It’s all over the nightly news: 70% of all Americans are overweight, and the number is multiplying every year. Surveys show people claim to understand the importance of healthful choices regarding food and exercise, but less than 40% of all Americans exercise on a regular basis.

As a parent these statistics make me think about my own family and our lifestyle. Are we as healthy as we could reasonably be? Usually there is room for improvement; sometimes a lot of improvement. This leads me to make small changes in our family menu or schedules. After I do this, I begin to wonder how I can teach my children, including my son with Down syndrome, to lead a healthy life on their own. Yet, what does that really mean for them? Is a healthy lifestyle for an adult with Down syndrome defined the same way? When I look through research articles, I see subtle differences for adults with Down syndrome: a decrease in basal metabolic rate, lower muscle tone, and a difference in motivation for exercise to name a few. I also wonder how community support or different living situations affect food and activity choices. Is it reasonable to suggest the same types of exercise programs for improved overall health?

Mia Peterson, a young woman with Down syndrome, and I have been talking for a long time about food and healthy lifestyles. In 1997, she moved into her own apartment and found cooking healthy foods and keeping active a challenge. Since Mia enjoys doing research, we decided it was time to ask adults with Down syndrome what they know about...
This issue of *Disability Solutions* is devoted to sharing some of lessons and experiences from a survey, *Healthy Lifestyles in Adults with Down Syndrome: What Do We Know?* The articles in this issue are written by one of the survey coordinators: Mia Peterson or myself.

Projects like this one are never the work of a few people. We have many people to thank for lending us their time and talent for the areas we could not do alone including:

- The Down Syndrome Association of Greater Cincinnati, The National Down Syndrome Congress, and The National Down Syndrome Society for allowing us to conduct our survey along with their meetings;
- the parents who wrote to participate in this survey;
- Jackie Holcombe for assistance with data input;
- Dennis Littlefield for database creation and technical assistance;
- Terry Johnson of Mayer-Johnson Company for use of PCS symbols;
- Brian Chicoine, M.D., Dennis McGuire, Ph.D., and Essie Peterson for survey feedback;
- Gretchen Koetters, Mitchell Levitz, Katie Maly, Tia Nelis, and Michelle Pettit for the “survey test drive”;
- Carol Christianson, MS for her continual review and assistance sculpting the manuscript;
- Ryan Medlen for assistance with mailing; and
- most importantly, the adults with Down syndrome who enthusiastically shared their time and thoughts with us.

We also wanted to conduct this survey in a way we could present the results to professionals working with adults and families of children with Down syndrome. This was not an easy task. However, with the help of many people, we are happy to tell you that the full survey results should be published in *The Down Syndrome Quarterly* sometime this year. This is the first article published in *The Down Syndrome Quarterly* with a co-author who is an adult with Down syndrome. We commend the editor and the review committee for including us.

Last, as you will learn, this was an invaluable experience for me personally. I owe the opportunity for these experiences to Mia Peterson. Her dedication and insatiable inquisitions about nutrition and doing research projects is unavoidable. This project belongs to her.

We hope this is only the beginning of projects that include adults with Down syndrome in our quest to learn.

Joan E. Guthrie Medlen, R.D., L.D.
leading a healthy lifestyle. Mia says it best: "I want to know how people with Down syndrome who are older than me feel about healthy lifestyles. It is up to us to stay healthy, exercise, and eat well. Parents can encourage us, give advice, and remind us now and then, but they can’t make us do anything. Only we can.”

When she shared this with me, I realized that once my son is an adult, his life is his to lead. If I want to encourage him to make healthy choices, I need to start now. It’s never too early—or too late—to shape good habits.

Together, Mia and I wrote a survey for adults with Down syndrome, “Healthy Lifestyles in Adults with Down Syndrome: What Do We Know?” The survey included questions similar to what a dietitian asks to learn about people’s eating and exercise habits. We asked them to remember what food groups, if any, were included at six different times in the day: breakfast, a morning snack, lunch, an afternoon snack, dinner, and an evening snack. We asked how often they exercised, how often they helped with or prepared their own meals, and how often they ate meals “away from home.” Last, we asked about their favorite foods and activities. We wanted everyone to complete the survey with as little help as possible, so we used symbols along with words to illustrate the questions and possible answers. We distributed 270 surveys. They were filled out at conferences, in local group meetings, and sent to people by U.S. mail. We received 183 surveys back. Of those, 137 were filled out completely. Those that were not were due to a mechanical error in creating the booklets, not because the individual missed sections of the survey. The adults with Down syndrome who completed our survey ranged in age from 15 to 45 years old, with an average age of 27 years old.

We would like to share with you the most important things we learned from our survey and explain how this information is helpful.

Survey Findings

The process of giving the survey, looking at the data, and comparing the findings to previous studies along with our own thoughts was thought-provoking. The conclusions we found the most poignant were in the areas of:

- Frequency of eating,
- Nutritional balance of meals and snacks, and
- Activity.

Frequency of Eating

Americans are notorious for skipping meals. If you ask people, you might hear they skip breakfast, work through lunch, and somehow find time to throw something together for dinner. As a dietitian, I’ve learned to dig a

<table>
<thead>
<tr>
<th># of meals &amp; snacks</th>
<th>% of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>4</td>
<td>26</td>
</tr>
</tbody>
</table>

Table 1: Eating Frequency

Continued on page 4
Healthy Lifestyles in Adults with Down Syndrome: A Survey

Continued from page 3

little deeper. As I do, I usually discover that it’s not that people skip meals; they never really stop eating. More and more Americans “graze” through the day: eating little bits of food all day long, but only sitting down to one meal a day. One of the first things to work on in this case is establishing meal times.

In our survey, Mia and I asked people to tell us when they were eating. We wanted to know if adults with Down syndrome were skipping meals. When the surveys were complete, we counted the number of times adults with Down syndrome said they were eating out of six opportunities (see Table 1). We learned 97% ate 3 or more times each day, with most eating 4-6 times in a day. That means meals are not being skipped. It also indicates that adults with Down syndrome are aware of when they are eating rather than eating without thinking about it. However, it is worrisome that the majority ate so many times each day, and particularly that most ate an evening snack. Eating this often requires tenacious attention to the amount and type of food eaten to avoid eating too much.

Table 2: Meal Balance

<table>
<thead>
<tr>
<th>Meal</th>
<th>% Who Ate Meal</th>
<th>% Whose Meal Was “Balanced”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Break- fast</td>
<td>94</td>
<td>54</td>
</tr>
<tr>
<td>Lunch</td>
<td>96</td>
<td>53</td>
</tr>
</tbody>
</table>

Table 3: Snack Balance

<table>
<thead>
<tr>
<th>Snack</th>
<th>% Who Ate Snack</th>
<th>% Whose Snacks Were “Balanced”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morning Snack</td>
<td>50</td>
<td>20</td>
</tr>
</tbody>
</table>

Meal Balance

Another aspect to healthy eating is including a variety of foods throughout the day. By choosing from all the food groups throughout the day, it is easier to include the majority of the vitamins, minerals, amino acids, and fiber that your body needs. We only asked participants to tell us which food groups they included in a meal and snack. This only allows a look at the variety of energy providing nutrients: protein, fat, and carbohydrate. If a meal is not “balanced” for carbohydrate, protein, and fat, there can be an effect on hunger or blood sugar, which often affects attention, behavior, and learning. A general and easy way to evaluate “energy balance” for a meal is to choose foods from at least 3 of the 5 bottom food groups (bread, fruit, vegetable, milk, or meat). A snack balanced for energy includes at least 2 of the 5 bottom food groups. Although this does not take into account the number of calories or amount of fat for a meal, it is a quick, general way to determine overall variety.

We used these guidelines to evaluate the balance of meals and snacks in the survey results. Almost everyone ate Breakfast, Lunch, and Dinner. Over 50% of those meals were balanced for energy (see Table 2). When we looked at what participants were eating
between meals (see Table 3), over 50% had between meal snacks, with 67% having a snack in the evening. Of those snacks, only 20-32% were balanced for energy.

One of the things I do as a dietitian is take this type of information and draw some general conclusions about eating habits, nutrition knowledge, and desire to make changes to improve overall health. To do this, I not only draw on information from an interview (the survey), but also from past experience. I consider it a place to start. In the last five years I've had the opportunity to work with a number of teens and adults with Down syndrome in a workshop environment. As a group, we’ve experimented with a variety of topics, but the best example of the current outcome of nutrition education and experiences goes something like this:

The room is charged with excitement of being together with friends, new and old, and curiosity about what we’ll be doing together. As I introduce the topic of nutrition, I can feel a handful of very sharp gazes directed at me. Rhetorically I ask the group, “You all know what the Food Guide Pyramid is, right?” while holding one in the air. They either say “yes!” or they groan aloud. Immediately, there are some comments from those who were giving me those sharp, guarded looks.

One woman says, “I know what you’re going to talk about.”

“What?” I reply.

“Calories” she says with a moan.

“Nope,” I reply.

She sits up a little straighter. Another participant, an older man who lives in his own apartment chimes in. “Well, I know. It’s F-A-T.”

“Nope,” I reply again.

“Really?” they ask together looking quizzical.

Yep,” I answer while addressing them along with the rest of the group. “Today, we’re going to talk about how to be healthy by eating a variety of foods—including desserts, French fries, and ice cream. We’ll figure out how to decide if a meal is balanced, and if you want, we can create menus for you to take home and try.”

Of course it doesn’t happen exactly like this every time, but the idea is always the same. As soon as they hear we’re going to discuss being healthy and food, those who have struggled with their weight or are meticulously managed with regard to food begin to build walls. Those who have not expect to hear the mantra they’ve been hearing for years: no pizza, no French fries, no ice cream, no goodies…no, no, NO. I’m always happy to get past this point without being mobbed or covered in rotten tomatoes.

The survey confirms these personal experiences and adds depth to them as well. In fact, I believe the outcome of nutrition education for adults with Down syndrome today is an understanding:

- of food groups,
- of the food pyramid,
- that too many calories cause you to be fat, and
- that avoiding foods that are high in fat or are in the “sometimes” group of the pyramid can help prevent weight problems.

What they seem unsure of is what they can do with food to be healthy.

Activity

We included some questions that gave us an idea of how often adults with Down syndrome exercise and how they feel about exercise in

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Healthy Lifestyles in Adults with Down Syndrome: A Survey

Continued from page 5

general. It is presumed by many that adults with Down syndrome avoid physical activity or exercise. This might be due to the stocky build or low muscle tone of many adults and children with Down syndrome. It isn’t always a sign of dislike for activity or even poor physical condition as parents of children and adults with Down syndrome know. I will always remember the physician who included, “people with Down syndrome don’t like to jog” in his description of what we could expect from our newborn child.

We were surprised to find an overwhelming 80% of our survey participants exercised the day of the survey. Out of that 80% who exercised that day, 95% said they exercise with some regularity (see Table 4). Most are working in some sort of activity every day. This is much higher than the national average of 46% of all Americans doing the same. This is a dramatic contradiction to what society presumes, which is most likely based on appearances and prejudice.

Is the difference how folks with Down syndrome view activity or is it in the type of activity? The answer may be both. If you have ever attended a convention that includes people with Down syndrome of all ages, you already know the most talked about events of the weekend are the dances. Everyone has fun and everyone dances until they can barely stand. There is dancing of all kinds: ballroom dancing, swing dancing, rock-and-roll type dancing, and even the bunny hop. Partners are not required. Knowing this, we were not surprised that the favorite activity chosen in the survey was dancing, closely followed by swimming and walking.

In addition, we asked them to tell us what they found the most difficult about exercise. The clear answer was “finding someone to do something with.” This answer is consistent with a study investigating Body Mass Index (BMI) in adults with Down syndrome. That study found adults with Down syndrome have a lower BMI, which is a sign of lower risk for weight-related problems, when they have friends to do things with regardless of the total amount of exercise each week. Those who did not have meaningful friendships had a higher BMI. In other words, friendships had a greater impact on BMI for the adults with Down syndrome in this study than how long or how often they exercised. Those with friends had lower BMI than those who did not. This means that for any activity or exercise program to be effective for your child of any age, she needs to have a friend who is also involved in the activity. The friendships discussed in the above study may not be limited to those involved in activities, though. It may be just as effective to have a full circle of friends outside of physical activity.

Putting It All Together

Feeling lost with all this information? Anyone would. It’s not easy to see what this might mean to you or your child. As a dietitian, these are questions I ask anyone when I first begin to work with them. It is important to have an idea of what things impact overall health for each person. The answers our participants provided give me an idea of some of the habits and attitudes adults with Down syndrome have in common regarding eating and activity. Here’s what I see:

<table>
<thead>
<tr>
<th>Exercise Frequency</th>
<th>Percent Exercising</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every Day</td>
<td>60</td>
</tr>
</tbody>
</table>

Table 4: Exercise
Healthy Lifestyles in Adults with Down Syndrome:
A Survey

- The average adult with Down syndrome eats five to six times each day, maybe more. When they sit down to a meal (breakfast, lunch, dinner), they are making an effort to eat a variety of foods. However, when they have a snack they are eating foods that are most likely high in calories and low in nutrition as most included a food from the “sometimes” group and one other food group. In both cases, adults with Down syndrome may be eating more calories at meals and snacks than are burned in a day. It would be very difficult to restrain food portions to a reasonable number of calories when eating five or six times a day.

- Adults with Down syndrome are more active than the average American. Additionally, the key motivating factors are very different from what most parents will consider: weight management. Folks with Down syndrome are more motivated to participate in an exercise or activity if it is done with a friend or group of friends. The social aspect to the exercise activity is more important than health or weight management. This means the definition of exercise or activity may be different than what parents see as activity. As parents, we may need to consider a broader range of activities that meet our children’s social needs as well. Some ideas include walking clubs in the neighborhood, at work, or at school; walking the neighbor’s dog; raking a neighbor’s leaves; walking with a friend to the store; joining an aerobics class; water aerobics; special Olympic events; going to a local dance; dance classes; and so on.

Where Do We Go From Here?
First, consider what habits you are encouraging for your child. Does your family regularly snack? If so, how do you choose what you eat for snacks? Some things to consider for your family are:

- Use snacks appropriately. Use this as a general guideline for the need for snacks: If there will be more than 5 hours between meals (except the night hours), then a snack is definitely needed. If not, why is your family having a snack? If it is a habit, such as eating while watching evening television, consider changing what is available to snack on during that time. However, if behavior in the workplace, at home, or at school changes in a negative way, try changing the snack rather than eliminating it.

- Consider the quality of snacks. As a family, brainstorm a list of snacks to have available. Encourage everyone, including yourself, to eat a balanced snack rather
than one from the “sometimes” group each time. For instance:

- Use water (bottled or sparkling) rather than sodas.
- Use smaller portions of the same snack foods.
- Try popcorn cakes or other lower fat crunchy foods.
- Try offering specially packaged vegetables: snow peas, baby carrots, broccoli florets, and so on.
- Try dried fruits in small portions. Dried pineapple is a favorite for many.
- Perhaps go for a short walk before sitting down to a snack.
- Maybe a snack isn’t necessary.

The second area to consider is activity. What types of activities are you encouraging your child to participate in? Do they feel comfortable doing them? Do they have friends who are involved in the activity? For teens and adults, a low impact aerobic class may be a good option. Check into local health clubs and community centers for a list of classes that are available. Visit the center to discuss your child’s needs before you go as some teachers use dance steps that are less complicated than others.

Last, and most important, when it comes to anything we as parents want to encourage our children with Down syndrome to do regarding lifestyle choices, we must remember, “parents [and professionals] can encourage us, give us advice, and remind us now and then, but they can’t make us do anything. Only we can.”

Partnering:
Lessons Learned Conducting Research

by Mia Peterson

My name is Mia Peterson, co-researcher to a project we called, “Healthy Lifestyles in Adults with Down Syndrome: What Do We Know?” Let me begin by telling you a story that describes one reason this project is important to me.

If you have a cookie and I have a cookie that is exactly like yours, it will do different things in our body when we eat it. When you eat the cookie, you will burn the calories from the cookie faster than I do. The reason is my metabolism is slower than the metabolism of people who do not have Down syndrome.

I have learned a lot about listening to my body and my own health doing this project, but I have learned a lot from other people with Down syndrome, too. A lot of us don’t get enough exercise or have healthy habits in the way we eat or sleep. We don’t always have a good balance in what we do everyday. For a long time people made decisions about people with disabilities by discussing what they think and do for themselves. But they forgot to ask us! I hear this when I talk to people filling out the survey and by reading their answers.

Sometimes our parents want us to do the same things as them. They do this because
they love us. But it is not about our parents. It’s about what we know and do for ourselves. It is a little tricky. We, as young adults, have to show our parents what we know by listening to ourselves and choosing things that will make us happy, and healthy. Our parents like to see us feeling good and feeling strong and especially feeling healthy. If we listen to our bodies and do things our own way that show we are happy, strong, and healthy, our parents will probably STOP discussing it. That is why I think this research is important. It helps us tell parents what we, adults with Down syndrome, know about being healthy and reminds us what we need to do in our habits.

Working with my fellow teens and adults I learned that listening to understand what they have to say is very important. This was the hardest when I gave the survey to a group. I felt like people wanted to agree with each other instead of filling in their own answers. A lot of times we gave the survey together: one person would read the question and the other would explain what it meant by using pictures or giving examples. It was hard to make it fun, but we wanted people not to be stressed about filling out the survey. It was important to tell them why we asked the questions because it made them more serious about answering them. This research is important.

For me, there are two things that are the best about doing the survey. One was finding out what someone had to say when they had trouble telling us. It was fun finding out how much a person knows and respecting their answer. The other was learning things like my cookie story.

Mostly, doing this helps me remember that people will always give us advice about what to do so we don’t hurt our bodies. Even though we all make mistakes that doesn’t make us failures. When I get advice I forget to follow it sometimes. I also know that it doesn’t help people to believe I am smart about my body if I don’t act like it. The same is true for everyone. Do it for yourself. Challenge yourself and be an example for others to see. We all have goals. What are yours? Run a 5K, run a marathon, swim 5 miles! Whatever you decide to do, make it count! Let everyone see how beautiful you are and never give up on yourself. I know if I can do it, you can do it too.

Mia Peterson works for The Down Syndrome Association of Greater Cincinnati, serves on the Board of Directors for the National Down Syndrome Society, and is the first president of People First Ohio. She resides in Cincinnati, Ohio.
Working on the survey, “Healthy Lifestyles in Adults with Down Syndrome: What Do We Know?” with Mia has been a thought-provoking experience. I expected to learn many things through this project, some related to health and some related to working with adults with Down syndrome. There were lessons in both areas, but I greatly underestimated their quality.

Mia is an invigorating co-worker. She is enthusiastic about the projects she is involved with and has a thirst for learning that has yet to be quenched. I thought it might be difficult for us to accomplish this survey because Mia lives in Cincinnati, Ohio and I live in Portland, Oregon. We spent some time together talking about nutrition and healthy lifestyles before we wrote the survey. Our discussions were mostly about the research that already exists about people with Down syndrome regarding metabolism, exercise, and lifestyle.

In the beginning, I worried that I wasn’t explaining things in a way that Mia would understand. For instance, research about metabolism in children with Down syndrome found there is up to a 15% decrease in basal metabolic rate. This means a child with Down syndrome who is the same height, weight, and age as a child without Down syndrome will use up to 15% fewer calories when she is completely at rest—asleep—than the child without Down syndrome. To calculate calorie needs, a mathematical equation is used to first determine basal energy expenditure (the amount burned while asleep). This number is then multiplied by an activity factor that represents the level and intensity of calories a child burns throughout the day from her activities. The reduction in calories is taken before the additional calories of activity are added to overall energy needs. This same research suggests the two children burn the same number calories in their play and movements through the day. In other words, Mia burns the same number of calories as anyone else when she does aerobics or goes for a walk, but when she is sleeping, she burns fewer calories than someone without Down syndrome. I thought this might be tough to understand, so I told her “the cookie story” (see page 8).

I’ve heard “the cookie story” at least a hundred times since I told it to her almost three years ago. She tells it whenever she wants to explain that there are differences in how her body and my body handle food. While I don’t know if Mia understands the intricate details of how her metabolism is different than mine, she understands the end result: It takes her longer to burn the calories from the cookie than it does for me. Which, in the end, is the important part when it comes to everyday living. After that, I didn’t worry about how difficult it might be to include Mia in this work, but I admonished myself for underestimating her ability to learn.

Mia is my equal, if not greater, partner in this project. To compensate for our geographical distance, we communicated through e-mail. We generated lists of what we wanted to learn from doing the survey.
and chose the most important ones. The files went back and forth until we agreed that we liked how it looked and read. We then shared it with a small group of Mia’s friends, our field testers, and asked them to tell us what they thought. We received some interesting replies:

- Needs a cover page.
- Should ask about sleep.
- Combine questions 14 and 15.
- Make one with pictures and one without.

From all the comments the most interesting was about the picture symbols. One person felt there should be a survey for people who can read and one for those who cannot. Mia and I explained to the group the survey needed to include the picture symbols with the words. We didn’t want to pass them out asking, “Can you read?” Once I explained how difficult it would be to pass out two different surveys and what it would sound like, it was no longer a concern. Our field testers were unanimous: no one should feel bad if they can’t read.

Even with this visual support added, administering the survey was a challenge. With about 50 adults with Down syndrome in the room, we had 5 volunteers to assist besides Mia and me. Mia read the questions one at a time to the group, while the volunteers and I ran from row to row to interpret when necessary. I was pleased to see participants who had finished their question turn to their neighbor to help at times. Even so, at any given moment there were 10 different conversations going on. Some were about the survey, but most were not. More volunteers would have been helpful.

Taking time to be sure each person understood what the question meant was essential. If the information we obtained was not from the perspective of adults with Down syndrome, the project would be useless. Without leading them into an answer, we had to define things. It was important to record the thoughts of the participants, not the volunteers. Watching everyone work together, self-advocates and volunteers, was like watching a dance. Survey participants were intent on speaking their minds and having fun, while volunteers were carefully, attentively listening.

Once we had our data, Mia and I had to sit down and talk about what it said. This has not been easy for either of us. I wanted to be sure the results were considered legitimate and not a “token project” because it included a person with Down syndrome. Mia worked hard finding people to do the survey. Now it was my turn to find ways to present the results of her work so it was valuable to everyone: families, self-advocates, and professionals. Mia and I believe there are a couple of important messages. Some of these are described in the article, “Healthy Lifestyles in Adults with Down Syndrome: A Survey” on page 1.

Sample Survey Pages

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**Partnering:**
Lessons Learned Working with an Adult with Down Syndrome

*Continued on page 12*
In addition, I learned how important it is to include people with Down syndrome directly in projects like this. The adults we spoke to were eager to share and learn from what everyone said—especially with Mia explaining the opportunity to them. I am not convinced they would be as excited if I did this alone. Mia learned what it means to make adaptations “on the fly” for her peers. When I talk to her these days, it seems she has become acutely aware of how hard it is to find people who will listen to what a self-advocate has to say rather than lead them into saying what they (the support person) want to hear. She is very skilled at doing this with her friends and acquaintances.

We both kept our lessons close to our hearts as we wrote a manuscript, which we have submitted for publication in *The Down Syndrome Quarterly*. The required writing style was difficult and unfamiliar to me. We decided the easiest way to do this was to use worksheets. I sent Mia questions, basically the 5 W’s of writing an article or story, which she answered over email. From them, I gathered quotes and the general direction for the manuscript. We have also used this method for writing the articles published in this issue. This only works for us because Mia knows she can ask questions and tell me what isn’t quite right, which she often does. If I rearrange things or use my own words rather than hers, it is a dishonest representation of her thoughts.

As a mother of a boy with autism and Down syndrome, I cherish this experience with Mia. I walk away knowing there are many, many untapped areas of interest and potential for adults with Down syndrome. And I remain committed to sharing my life in ways that are as fun and challenging to me as for those I work with. I have also learned something very important: *Pizza is the* favorite food. What more could I ask for?

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**Top Ten Favorite Foods**

1. Pizza  
2. Burgers  
3. Chicken  
4. Spaghetti  
5. Hot Dogs  
6. Ice Cream  
7. French Fries  
8. Salad  
9. Fish  
10. Chips

PCS Symbols shown in sample survey pages are used with permission of Mayer-Johnson, Co. © copyright 1981-2001.
Being a part of the “Youth and Adult” portion of the national conferences isn’t a new experience for me. The first conference activity I participated in was with the Youth and Adults. I can say without hesitating that it is in these workshops and activities that I have learned the most. I have experimented with different topics, methods, and activities. One thing is perfectly clear: as long as you are able to laugh at yourself, you will be an effective presenter.

Although national conferences attract a limited audience it is still a great way to make a difference for teens and adults with Down syndrome. Think about it. There are two national conferences with Youth and Adult sections each year: The National Down Syndrome Congress and The National Down Syndrome Society. Together, approximately 200 youth and adults with Down syndrome participate each year. Additionally, there are local conferences that include adults with Down syndrome such as NADS in Chicago. And if you have a desire to see how they do things in Canada, there are two groups who have conferences with offerings for adults with Down syndrome. Opportunities do exist, and you don’t need experience to make a difference.

Volunteering to present workshops for the youth and adults is an opportunity for people to offer topics to those attending the conference that may not have been available when they were in school. This is a great way to enhance the skills of self-advocates already out on their own. The most important element to success is to have a small, specific educational goal, an engaging and fun way to explore the topic in an interactive manner, and the ability to laugh. If there’s no laughter, they won’t remember it in the morning.

Over the years I’ve learned adults with Down syndrome are the most forgiving group to work with. They honestly don’t care if my hair is a mess, if I have slides, or if I stumble over my words. What this audience cares about the most is whether or not I know how to have fun. I can’t tell you how many people leave with something they will do differently when they get home, but if they have a good time doing it, the chances are better than if they don’t.

It’s not necessary to lead a workshop, nor do you have to dedicate a lot of time. You can volunteer for an hour or for the entire weekend. It’s a great experience for anyone: parent, sister, brother, aunt, uncle, grandparent, college student, or college professor.

Here is the information on the conferences coming up this year. Why not give the conference coordinator a call to see how you can help with the Youth and Adult Conference?

**National Down Syndrome Society**
July 6-8, 2001
Westin Hotel
San Diego, California
Contact: Rob Bonney
rbonney@ndss.org
800-221-4602
www.ndss.org

**National Down Syndrome Congress**
September 21-23, 2001
Denver Hyatt Regency Tech Center
Denver, Colorado
Contact: Judy Martz
Email: NDSCcenter@aol.com
800-232-NDSC
www.ndsccenter.org
I n the last eleven years, I have read dozens of books about children with special needs. Books about medical concerns, education strategies, curricular adaptation, therapies, positive behavior support, family dynamics, siblings, and countless personal accounts written by loving, devoted mothers and fathers whose lives are irrevocably changed by their sons and daughters. In the last few years, I lost interest in books detailing the impact a child with a disability has on a person’s life. I’m not sure why. Maybe it’s because I cannot bear to hear the anger, hurt, and confusion one more time. Maybe it’s because I’ve grown to accept both my children, with all their warts, just as they are. Maybe it’s because I don’t want someone to provide me with statements about my son’s value or significance to the world. Maybe it’s because I am looking for something more tangible for his education. Or maybe it’s because I’m just tired of it all. I don’t know.

Whatever the reason, when I began reading Jeanne McDermott’s story of her son, Nathaniel, who has Apert Syndrome, I thought I would struggle to finish. I was wrong. In her book, Babyface: A Story of Heart and Bones, McDermott shares her thoughts in a quietly inviting way. She shares her reflections about the issues all parents of children with disabilities confront—fear, staring, “helpful” comments, early intervention, and being different—without anger or bitterness. She uses comparisons to history, science, and everyday occurrences to analyze what she is experiencing.

"I force myself to take Torrey to the playground every day," Cindy said as we loaded the boys in the swings and pushed them until they soared through the blue sky. Torrey was her first and only child. "Why?" I asked.

"I wouldn’t go otherwise. I hate the staring," she said. "How do you do it?"

At the moment I felt a sweet liberation because two “abnormal” kids in public corrupted the whole idea of normality. I didn’t respond at first, just slowed the swing down. It seemed like a waste of energy to fight the staring, when, after all, I did it myself.

But the visual loitering was no longer as painful as it had once been. The hurt had first diminished when an athlete scheduled to race in the Boston Marathon stayed at our house. Our friend Alice, who was filming the marathon for a short documentary, asked if we could put Craig Blanchette up for the night. Nike sponsored Craig and featured him in a commercial, lunging for a squash shot, chasing a rebound, zooming around a bicycle track, just doing it—but in a wheelchair. Actually, Craig ambulated whatever way he wished—on stumps, prosthesis, in a chair. Twenty-two years earlier, he had been born without legs.

In the morning, Craig thumped out of the guest room, dressed for the day’s speed trials in a warm-up suit whose pant legs trailed behind like the train of a bridal gown. Instead of being six feet tall as he had been the night before, he was shorter than Jeremy. Nathaniel beamed at Craig, who was digging into his official pre-race breakfast, a large bowl of unsweetened Cheerios and skim milk. Craig smiled back, looking at Nathaniel’s head, the rail-


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road track scar, mitten fingers, with the boldest, longest, hardest, and at the same time, the least stingless stare I had yet encountered. Craig demonstrated that, in its pure uncontaminated form, staring is an utterly harmless but essential act, nothing more than the time required by the brain to process what the eyes have seen.

People need to stare at the unexpected and experience it. Wallace Stegner once wrote that when the first European settlers came to the rim of the Grand Canyon, nothing in their experience prepared them for its utter vastness. Its scale was so beyond their norm that they had no place in the mental circuitry for comprehending it. They did the logical thing and denied its size. Only when they actually hiked down to the bottom did they realize.

The face, like the Grand Canyon, is a natural wonder. But uncommon faces have, by definition, landmarks that fall outside the accustomed parameters. Those whose perceptions have been trained on one landscape initially have a hard time seeing a person with a “different” face. The uncommon face can look alien, even ugly at first until the viewer experiences the person and that alters something deeper in the viewer’s psyche and soul.

As she shares, McDermott reminds us children with disabilities and their families are more like others than not. These reminders are offered with a peaceful, eloquent grace rather than scolding. They are laced with depth and careful consideration, rather than quick or superficial detail. Her reflections are easy to take in and though she never asks, they compel us to search our hearts.

There were many times McDermott shared experiences that I hope I never encounter: delicate cranial surgeries and years of less dangerous cosmetic surgery to rebuild Nathaniel’s skull, face, and fingers. But some of her experiences I understand too well such as wondering if my son will always stand out even from other children with Down syndrome because of his autism.

In the relative quiet on the adults’ side of the divider, the fatigue of the last six months mixed with the glow of relief that the wait for Early Intervention had finally ended, that help, even in the form of slightly burnt coffee, was here. At the social worker’s request, the mothers seated around the round table introduced themselves. The fashionably dressed woman with an expensive haircut said that her baby—the girl I had seen scowling—had Down syndrome. Next to her, the heavyset woman who had the boy who wore glasses—also Down syndrome. The quiet woman was the mother of the scooter with, no surprise, Down syndrome.

Of all “birth defects,” Down syndrome qualified as one of the most common. Tomes had been penned, careers built, a prime-time TV show launched, and our HMO had so many families that it had started a monthly support group.

It was my turn. “My name is Jeanne and my son Nathaniel does not have Down syndrome.” They laughed good-humoredly, mocking the sense of placelessness that comes when a child’s development is not sheltered under the great umbrella of the bell curve. In the big world and even in this little red schoolhouse, Nathaniel was not an average kid but an outlier, at the map’s edge where ships fall off the flat Earth and dragons roam. Suddenly I wished for a child with Down syndrome so he would not be peerless, in a class all by himself.

While McDermott queries her son’s potential isolation, she does not linger over it or allow her worry to invade her joy in him.

Each chapter begins with a short paragraph written by Nathaniel. They are clearly the thoughts of a young boy and add delight to the book. They are printed in his handwriting adding another dimension to our image of him. McDermott is a mother who is madly in love with her son, and it shows. In fact, Babyface is less a story about a family of a child with Apert Syndrome than a story of a mother loving her children and experiencing life beside them.

Reading Babyface left me with a warm feeling about life and my own family. Maybe it was McDermott’s understanding of the isolation I feel and fear for my son. Maybe I was ready to read a story of reflection. Maybe it was her eloquent writing style. Or maybe it was simply a great book.
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