, not the areas where your child is having trouble.

Making accommodations

People with Down syndrome have greater challenges when it comes to weight management. These include:

- Burning calories at a slower rate than people without Down syndrome.
- Learning often takes longer for people with Down syndrome.
- Weight management is not tied to instantaneous consequences. For example, a weight gain of 10 pounds in a year can be the result of eating a mere 100 calories extra a day, every day. One hundred calories is a piece of bread or a glass of milk. Seeing or feeling the consequences of constant overeating takes time.
- Needed medications may make weight management more difficult or promote weight gain.
- Learning from natural consequences takes a very long time or may not happen before serious health concerns arise.
- Effective learning requires support and education. Your child likely required lots of time, teaching, and support to learn to do laundry or ride the bus. The same is true for weight management. It requires education with modification, accommodation, and support specific to your child.

The challenge is finding or creating a weight management program that includes the appropriate accommodations, modifications, and support for the individual to master the concepts, choices, consequences, and skills for successful, life-long weight management.

Support for success

Good weight management programs are designed for success. Designing Jared's weight management program was a challenge – it took time to convince Jared's parents it was important for Jared to be in control. It also took time for Jared to trust his parents would not police his every move. One of the first group activities was gathering information and making a list of possible goals for each person to consider. Everyone provided suggestions for Jared's goals: Jared, his parents, his siblings, and his best friend. Some of the options included:

- Walking the dog,
- Joining the local gym,
- Taking the stairs rather than an escalator or elevator,
- Taking a different route to work,
- Using the treadmill while watching a favorite television show,
- Cooking for the family one night a week,
- Drinking less soda,
- Learning about writing a balanced menu, or
- Doing a favorite activity (reading or doing a puzzle) instead of snacking in the afternoon.

In the first weeks, Jared's goals were modest. He didn't believe there would be no food police to scold him at every turn. But Jared wasn't the only one setting goals and changing habits. Everyone set personal goals each week. At the end of the week, everyone shared the progress they made. Sometimes goals were easily met. Other times, they were not met at all. In time, Jared began to see that everyone has ups and downs. He became everyone's cheerleader.

He liked the process we had designed. In turn, Jared's parents learned to appreciate what Jared was learning about being healthy. His enthusiasm was contagious. This support and discussion is a key element to many good weight management programs such as Weight Watchers.

The role of the support person

The most successful support is based on the concepts of positive behavior support. Focus on what is going well rather than what is not. Set attainable, discrete goals with rewards. Talk about options, but do not chastise. If challenged, do not react. For example, if Jared chose to eat an entire half gallon of ice cream in one sitting, no one said a word. At times, Jared would set out to do just that, but when no one commented, he gave up before finishing the container. He didn't get the desired attention, even though it would have been negative, so it wasn't worth continuing.

The role of the support person is to encourage and coach, but not to judge. Some methods for doing this are:

- Use visual tools. If the person you are supporting is working toward a specific goal for the week, find a way to make progress visual such as charting minutes of exercise, steps per day, or number of sodas consumed (with a set limit).
- Assist with problem solving. Talk about the choices there are to a situation that is difficult. For example, make a list of easy and enjoyable things to do rather than eating: read a book, call a friend, do a puzzle, shoot some hoops, and so on.
- Set a schedule for activities. Few people do well if someone else is choosing when to go exercise. Let the person set the schedule or rearrange it as needed.

These are just a few examples of ways to offer structured support using self determination that shape new habits. They are much more effective and educative than asking yes or no questions or taking an authoritative approach.

Tools for success

There are many ways to encourage change through structure. Here are some categories and suggestions to consider.

Change the environment

- Keep only the things you want to eat in the house.
- Use recipes that yield exactly the number of servings needed for a meal.
- Follow a planned menu to reduce the risk of hasty fast-food or take-away choices.
- Change how often you shop to reduce the amount of food available at home – shop for only one or two days of a menu at a time.

Nutrition Education and Portion Control

- Plan meal size so there is nothing left over. When the food is gone, it is gone.
- Measure the servings provided.
- Practice looking for options when eating out. Pick up a copy of the menu for a favorite restaurant to read and discuss at home.

• Focus on what to do rather than what not to do. Self-determination and weight management are not incompatible. In fact they are inextricably linked to each other in a good weight management program. If a person, with or without Down syndrome, does not fully understand the choices available and how to reach the goals they are seeking, they are not making "informed choices." Does that mean they never will? No. It means it is time to plan, educate, and practice. Leading a healthy lifestyle doesn't mean being perfect. It means making choices that promote health and well-being.

This article is reproduced, with permission, from edited articles by Dan Baker and Joan Guthrie Medlen originally published in Disability Solutions Vol 6 issue 2 (2005). This edition featured the topic of informed choice with special reference to healthy eating.

You can download the whole issue at <http://www.disabilitysolutions.org/newsletters/files/six/6-2.pdf>

Disability Solutions is a great resource for families, with the entire collection of past issues available online. Each issue features a particular topic with additional recommended reading, book and resource reviews.

For a wealth of information, advice and ideas about healthy eating, teaching healthy food choices and healthy lifestyles: The Down Syndrome Nutrition Handbook. A guide to promoting healthy lifestyles (2006 second edition) by Joan Guthrie Medlen Phronesis Publishing is available for Down Syndrome Victoria members to borrow from our Resource Library.

WAYS TO OFFER SUPPORT FOR SUCCESS

Be good role models: Be a role model for making healthy choices. Improve your own weight and fitness as an example and feel better yourself too. Subscribe to magazines that promote healthy living in an appealing, positive manner.

Talk about it: Talk about the images on television, including commercials, and in other media that are not conducive to a healthy lifestyle.

Do It! Don't just talk about it! Do it together. You want your child to understand what he can do to be healthy as well as what foods to think twice about

Teach: Teach which food choices are healthier at a fast food restaurant. Regularly practice going to different fast food restaurants and ordering a more healthful selection than usual. Talk about why this is a better choice. Start a list of what menu items are better choices at each restaurant which can be a reference when (s)he goes there with her friends.

Repeat, repeat, repeat

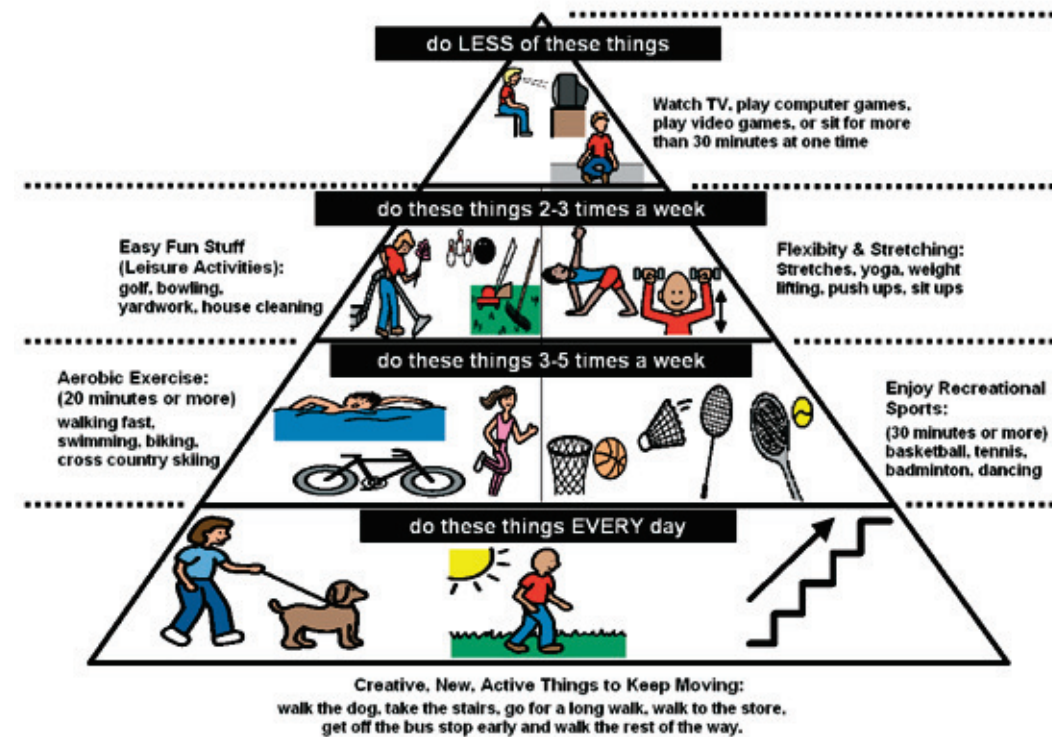
Practice, practice, practice:

Present information about serving size, food selection, and how to eat more balanced, healthy meals often, and in as many different formats as possible.

Support a healthy lifestyle: Build in opportunities for instruction and support regarding recreation, eg a goal to do something with a friend three days a week. Provide supports to facilitate these goals, such as a calendar to mark social activities and cue cards to structure telephone conversations for organising these.

[Daniel Baker (2005) 'Whose choice is it? A primer on making informed choices' Disability Solutions vol 6 issue 2 <http://www.disabilitysolutions.org/newsletters/files/six/6-2.pdf>]

Activity Pyramid



Source: The Down Syndrome Nutrition Handbook. A guide to promoting healthy lifestyles (2006 second edition) by Joan Guthrie Medlen Phronesis Publishing.