

Disability Solutions

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Whose Choice is It? A Primer on Making Informed Choices

by Daniel Baker, Ph.D.

Jared is 27 years old and lives in a group home. This is the second group home Jared has lived in since he moved out of his parents' home, something he really wanted to do. The first group home was too restrictive and Jared was very unhappy living there. He was constantly battling with the staff because he wanted to do something different from what they had planned for him. Jared's parents want their son to make choices about how he spends his time, what he eats, how he dresses, when he goes to sleep, and so on. He does need support and they feel a group living situation is the best option for him right now. The management and staff at Jared's current group home believe strongly in letting the people they support make choices throughout the day. This philosophy is consistent with how Jared's parents raised him. They knew he would be happier in this environment. And he is.

However, over the past 10 months Jared has gained weight at an amazing rate: 4 pounds a month. In other words, he was at a reasonable weight, but now he is visibly overweight. His parents are concerned that if he continues to gain weight at this rate, he will soon have trouble walking long distances or develop knee problems, which will limit his activities. When they 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."

What can Jared's parents do? Jared is making choices that are not compatible with his desire not to gain any more weight. The group home management's philosophy will not allow for a program in which Jared doesn't have the option to refuse an activity or choose his own food or 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. While there are many

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Letter from the Editor

Informed Choices: Just Make Them!

"The real issue is not so much choice as power.
Most ordinary people are not "allowed" choices; they just make them."

Herb Lovett in *Learning to Listen*

I firmly believe that anyone, regardless of ability, can and should craft the direction of their life. Being in control of what happens to you is essential to a healthy, fulfilling, and happy life. When you do not have meaningful control about important decisions in your life, you feel oppressed. You may withdraw, become depressed, or act aggressively. You are unhappy. For people with disabilities, these normal reactions are sometimes considered a "regression."

Not having control of your life is unacceptable for anyone. It happens far too often to people with Down syndrome or developmental disabilities. It doesn't have to, though. There are endless strategies for teaching, communicating and supporting people with Down syndrome to help them understand every decision. It takes time, but it is time well spent. It is important for everyone to understand what choices are available, what the consequences are, and then to make their own decisions.

If that is the case, why is it so hard to do?

There are probably two reasons. One is that it is easier and faster to make the decisions for people when they do not immediately understand the choices. The other is that it means we

must let go. As parents, we all have trouble letting go, whether our child has a disability or not. Mother does know best! For professionals who support people with developmental disabilities, it also means giving up control. Sometimes it means falling behind schedule or dealing with difficult situations. In both cases, supporting others to make decisions means letting them make decisions we may not agree with and supporting them, no matter what happens.

Making informed decisions and giving informed consent is not as simple as offering a set of options hand picked by you. The process of making informed choices takes time, teaching, and tenacity that is easy to overlook. The collection of articles in this issue of *Disability Solutions* will help propel you past making decisions from a limited set of choices to teaching your child how to understand her choices and the potential consequences of them.

In his article, "*Whose Choice Is It? A Primer on Making Informed Choices*," Dan Baker dissects the process of making a truly informed choice. His explanations bring clarity to a topic that can make or break many living situations for adults with Down syndrome: weight management. In the article "*Healthy*

Lives and Informed Choices: Can You Have Both?" I begin to apply Dan's concept to a common battlefield between parents, support professionals, and people with Down syndrome of all ages. Jamie Todd shares her son's journey with weight management over a number of years. A key to Stephen's success is Jamie's awareness they would continue to battle unless she involved Stephen in the process. She focuses on teaching him what he *can* do to lead a healthy life. "*Stephen's Story*" is an exemplary model of using positive behavior support and teaching skills for success that create a grasp of healthful habits Stephen will use all his life to make informed choices.

This is one of the most abstract concepts we have tackled in *Disability Solutions*, but it is clearly an important one. If you have ideas or comments on this topic, I would love to hear from you. There is much to discover.

Warm regards,



Joan Guthrie Medlen is the Project Director of *Creating Solutions* and Editor of *Disability Solutions*. She is the mother of two teenaged boys, one of whom has Down syndrome and autism.

Feature Story

Healthy Lives and Informed Choices You Can Have Both!



by Joan Guthrie Medlen, R.D., L.D.

What happened to Jared? We last heard Jared was living in a group home gaining weight nonstop. 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. Weight management nightmares for people with Down syndrome occur in every type of living situation: at home, in group living environments, in an apartment with support, or in adult foster homes. The issues are mired in ideology creating barriers to reaching the same goal: a healthy,

fulfilling life for the person with Down syndrome.

Self-Determination vs Weight Management: Can You Have Both?

Over the years I have received countless email and phone inquiries regarding situations similar to Jared's. In fact, this story is a composite of those experiences. The greatest challenge appears to be the clash between instantaneous, boundless self-determined freedom and teaching the concepts that lay the foundation for making informed choices. In the quest to do the right thing, people forget weight management and making choices are not incompatible.

This clash between self-determination and health often results in parents and support staff being at polar opposite ends of the issue. On one hand, parents appear to say their children with Down syndrome cannot make choices, suggesting a need for control or loss of freedom. On the other hand, support people appear to say they cannot intervene in choice making in any way, suggesting there's nothing that can be done. A little investigation usually reveals that everyone, including the person with Down syndrome, wants the same outcome.

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

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Feature Story

Stephen's Success

A Tale of Teaching and Tenacity

by Jamie Todd



Stephen was born with a heart defect that was corrected when he was 5 years old. During those first five years, it took a lot of work for Stephen to eat enough calories to gain weight. We were constantly aware of how much he gained.

After his surgery, Stephen thrived. It was a relief to see him eat well and grow without any effort at all. We were programmed to promote weight gain, and we did a good job, because he continued to gain weight. He, and we, had formed habits in those first five years that snuck up on all of us. Eventually we realized he had gained too much weight. Something needed to be done.

We first focused on increasing his activity. We kept Stephen so

busy he never had a quiet moment. He spent all of his free time, and ours, at Special Olympics, Challenger Baseball, or horseback riding. It was good for him, but it didn't bring the change we had hoped for.

It was time to look at eating habits, too. Making changes to our eating habits has paid off. The progress has been very gradual. It has

taken years and there's always room to improve. I see tremendous changes in Stephen's habits and his appearance. He is learning and taking control of his eating slowly, but surely.

It began with baby steps. For example, my children have always taken their lunch to school. At first I made Stephen healthy low fat lunches. He would slyly trade them away for junk food for the better part of one school year. His classmates enjoyed them! I realized part of the problem was that I wasn't involving Stephen in the process. He wanted some control about what he ate. I began offering him choices about what to make for his lunch each day. By offering him choices, he felt he

"owned" that lunch and he ate it.

We also changed the environment at home. I began by purchasing healthier snacks, learning what the boys liked. I used subtle redirection to begin to change habits. Stephen constantly asked me for a snack when he was bored. We spent a lot of time rationalizing and negotiating about the types of snacks to choose. Then I began to encourage him to do a different favorite activity when he was bored: read. It was tedious and time consuming, but it worked. Soon, reading became the first response to being bored instead of seeking a snack. Once he had developed a different coping strategy to boredom, it was easier to talk about making healthy food choices for snacks.

Taking family trips is a natural time for everyone to be bored. We used a "snack bar" for the boys. Celery and baby carrots were cheap while Doritos and soda were very expensive. The boys were given a set amount of money to spend on snacks for the trip. They learned money management skills so their snack budget would last longer.

The greatest challenge we still face is portion control. A buffet is a disaster for Stephen. However, he does great when he is making a meal or snack with built in portion control. He has been testing recipes that are designed to serve one or two people. He loves cooking and is good at it. With the portion control embedded in the recipe, he doesn't think twice about how much he is going to eat. Plus, if he wants more, the recipe is the bad guy, not me. Having the portion controlled by how much you

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issues to investigate in this situation, the first thing to do is to find out if Jared really understands what his choices are and how those choices impact his life—in this case his weight and overall health. The concept of understanding what choices are available and how those choices impact your life is called “informed consent” or “making an informed choice.” Being able to provide informed consent regarding choices made is a key element to self-determination. This article will explore the concept of informed consent and how it relates to making healthy choices.

Defining Informed Consent

Informed consent is a legal term that is seen quite a bit in questions about guardianship. People must be able to give informed consent to participate in some types of activities, such as being in a research project or having certain medical procedures performed, such as surgery. Informed consent means basically that three things must occur. A person must:

- know what the choices are,
- know the consequences of the choices they make, and
- make choices a “reasonable person” would make. This means making choices that are legal as well as reasonable.

The first two components are easy to understand. The third is more difficult. The concept of “reasonable” is really in the eye of the beholder. What is reasonable to one person may not be reasonable to another person.

This is especially true between different generations and cultures. For people with Down syndrome and related disabilities, the definition of reasonable is influenced by what will hold up in a court of law. The court system tends to have a conservative, or narrow, perspective on what is considered to be reasonable. The legal definition of *reasonable person* is: *A phrase used to denote a hypothetical person who exercises qualities of attention, knowledge, intelligence, and judgment that society requires of its members for the protection of their own interest and the interests of others.*

Using myself as the focus, here are some examples of how the court would determine if I am able to provide informed consent in different situations:

Do I have the right to overeat?

- *Do I understand my choices?*
Yes, I know my choice is to eat reasonable amounts of food or to eat twice as much as my body needs.
- *Do I understand the consequences of the choices I make?*
Yes. If I eat healthy, it will be easier to maintain a healthy weight, I will have more energy, and I will have a lower risk of medical problems related to being overweight such as high cholesterol or diabetes. However, eating meals at fast food restaurants and junk food often saves time. Sometimes it costs less, too.

- *Am I making a choice that is “reasonable?”*

Yes. Many reasonable people choose to overeat.

By the three standards of informed consent, I can make the choice to eat an unhealthy diet.

Do I have the right to smoke cigarettes?

The same questions apply to this decision.

- *Do I understand my choices?*
Yes, I know it is my choice to smoke cigarettes or to not smoke cigarettes. No one can force me to smoke or not smoke.
- *Do I understand the consequences of my choices?*

Yes. If I smoke cigarettes, I am increasing my risks of many significant diseases, such as lung cancer and emphysema. Smoking is also expensive. I may not be able to afford other things if I choose to smoke. On the other hand, if I don’t smoke cigarettes, the risks to my health are greatly reduced and I will have money to spend on other things.

- *Am I making a choice that is “reasonable?”*

Yes. Many reasonable people choose to smoke cigarettes.

By the three standards of informed consent, I can make the choice to smoke.

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Whose Choice Is It?

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Do I have the right to use street drugs or purchase prescription drugs without a prescription?

No. That is illegal. The three part tests are not used if something is against the law. A reasonable person will not choose to do something that is illegal in the eyes of the court.

Do I have the right to sit in the middle of a busy street (either on the yellow line or in the middle of the lane)?

• *Do I understand my choices?*

Yes, I can sit in the middle of a street or I can sit on the sidewalk.

• *Do I understand the consequences of my choices?*

Yes, if I sit in the middle of a busy street, I am likely to be hit by a car and injured.

• *Am I making a choice that is "reasonable"?*

No, I am not. The conservative interpretation of the courts is that directly facing that type of risk is not a reasonable person's choice, even if it is done as a political statement.

Do I have the right to ignore a diabetic diet?

That is a dangerous act, just like sitting in a street. But the risk tends to be more long-term and not so immediate. Can I do that?

• *Do I understand my choices?*

Yes. I can choose to follow the program I learned from the Diabetic Educator or not.

• *Do I understand the consequences of my choices?*

Yes. Following the guidelines of a diabetic diet will help control my blood sugar levels. This reduces my need for medication. It also reduces my risk for medical complications including the loss of a toe or vision. I have been taught by a dietitian how to implement my diabetic diet. I know if I do not follow the guidelines I learned, I risk complications and even hospitalization if my blood sugar goes too high.

• *Am I making a choice that a reasonable person would make?*

The courts would rule that I can choose to ignore my diet, as it is something that a reasonable person might do.

Do I have the right to engage in high-risk sexual activity?

• *Do I understand my choices?*

Yes, I know it is my choice whether or not to engage in unsafe sexual behavior.

• *Do I understand the consequences of my choices?*

Yes, if I engage in high-risk sexual behavior, I may develop a disease or there may be an unwanted pregnancy as a result.

• *Am I making a choice that is "reasonable"?*

Yes. Many reasonable people choose to engage in high-risk sexual behavior.

Reviewing these examples, as long as a person is their own guardian, they understand the choices of an act,

they understand the consequences of the act, and the act is legal and does not pose an immediate, grave threat, it will be seen as reasonable, whether or not they have Down syndrome.

In some cases, the test for informed consent fails because a person is unable to show they understand the consequences for their choices. This happens most often as we age. However it sometimes occurs when people are struggling with depression or other tough situations. Using myself again as the person involved, here is an example:

I have been clinically depressed. I am in bed and have been there for 36 hours. I will not eat or drink. My family wants to take me to the emergency room even though I say I do not want to go. Once at the emergency room, the medical team needs to determine whether or not I am able to give informed consent.

Do I have the right to refuse food and drink for an extended period of time?

• *Do I understand my choices?*

Yes. I know I can stay in bed and refuse food and water for a long period of time.

• *Do I understand the consequences of my choices?*

When I am asked if I understand the consequences, I reply "I do not care. It does not matter." I explain I know if I do not eat or drink I will only feel worse. These answers suggest I do not truly understand the consequences of my choices.

- *Am I making a choice a reasonable person would make?*

No. A court would say that I cannot give informed consent for failure to eat and drink for long periods of time. If I were making a political statement, the courts may rule differently.

Informed consent is no different for a person with a disability, including intellectual disabilities. In fact, even if your child is 18 or older and has a guardian, he still has the right to make a choice if he can provide informed consent.

Your child's legal guardian, whether it is himself or someone else, will have final say in these areas in these circumstances: consent for medical procedures, where your child lives, and legal authority. Examples of circumstances that require legal authority include signing legal contracts, purchasing health club memberships, or participating in a research study. These legal rights are very similar to those of a person without a developmental disability.

Informed Consent & Everyday Life for Adults with Down Syndrome

What is different in day-to-day situations for your child with Down syndrome? The second test for informed consent: *understanding the consequences of an action*. This is the key difference in decision making for your child.

Understanding consequences is tough for everyone. It takes, years of experiences and trial-and-error

lessons everyday life. These lessons are often more difficult for children and adults with Down syndrome. The natural learning that takes place with trial and error is limited by social, cultural, and societal barriers because related to having a disability.

Providing opportunities to learn about the consequences of making a choice is a difficult thing to do with any child. It's hard to watch your child struggle with an unexpected and unwanted outcome. It is even more difficult for your child with Down syndrome because you, along with your child's teachers, try to set your child up for success as often as possible. This means we unwittingly remove natural consequences. This isn't necessarily bad, but it is something to think about. To compensate, parents and professionals need to make the most out of teachable moments. This means being aware of times when you and your child are open to natural instruction that occurs. Using teachable moments enables you to provide opportunities for your child to learn with positive support and feedback. Sometimes teachable moments occur naturally and sometimes you must arrange for them to happen. Both are valuable to your child. The more opportunities your child has, the more quickly he will be able to understand the consequences of his choices.

Teaching Informed Consent

The importance of proactive teaching and modeling of a healthy lifestyle becomes very clear when considering

the importance of informed consent. When your child is young and living at home, parents have a great deal of influence on what happens each day. Lessons can be built into everyday activities such as grocery shopping, going to a restaurant, and yearning for another helping.

How does this main concept of *informed consent* work once your adult child lives away from home? This can be a tricky maze to navigate. The first consideration is, who is the legal guardian? If your child is their own legal guardian, he has the legal right to make his own decisions about what he eats.

Living at Home

If your adult child is living at home you have a good deal of influence regarding your child's instruction and support each day. You may or may not have guardianship, but the real battles will be fought over everyday choices about what to eat and when. It is important to honor your adult child's choices. That doesn't preclude instruction and positive support for learning about basic nutrition and health promotion. Use the opportunity to improve everyone's grasp of how to improve health.

Living in a group setting

If your child is living in a group setting, such as a group home, there are paid staff members around the clock who provide support and instruction based on your child's Individual Service Plan (ISP). In group living situations parents have far less influence regarding the

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instruction and support your child will receive than at home.

The group home management and staff determine the quality, quantity, and method of instruction and support your child receives. You are, however, pivotal to the planning process. Together, with the team, you determine whether or not your child understands his choices and the consequences of them. If your child does not have this understanding, then proper instruction should become a focus point of support for your child by the staff and team members. You will need to work closely with your child, the management, and the staff to agree on instructional goals that teach informed consent and the method for supporting your child as he learns these lessons. As you develop the plan for instruction and support, ask about the philosophy and training that has already been completed regarding self-determination for the staff.

In group living situations, the staff typically does not prepare a different meal for each person based on individual preferences. However, if your child wants to prepare his own meals and he understands his choices, their consequences, and he can safely prepare his meal, he should be able to do so. The support plan for your child needs to give clear instructions for staff regarding choice making and instructional response to the choices he makes. Most important, staff and family should be on the same page regarding the process and method of instruction.

Supported Living or Living at Home With Support

If your child lives in an apartment or home with periodic support, the only difference is the amount of instruction, support, and monitoring staff can provide. Some families hire support people to work specifically on nutrition education and health promotion with their child in their own home. This is not very different from hiring a personal trainer or going to a weight management or cooking class. There is typically little or no constant monitoring, which allows for plenty of opportunity for natural consequences.

A Case Study

Sheila is a 17-year-old woman with Down syndrome. She attends high school where she spends a lot of the day around students without disabilities. She is very social, and loves people and hanging around. She loves to watch television at home and dreams of being like characters in her favorite movies. Sheila reads well and is comfortable with basic math using a calculator. The school team thinks she will be able to be competitively employed (work for competitive wages and benefits with minimal or no support) after she graduates. She does very well with complex tasks once she has learned them and is comfortable with her fellow students or coworkers.

Sheila is very overweight. Her parents have spoken to her many, many times about her diet and exercise patterns. She can tell you that if she keeps eating junk food she will have trouble going up and

down stairs. Even so, she says she likes eating a large burger, fries, and milkshake for lunch because that is what her friends are eating. It is difficult for Sheila to imagine consequences that will come in some distant future, including losing weight. Her decisions tend to be based on what is happening in each moment. She does understand that not eating well can cause a person to develop some disease, but she doesn't understand how that relates to her own life.

Applying Informed Choicemaking

When looking at this from a standpoint of informed consent, Sheila needs instruction and support to gain an understanding of the consequences of her choices, the second part of the three-part test. What are some things that Sheila's family can do to help her learn how her choices determine the consequences to her health? Any instruction and support Sheila's family offers needs to have relatively immediate consequences. The following ideas are not inclusive, but rather a menu of options from which Sheila's family can choose.

Be good role models

To combat the deluge of images Sheila sees of people eating seemingly endless amounts of food without gaining weight in the media, she needs to see just as many examples of what it means to make healthy choices. Her parents chose to be better role models for making healthy choices. They are hoping to improve their own weight and

fitness as an example to Sheila and to feel better themselves. They have begun subscribing to magazines that promote healthy living in an appealing, positive manner, such as *Cooking Light* and *Weight Watcher's Magazine*.

Talk about it

Sheila's parents are beginning to talk about the images Sheila sees when they watch television together, including commercials that are not conducive to a healthy lifestyle. (This is also a great idea for instruction and support when somebody watches television shows or movies with inappropriate images of sexuality, or even shows like professional wrestling.)

Do It!

Don't just talk about it! Do it *together*. Rather than having your child listen to speakers in health class, illustrate other appropriate, healthy food choices. 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. Every restaurant has popular, higher fat-higher calorie entrées along with choices that are healthier.

Practice going to different fast food restaurants and ordering a more healthful selection than usual. Talk about why this is a better choice than what your child is used to ordering. Sheila and her mother have started going to lunch together once a

week at different restaurants to practice finding and ordering more healthful entrées from the menus. Sheila keeps a list in her purse of what menu items are better choices at each restaurant so she can refer to it when she goes there with her friends.

Repeat, repeat, repeat Practice, practice, practice

Present information often in as many different formats as possible. Sheila's family is using menu cards, similar to the old "Deal-a-Meal" method, to help Sheila understand how many servings she is eating from each food group each day. Sheila enjoys the checkbook method and is learning more about serving size, food selection, and how to eat more balanced, healthy meals.

Support a healthy lifestyle

Build in opportunities for instruction and support regarding recreation. Sheila's parents set up a calendar for her to fill in with activities with her friends. Sheila's goal is to do something with a friend three days a week. Since she likes being with her friends, she is very motivated to do this. She likes having a calendar and a cue card for what to say when she calls her friends. Her mother believes she will stop using the cue card after she has more practice calling her friends.

These are some of the ideas Sheila's family used to build in instruction and support providing Sheila with an understanding of the consequences for her actions.

The key is to teach issues around diet and lifestyle choices with the same precision and support you use to teach any other skill to your child. Our goal (professionals, parents, and caregivers) for any young person who is graduating from high school is to be able to live, work, and lead healthy lives. It is just as important to pay attention to provide instruction and support regarding living a healthy life. There's no better time to start than now!

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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?

Everyone is actively practicing weight management in one way or another. Sometimes it is more obvious than others. For example, competitive athletes choose a training plan that includes a weight-related goal as well as food and activity goals. People who join a program such as Weight Watchers or hire a trainer at the local gym have weight-related goals. Some people use weight management to improve their health, lower cholesterol, or manage diabetes. Most people, with and without disabilities, have a “point of no return” such as tight-fitting clothes, a particular number on the scale, or a special event on the horizon. These are all examples of “weight management.”

Weight management is not losing weight. It is not implementing a strict diet. It is also not looking like a favorite celebrity or eating “perfectly.” 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. Use the information in the article, *Whose Choice Is It?* to help you and your child understand their decision. Once stated, it is possible to begin to design education, support, and structure needed to make choices leading to a healthier lifestyle. 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 or a class at your local YMCA or hospital community education center, look for the following elements to the program:

- **FUN.**
- **Social component.** Are people open to your child’s presence? Is the atmosphere one of acceptance and support? Your child wants to be greeted warmly when he arrives.
- **Variety.** This is more relevant for the physical activity component to a program. Are there a variety of activities to choose from?
- **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.** Everyone enjoys working toward something if there is a reward. Your child should choose nonfood rewards for certain benchmarks. CDs, workout clothes, a special trip are some examples.
- **Individually competitive.** By setting goals, your child competes with himself. Some examples are 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 means not having trigger foods in the house if asked or

modifying your own behavior if it supports your child's goals. Focus on successes, not the areas where your child is having trouble.

Making Accommodations

Jared's experience is not different from any other young adult in their first years away from home. Yet sometimes in our eagerness to see our children gain successful independence, we forget they have Down syndrome. 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. Even so, he probably has his own unique way of accomplishing the task. 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 because everyone's emotions were frazzled. 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 take his food away, make him eat rice cakes all day, or stand over him and 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: Jared, his parents, his siblings, and his best friend. Some of the options included:

- Walking the dog,
- Joining the local gym,



Key to success?
Fun! Friends! Fun!

Continued on page 12

continued from page 11

- 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. *Stephen's Story* on page 4 has many examples of how a change in structure teaches concepts and shapes new habits. 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 the number of servings needed for a meal. Making the appropriate amount of food for a meal reduces the tendency to overeat.
- Follow a menu. This reduces the number of times pizza delivery is called in at the last minute.
- Change how often you shop. For some people just having food in the house is too tempting. One way to reduce the amount of food available for unplanned eating is to 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. (see *Build-A-Sandwich* on page 13). It's more important to know what you want to do and how to accomplish it 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.

Joan Guthrie Medlen, R.D., L.D., is a registered dietitian interested in healthy lifestyle coaching for people with developmental disabilities. She is the author of *The Down Syndrome Nutrition Handbook: A Guide to Promoting Healthy Lifestyles* and volunteers for Special Olympics International's Healthy Athlete, Health Promotion Program. Joan is the mother of two teenaged boys, one of whom has Down syndrome and autistic spectrum disorder.

Build-A-Sandwich

Step 1

Choose One

Bread options:

- ✓ White Bread
- ✓ Wheat Bread
- ✓ Rye Bread
- ✓ Potato Bread
- ✓ Pumpernickle
- ✓ (basically, any bread that looks good at the store)
- ✓ Hoagie buns (6 inches)
- ✓ Hamburger bun
- ✓ Small Baguettes (little french bread rolls)
- ✓ Bagels
- ✓ English Muffins
- ✓ Wraps:
 - ✓ Regular flour
 - ✓ Tomato
 - ✓ Whole wheat
 - ✓ Spinach

Step 2

Choose One or Two

Sandwich Fillers

- ✓ Deli meats: turkey, roast beef, ham, salami, pastrami.
- ✓ Cheeses: use white cheeses. Mozerella, ricotta (to spread on), and *Laughing Cow Cheese*.
- ✓ Tuna Salad (see recipe)
- ✓ Chicken Salad (see recipe)
- ✓ Meatballs and Sauce (see recipe)
- ✓ Leftover chicken, steak, ham, or pork
- ✓ Peanut butter and jelly

Step 3

Choose One

Spreads

- ✓ Light mayonnaise
- ✓ Italian dressing
- ✓ Ricotta Cheese
- ✓ Hummus
- ✓ Pesto

Step 4

Choose as Many as You Want!

Vegetables

- ✓ Tomatoes
- ✓ Lettuce
- ✓ Cucumbers
- ✓ Sprouts
- ✓ Pickles
- ✓ Olives
- ✓ Sliced or shredded carrots
- ✓ Sliced red or green peppers

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Build-A-Sandwich is a template to help people create healthy sandwiches. Stephen is shown using this template on page 3. Defining the amount of each category helps to prevent the creation of "A Dagwood" sandwich.

Recipes are © 2004 Joan Guthrie Medlen, R.D., L.D. and used here with permission. For more information on this cooking system in development, email cookbook@disabilitysolutions.org.

Directions:

- ☐ Wash hands.
- ☐ Gather ingredients and tools.
- ☐ Choose a type of bread for your sandwich
- ☐ Choose a spread for your sandwich (if you want one).
- ☐ Choose the type of filling for your sandwich.
- ☐ Choose the vegetables for your sandwich.
- ☐ Using the bread knife, cut bread if needed (hoagie buns and bagels sometimes need to be sliced in half).
- ☐ Use a butter knife (the kind from your flatware) to spread ricotta cheese or other spread on your sandwich.
- ☐ Add filling. (no more than 6 slices total of deli meat AND cheese per sandwich).
- ☐ Put top on sandwich or roll wrap (see recipe for making a wrap).
- ☐ Eat or wrap in plastic wrap for sack lunch.
- ☐ Clean up.
- ☐ You are done.

Build-A-Sandwich

(continued)



Tip:
If you are packing a sack lunch, put the vegetables in a separate plastic bag or container to keep the bread from getting soggy.



Tip:
Directions for filling and rolling a wrap to eat now or put in a sack lunch are included in the recipe, "How to Wrap a Wrap"

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Stephen's Success

continued from page 4

make gives me a much-needed break from feeling like the food police. But if you give him a platter of food from which he serves himself, he'll take enough for an entire family.

"Stephen loves cooking and is good at it. With the portion control embedded in the recipe, he doesn't think twice about how much he is going to eat."

One of his favorite recipes is called, "Build-A-Sandwich" (see page 13). The recipe provides guidance

regarding how much of different types of food to use on a sandwich. He happily piles on vegetables galore because the recipes says, "Choose as Many as You Want." This particular recipe has been a great lesson: you can eat MORE if you choose wisely.

At his heaviest, there was no way Stephen could button a pair of pants. His stomach literally rolled over the waist of the pants. One day he announced he wanted to "wear button pants like Dad." I am proud to say that after years of work, he can now wear "button pants like Dad."

Stephen, and the rest of us, are learning important lessons about healthy living together. By looking at habits and building in environmental controls for everyone, Stephen has experienced success without the pain of a "diet." There are tough lessons, of course, but the focus has been on making choices and learning what he **can** do to meet his goals. It has allowed us to be positive rather than feeling like we have to police him every moment of the day. Are his choices always healthy? No. But then, neither are mine.

Jamie Todd is the proud mother of Stephen, a middle school student who has Down syndrome. She resides in Virginia Beach, VA with her husband and three sons.

From the Toolbox

Don't Think it Will Work? Customize It!

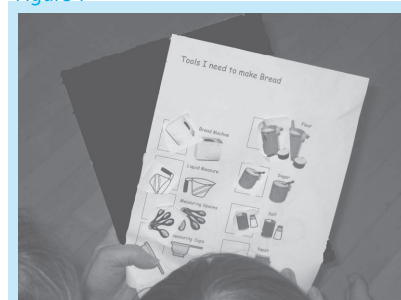
by Andy & Joan Medlen

There are many times, if not most of the time, the ideas and tips written for *Disability Solutions* seem unreachable for parents of children who have dual diagnoses, multiple disabilities, or who struggle with learning for mysterious reasons. The truth is, most of the stories have to be changed in some way for anyone's family. But when there is more gong on than "just Down syndrome" (as if that isn't enough), it is overwhelming and discouraging at times. Sometimes it is hard to imagine how your child can do the even a part of what you are reading.

You are far from alone. Most of the ideas in the newsletter require a good deal of changes to work for my son, Andy, who has Down syndrome, autism, and is nonverbal. He and I wanted to share how we modify the recipes designed for people who are better readers than he is. Andy uses symbols to communicate and works best on a task if it is in a checklist format. He also learns new vocabulary quickly if we use a "match, select, name" format.

Andy has been showing an interest in cooking for a while. He loves being in the middle of the activity when I

Figure 1

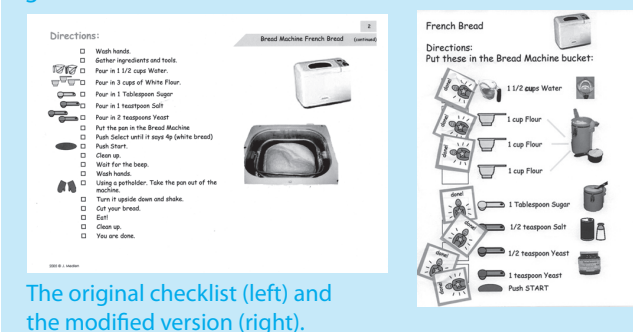


Matching symbols to learn vocabulary.

am in the kitchen. I am not easy to share the kitchen with, however. Cooking, or playing with food, is one of my favorite hobbies. I began to think about how to adapt the visual recipe system I was developing for others to teach Andy how to cook something.

continued from page 14

figure 2



The original checklist (left) and the modified version (right).

Step One: Decide What to Do

First I had some decisions to make. What will he cook? *Bread*. How will he make it? *In the bread machine*. What recipe will I use? *French Bread from **Electric Bread: A Bread Machine Activity Book for Kids***. Does Andy know all the symbols and words we will use? *No*. Which symbols do I need to teach? *I made a list*. What materials do I need? *I made another list*.

Step Two: Make the Materials

With those decisions made, I went to work printing symbols, turning them into stickers, printing pages for matching symbols, and checklists for Andy based on the recipe format seen on page 13. Here is a brief description of our first session baking bread.

Step 3: Learn New Vocabulary

Andy took to this task very well. We put laminated symbol cards (always with the printed word on them) **in** or **on** the object of each new word: flour, sugar, yeast. We pulled it out and placed it next to the sticker symbol. He then matched the sticker to the symbol on a worksheet (see figure 1).

Step 4: Follow the Checklist

I goofed on this one. Andy has always been a “big bang” learner. He wants the biggest bang for his buck the first time around. I started by asking him to follow the checklist: Find the water.

Dump it in. Check it off. Find one cup of flour. Dump it in. Check it off. (see figure 2) This was too many small steps for Andy. Our goal wasn’t independence, it was participation.

Step 5: Review and Fine Tune

Later, as I looked over the photos, I realized Andy needed a much more simple checklist right now. I have modified the checklist to eight steps:

- Gather tools and ingredients (“Get everything you need.”).
- Pour in the water.
- Pour in the flour
- Pour in the other dry stuff (I measure it all together).
- Put the pan in the machine.
- Push START.
- Wait, Wait, Wait (this is an important lesson)
- Eat.

As with all learning activities, be prepared to suffer the consequences of your hard work. I can no longer pull out the bread machine to make something alone. Andy is always there, eager to help. We now try

to make bread or bread dough together at least once a month. Is the outcome the same for Andy as it is for Stephen? No. But teaching him how to cook, even if modified, changes the choices he can reasonably make and the quality of his life. Learning takes a lifetime. Who knows? It’s hard for me to imagine today, but I am hoping one day, he’ll be a relatively independent cook.

A more detailed description of how we taught the symbols and steps is posted on our website at: www.disabilitysolutions.org/bread.htm.



Happy Cooking!

Andy is a freshman at Wilson High School in Portland, OR. He continually challenges people to think beyond his disabilities. His mother, Joan Guthrie Medlen, enjoys finding ways to unleash Andy’s interests, talents, and charm. Andy has an older brother, whom he adores. Andy resides with his family in Portland, OR.

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