

# Disability Solutions

A resource for families and others interested in Down syndrome and related disabilities.

November/December, 1997

Volume 2, Issue 4

## In This Issue:

Including Self-Advocates in Community Leadership	1
Letter from the Editor: The Art of Believing	2
Resources: Including Self-Advocates in Leadership Roles	9
Weight Management in Down Syndrome: The Early Childhood Years	10
Resources: Nutrition Education for Young Children	13
A New Team Member: Gretchen Koettters	13
Reviews: Radiance Descending	14
Laying Community Foundations	15
Share Your Thoughts	16

## Focus: Self-Advocates as Leaders

# Including Self-Advocates in Community Leadership

by Essie Pederson, M.Ed.

It's a common scene: parents meet with well-meaning professionals to discuss the Individualized Education Plan for their child with Down syndrome. In the weeks prior to the meeting, they have read reports from the group they are about to meet. They have discussed between them ideas they have for their child's education. When they arrive, they are met by what feels like a gaggle of professionals with date books and reports piled in front of them. The meeting begins and ends with little input from the parents. They leave bewildered, confused, and disoriented, feeling they have failed somehow. Later, feelings of frustration build because these parents desired to be a part of a team that will shape their child's education, but

were not. Somehow the language used became distorted, the environment overwhelming, and they were paralyzed. Someone else, at least for the moment, holds the control to their child's education.

Similarly, Mary, an adult with Down syndrome, has been asked to serve on the board of directors to a local advocacy group. Mary has been active and effective with her local People First group and is excited about the opportunity. She has ideas of how this organization can advocate better for her peers, and opportunities to involve more people with developmental disabilities to create an inclusive, diverse community. At the meeting, however, she is overwhelmed by the

Continued on page 3

# Disability Solutions

ISSN:  
1087-0520

A  
resource for  
families  
and others  
interested in  
Down syndrome  
and related  
disabilities

*Disability Solutions* is published 6 times yearly by The Enoch-Gelbard Foundation, a nonprofit, independent, private foundation. If you would like to continue to receive this free publication or stop receiving it, please write to the publication address.

Readers are welcome to submit articles, reviews, letters to the editor, photographs, or commentary to the publication address. Please include your name, address, and phone number with your submission. All submissions will be reviewed and edited for content and style.

No contribution or subscription is required to receive *Disability Solutions*. If you would like to help with the cost, you may send a tax deductible contribution to The Enoch-Gelbard Foundation at the publication address.

Copyright © 1997 *Disability Solutions*. You may reprint all or part of this publication for a newsletter or to share. When you do, please include the *author's name* and list *Disability Solutions* as the source. When possible, it would be nice to see a copy of the article reprinted. You can download back issues of *Disability Solutions* free from our website (see below), or request a hard copy at a cost of \$2.50.

Opinions and information published in *Disability Solutions* are not necessarily those of The Enoch-Gelbard Foundation.

❖ ❖ ❖

Send all correspondence to:

*Disability Solutions*  
9220 S.W. Barbur Blvd. #119-179  
Portland, OR 97219-5428

503/244-7662  
503/246-3869 (fax)  
email: [dsolns@teleport.com](mailto:dsolns@teleport.com)  
WWW: <http://www.teleport.com/~dsolns>

Editor: Joan E. Medlen, R.D.

from the editor:

## The Art of Believing

To fully understand the concept of TEAM (Together Everyone Achieves More), you really need to see it in action. In my opinion, one of the best places to do this is in the first floor of a home in the Hyde Park area of Cincinnati, Ohio. There you will find *Capabilities Unlimited, Inc.*

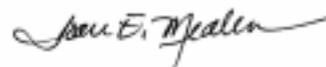
At first glance, it looks like many home offices. It is full of desks, computers, file cabinets and so on. However, once CUI starts moving, life begins to change. At one desk, Mitchell Levitz is on the telephone with one of the reporters for *The Community Advocacy Press* (see page 9). At another, Mia Peterson is typing up new text for the CUI Web Page (soon to be released). At yet another desk, you will find Gretchen Koeters (see page 13) diligently typing in new subscribers to *Disability Solutions* and *The Community Advocacy Press*. Later in the afternoon, after working at the local YMCA, Katy Maly joins the group to work on the newsletter for Cincinnati's *Inclusion Network*. Working from their homes across the United States are *Community Advocacy Press* Co-Editors Tia Nelis and Michelle Pettit and the group of reporters all the editors (Mitch, Mia, Tia, and Michelle) coordinate. Also sharing the office are Ruth Sumner, Sandy Keene, and Essie Pederson—the only ones without Down syndrome or a related disability. It is one busy place. More than that, though, CUI is where I learned what it meant to believe in abilities.

CUI is the realization of a dream for Essie. Here, she puts her belief in self-advocates and their abilities into practice. One of 7 children, Essie has an older brother with Down syndrome. Though I've never asked, I suspect that Jim was one of the reasons Essie studied special education. Yet Essie is far from a "special educator." A look at her work experiences tells you that: Executive Director of CUI, a founding member of Cincinnati's Inclusion Network, Researcher for the RRTC Institute on Aging with Mental Retardation, Advisor to Self Advocates Becoming Empowered, and, well, "Mom" to a group of self-advocates who have benefited from her talent.

What talent? That is hard to explain. Essie does what we parents dream of for our children: she believes in them, she builds on their abilities, and all she asks in return is that they be willing to work hard. And they deliver. I've asked her where she learned to do this a few times. She tells me that she has learned by doing and listening to the self-advocates she works with.

For the last four years, Essie has been conducting research with self-advocates involved in leadership roles, their support people, and the boards and committees they work with. In the process, she has been able to create systems that make including a person with a developmental disability on the board of a community organization look easy if they are willing make a few changes. Through this research, she has also found that self-advocates who wish to become participating leaders in community organizations need to develop the same types of leadership skills anyone else does. As a result, she is working with *Leadership Today* from Alberta, Canada to create the first *Leadership Institute* for self-advocates. This Institute will be the first ever to provide the *Covey Leadership Training* to self-advocates. From here, the possibilities overwhelm me.

If you have been interested in involving self-advocates or improving the involvement of self-advocates in an organization you work with, you will find the information you need to get started in this issue of *Disability Solutions*. Where do you start? You start by believing.



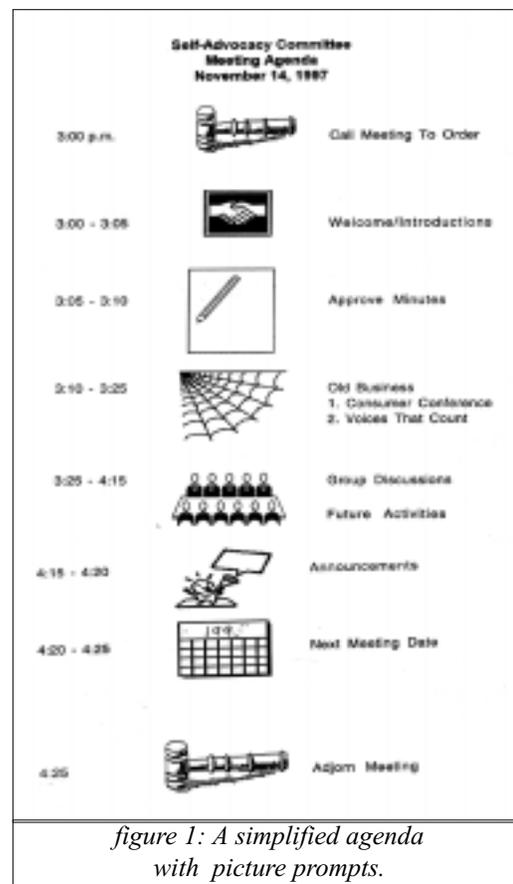
# Including Self-Advocates in Community Leadership

↪ Continued from page 1

language, the number of people without disabilities, and the speed at which the meeting progresses. She feels ineffective, alone, and, to some extent, she is scared. The group, although they have included a person with a developmental disability, has missed an opportunity for understanding and growth for the organization. Mary leaves the meeting with a sense of failure.

Too often, individuals with disabilities and their families find themselves seeking support or service from agencies that are run by well-meaning boards and committees that are devoid of the perspective of those they serve: persons with developmental disabilities. However, with the increased growth of self-advocacy skills among persons with developmental disabilities, self-advocates have become empowered to speak out and learn to make decisions about their own life circumstances and futures. They are seeking and assuming leadership roles in their communities. These roles include volunteering on boards and committees of non-profit organizations such as local Arcs, YMCAs, Lions Clubs, Rotary, and advocacy organizations. The number of self-advocates in leadership roles is not large, but the desire by them to be involved is increasing. Self-advocates are becoming more aware of decision-making groups. They are learning about the goals and missions of organizations so they can choose to be involved with the groups they want to be a part of based on the group's values and beliefs. This is the first step to becoming a leader: understanding your personal values and working to improve your own community based on them. Additionally, more organizations are seeking the involvement of self-advocates in their decision-making groups. Professionals and policy makers endorse the participation of self-advocates and family members, but often are uncomfortable with the idea or unwilling to adjust the way the organization runs meetings or makes decisions so that everyone can be included. For example, the addition of pictures to an agenda helps self-advocates understand the sequence of the meeting more quickly (figure 1). For those who have not had the opportunity to learn to read, these

pictures are essential. However, the process of creating a simplified agenda with picture prompts takes additional time. The extra time involved is the step that nondisabled members often find difficult to accommodate. Understanding and accepting the wide range of abilities and experiences of individuals (self-advocates and parents) continues to be a challenge for decision-making groups.



For change to occur, everyone must be willing to involve all members of the group. New members with and without disabilities often have the feelings of uncertainty when they join a new decision-making group. Without a concentrated effort to welcome self-advocates and parents, both will continue to feel excluded from the group just as the parents in the IEP meeting

Continued on page 4 ↪

# Including Self-Advocates in Community Leadership

↪ Continued from page 3

and Mary felt. For people to work together in the best interest of a cause or group, three essential elements must be present:

- ❖ Adequate preparation and training of persons with developmental disabilities about their new leadership role,
- ❖ Adequate, ongoing support for self-advocates in the leadership role, and
- ❖ Adequate training of professionals and other committee members (including parents) regarding sharing leadership roles.

## Becoming a Leader

Becoming a leader is a process. Although it is often thought that people are born leaders and followers, most leaders develop their leadership skills through life experiences that come with support from family and friends. Additionally, many people who are seen as followers become dynamic leaders once they are given the support and opportunity they need. The basic skills needed to be a leader rather than a follower in-

clude voicing an opinion and choosing a direction. For people with disabilities, these skills are called “self-advocacy” (speaking for oneself) and “self-determination” (making the decisions that control one’s life).

Generally, adults with disabilities have been denied opportunities to learn to work in a group and develop leadership skills such as student government, team sports, and school clubs. As a result, adults with disabilities may be hesitant to seek opportunities to participate in committees, community groups, and organizations. However, once an interest is known this hesitancy is overcome through training and mentoring experiences regarding how to be a participating member of a group and leadership team. Training and mentoring begins by teaching the mechanics of how a meeting is run, understanding the vision and mission of a group, and each member’s role in a meeting. Self-advocates who have experience with meetings and community groups can mentor less-experienced peers by sharing what they have learned. These mentors can also assist with some social concerns such as appearance, notification of tardiness or absence, transportation, and overall coaching. The selected support person or a fellow member of the board or committee can address the specific processes the group uses, such as who to call for information and how to use *Robert’s Rules of Order*.

In addition to training and mentoring, self-advocates who have become local, state, and national leaders work hard to help new members in self-advocacy organizations become effective leaders. The first skill “new” self-advocates are introduced to is “using their voice.” This is done through “open mike” time at meetings. Each person at the meeting is given a designated amount of time at the microphone to talk about anything they want. The purpose is to build self-confidence when sharing thoughts and opinions. Gradually the concept of working as a TEAM (Together Everyone Achieves More) is introduced. Through practice and mentoring, “new” self-advocates



*Susan Scott of Louisville, Kentucky shares information about teaching self-advocates to be leaders.*



# Including Self-Advocates in Community Leadership

cates learn to speak up on topics that concern the group at “open mike” time.

Experienced self-advocate leaders feel that self-advocates who want to serve on boards and committees must have diverse skills. Some are easier to learn than others. Skills that self-advocates say are very hard for them to learn include:

- ❖ Learning how to be an equal member of a group,
- ❖ Knowing what their role is in the group,
- ❖ Knowing how to lead a discussion, and
- ❖ Knowing how a committee meeting is run.

Learning to be part of a group and make decisions together takes time, practice, and a willingness to take risks. Before a self-advocate seeks a leadership role, it is best to seek opportunities to participate in a group. These opportunities are found in school clubs, housing associations, task forces, or small committees with a specific purpose (such as a zoo committee, library committee, or religious social committee), and local People First Groups. By participating in smaller groups, self-advocates can experiment and practice sharing their opinion, working with others, and evaluating the type of support they need.



*“Experienced members of committees and boards with developmental disabilities say one of the hardest things to do in a meeting is to ask questions of the group and to learn how the committee runs their meetings.”*



## Preparing Committees and Boards to Include People with Developmental Disabilities

Just as self-advocates need to prepare to be leaders, community organizations need to prepare their boards and committees for successful inclusion of people with disabilities. The uniqueness of any board or committee is the combination of the members’ life experiences and talents. Generally decision-making groups that successfully include members with developmental disabilities create an environment that encourages participation.

In large, fast-paced meetings it is easy for the person with a developmental disability to be forgotten. This makes them feel their opinion is not welcome or valued by the group. It is the responsibility of the chairperson of the meeting to ensure this does not happen. The role of the chairperson is vital to the ability of all the members to participate fully. Sometimes self-advocates do not raise their hand when they have something to say. The chairperson must remember to look for other clues that the self-advocate would like to share something. Self-advocates are not typically intimidated if the chairperson invites them to comment. Other members of the group will learn how to encourage participation of all members by watching an effective chairperson.

Another area to evaluate is alternative leadership methods. For instance, self-advocates may benefit greatly from opportunities such as *supported leadership* or *co-leadership*.

**Supported leadership** is created by having a member in a leadership role (an officer position or committee chair) select a partner to help them with their duties. The partner offers assistance with meeting mechanics or pre-meeting sessions to discuss issues that will be presented. For example, the secretary of the group must take minutes. What better way to learn about being

*Continued on page 6* ↪

# Including Self-Advocates in Community Leadership

↪ Continued from page 5

secretary than to learn to take minutes? This may require some adaptation (see figure 2), but is helpful to both the current secretary and the self-advocate who wishes to learn this skill.

figure 2: An outline designed to assist in taking meeting minutes.

**Co-leadership** is when two people assume the responsibilities normally done by a single position. This creates a partnership between two members of the group and lessens the fear related to a new role or responsibility.

As committees and boards include more persons with disabilities, they must also consider the financial impact of participation for self-advocates. It might be necessary to pay for an experienced support person, training for a new support person, or for time for the support person and self-advocate to develop a system that will enable the self-advocate to work effectively with the organization (see “The Power of Support”). The

cost of materials for individualized support systems (file folders, boxes, color-coded labels) should be the responsibility of the group. It is also important to determine if the self-advocate will lose money as a result of participating in the group by needing time away from a job or having to pay transportation fees. Addressing these financial considerations and providing individualized support have proven to be important to ensure active, meaningful participation by self-advocates.

Most committee members feel that ideas that are raised by a person with developmental disabilities are treated with the same importance as those raised by other members of the group. They often feel that having a person with a disability included in the group is essential for understanding the problems and desires of people with developmental disabilities. That understanding has a positive effect on their ability to carry out the overall mission as a group and improve the community for everyone.

## The Power of Support

Preparation by the board is an important part of success for persons with developmental disabilities. However, once a self-advocate is a member of a board or committee, it is important they are supported in their role. The quality of the support and the skills of a support person directly affect the ability of the self-advocate to participate meaningfully. Proper support prevents self-advocates from being a token member.

Support can mean many different things. Overall, it is the process, discussions, or adaptations that bridge gaps between abilities. The most important aspect of any support is that it meets the needs of the individual. Too much support is insulting and prevents participation. Too little support also prevents participation: a member of the group does not have what they need to fully understand or contribute to the work

↪

# Including Self-Advocates in Community Leadership

being done. Some examples of ways committees and boards can adapt their procedures to support the needs of self-advocates include:

- ❖ **Providing appropriately written materials.** This may mean adapting language so it is easy to understand, or making sure the material is presented on paper that provides a high contrast for those with visual impairments.
- ❖ **Organizing handout topics by color.** This will help self-advocates find information easily at the meeting and for reference later.
- ❖ **Providing information well in advance.** Providing information in advance gives self-advocates time to read it and ask questions. This allows them to understand the topic by asking questions. They will be able spend their time participating in the discussion at the meeting rather than trying to understand the topic.
- ❖ **Allowing time for discussion in a way that is open to all questions.** Experienced members of committees and boards with developmental disabilities say one of the hardest things to do in a meeting is to ask questions of the group and to learn how the committee runs their meetings. A good policy is: "There are no dumb questions."

Providing organizational support allows the self-advocate to concentrate on more difficult tasks during meetings and participate in discussions.

## The Support Person

The role of the support person is very important. The support person selected by the self-advocate must believe that people with disabilities want to help and can make decisions that affect the organization and community. They must present information in a manner that allows the self-advocate to understand the facts which they will use to make their own decision. It is

essential that the person providing support presents information completely free of bias.

Self-advocates must be involved in the selection of their support person. This may be someone who is already associated with the group (either as a staff person or a board member), or it may be a family member or friend from the community. Being selected as the person to provide support to a self-advocate must not be taken lightly. As people with developmental disabilities become more sophisticated advocates, they are more selective regarding who they choose to support them. A support person can be anyone, but there are some basic principles and values that self-advocates feel very strongly about.

Self-advocates feel support people must:

- ❖ Treat self-advocates with respect
- ❖ Believe that self-advocates can and want to be good leaders
- ❖ Take time to build a trusting relationship by spending time with the self-advocate,
- ❖ Listen carefully,
- ❖ Know how much support to give and when it is needed,
- ❖ Be honest,
- ❖ Be nonjudgmental,
- ❖ Be able to explain issues by providing facts without sharing their opinion, and
- ❖ Believe in the right of people with disabilities to live in and be a part of their communities.

When the self-advocate and the support person have a relationship that includes these values and goals, then the self-advocate will be able to participate effectively, meaningfully, and genuinely.

Many people participate on various boards and committees solely as a support person to people with developmental disabilities and are experienced in this role. They have developed their skills and abilities as effective support persons by listening to self-advocates, learning from their experiences as a support person,

*Continued on page 8* ↪

# Including Self-Advocates in Community Leadership

↪ *Continued from page 7*

and talking with other support people.

People experienced in providing support say that successful leaders with developmental disabilities have some specific qualities in common. Not surprisingly, they are qualities that are important to successful leaders of all abilities such as:

- ❖ Motivation and desire to share in the common vision of the group,
- ❖ Interest in people beyond themselves,
- ❖ Assertiveness,
- ❖ Commitment to and an understanding of self-advocacy,
- ❖ Honesty,
- ❖ Self-determination,
- ❖ Eagerness to take on new challenges,
- ❖ Decision-making skills,
- ❖ Willingness to listen to and learn the facts surrounding a topic, and
- ❖ Recognition that they might receive support, but that they can also provide support to others.

## What Can Parents Do?

Many parents are involved in committees, groups, and boards in their communities. Like self-advocates, parents are trying to change the way communities view people with disabilities. They are working to make a difference through community organizations. It is important, however, to remember that the parents' view of what is important is not always shared by people with developmental disabilities. Common disagreements center around recommendations that involve taking a risk and putting the desires of the self-advocate before the desires of a parent. Examples include topics such as relationships, housing and political decisions. While advocating for programs that improve community inclusion for families of children with disabilities, parents must also support the concerns of adult self-advocates. Parents must not impede what adults

with disabilities have to say—they must augment it.

Parents can also encourage organizations to include people with developmental disabilities. For instance, ask the group if they are willing to include people with disabilities in their leadership. If they are, discuss the importance of making changes that will elicit meaningful participation from the self-advocate. If there are no self-advocates serving in leadership roles in the organization, submit the names of adults with disabilities who might be interested to the nominating committee and see what happens. However, be prepared to share why including a person with a developmental disability supports the mission of the organization. Some general reasons include:

1. Organizations serve a diverse community. People with developmental disabilities are a part of that community and have specific concerns that are important to address.
2. Including a person with a developmental disability on the board or committee enables it to represent its community more realistically.
3. More people with developmental disabilities are living in apartments, condominiums, and homes in the community than in institutions and group homes. They are becoming active members of communities by volunteering their time and talents to different agencies and groups that interest them. By doing that, self-advocates are not only a portion of the community the organization serves, but also a part of the manpower doing the work of the group.

If people with disabilities are already included in the organization's boards and committees, are they participating meaningfully? Do not rely on the perceptions of members without disabilities. Ask the self-advocate. As a fellow committee member, call the self-advocate and discuss meeting topics with them and learn their perspective. Encourage them to call you regarding future meetings. Ask them if they have the

↪

## Self-Advocates in Community Leadership

support they need to understand and provide meaningful input to the decisions of the group. Parents can learn to be effective support people for their children by supporting someone else.

Even parents who are *not* involved in committees and boards can be helpful. Look for typical, unexpected opportunities to work with self-advocates. Provide support to someone with a disability during worship services, social gatherings, or at the supermarket.

Building an inclusive community is an enormous task. Encouraging the efforts of grass-root groups such as Self Advocates Becoming Empowered, Community Partnerships, and People First Organizations are just a beginning. As community organizations begin to successfully include self-advocates on their boards and committees as partners, the needs of the community will be met more effectively. Self-advocates will be able to participate as partners in the decision-making process, which will change everyone's vision of the future.

❖ ❖ ❖

*Esther Lee Pederson, M.Ed. is the Executive Director of Capabilities Unlimited, Inc. in Cincinnati, Ohio. She serves as an advisor to Self Advocates Becoming Empowered and has led research on training self-advocates as leaders. She is the sister of Jim Poslakos, 53, who has Down syndrome.*



*Members of the Down Syndrome Association of Greater Cincinnati work together (l-r): Jane Page Steiner, Mitchell Levitz, and Mark Shannon, President.*

## Resources: Including Self-Advocates in Leadership Roles

***Self Advocates Becoming Empowered:*** A grass roots organization of local self-advocacy groups in the United States. SABE, P.O. Box 15165, Loves Park, IL 61132.

“People with disabilities across the United States have united for the purpose of forming a national self-advocacy organization. This organization is called *Self Advocates Becoming Empowered*. As we struggle through this process, it makes us stronger as a team and gives us more confidence in ourselves. This is what empowerment is all about.” SABE is the umbrella organization of most *People First* Chapters.

❖ ❖ ❖

***Voices That Count Training Package.*** Pederson, E., Chaikin, M. 1993. Item Number 100.001. Clearing House on Aging and Developmental Disabilities, RRTC on Aging with Mental Retardation, Institute on Disability and Human Development, M/C 626, 1640 W. Roosevelt Road, Chicago, IL 60608-6904. 800/996-8845. \$85.00.

*Voices That Count* is a program developed for the purpose of preparing boards and committees to include persons with disabilities.

❖ ❖ ❖

***The Community Advocacy Press.*** Feature issue on Self-Advocates in Leadership. Vol. 1, Issue 4. Published by Capabilities Unlimited, Inc., 1996. 2495 Erie Ave., Cincinnati, OH 45208. 800/871-2181. Free.

❖ ❖ ❖

***New Voices: Self-Advocacy by People with Disabilities.*** Gunnar Dybwad and Hank Bersani, Jr. Published by Brookline Books, 1996. P.O. Box 1047, Cambridge, MA 02238-1047. ISBN: 1-57129-004-4. \$29.95.

❖ ❖ ❖

# Weight Management in Down Syndrome: The Early Childhood Years

by Joan E. Medlen, R.D.

A common concern for families of children with Down syndrome is weight management. Since many people have a stereotypical opinion that people with Down syndrome are obese and Americans aren't the leanest group of people overall, this is a reasonable concern.

Preventing obesity through an active lifestyle, nutrition education, and emotional support from family and friends is the ideal answer. In a perfect world, this begins in early childhood. Great idea, but not always easy to put into practice. This is part one of a series of three articles promoting sound weight management and food-related habits in: 1) Early Childhood, 2) School Age and Adolescence, and 3) Adults: At Home and in the Community.

Recent research suggests that children with Down syndrome have a lowered resting metabolic rate than their friends who are the same age.<sup>1</sup> This means that children with Down syndrome use fewer calories when they are asleep than children the same age. This probably isn't going to change as they get older. The same research showed that children with Down syndrome are just as active as other kids their age during the course of the day. Additionally researchers found that, like other children their age, when making their food choices without adult direction, children with Down syndrome chose foods that met their overall caloric needs and were nutritionally balanced over time. However, because their overall calorie needs were lower, the total amount of food chosen was less.<sup>2</sup> This means they may be at risk for vitamin and mineral deficiencies. These deficiencies are best met by supplementing with a standard over-the-counter multivitamin rather than over-management of food choices.

Clinically, there are different categories to describe a child's weight:

- ☉ Appropriate: within 90-110% of desired weight.
- ☉ Overweight: 111-120% of desired weight.
- ☉ Obese: > 120% of desired weight.
- ☉ Morbidly Obese: > 200% of desired weight.

Chances are parents already have an idea where their child fits on the scale. If not, adapted growth charts for children are widely available in books like *Babies with Down Syndrome: A New Parent's Guide* (p. 105-108),<sup>3</sup> or off the Internet at: <http://www.growthcharts.com/charts/DS/charts.htm>. Beyond the 95<sup>th</sup> percentile, an educated guess is probably sufficient. Also, if a child is beyond the 95<sup>th</sup> percentile for weight, that does not mean they are above their desired weight. For instance a child can be off those charts for both height and weight, and not be overweight. The most important use of growth charts, especially in the younger years is to look for unexpected changes in how children are following the growth curve. An unexpected drop from over the 95<sup>th</sup> percentile to the 50<sup>th</sup> percentile is just as worrisome as an unexpected jump from the 50<sup>th</sup> percentile to the 95<sup>th</sup> percentile.

It is difficult to hear these medical categorizations attributed to a child because of the emotions we feel when we hear the terms "obese" and "morbidly obese." Remember, they are simply words that describe a condition. The real question is "What to do about it?"

As with everything, it is best to begin at the beginning. First, check with your pediatrician to eliminate



# Weight Management in Early Childhood

any medical reasons that might cause a child to be overweight such as a low thyroid level. If there are no medical concerns, then the child is usually overweight or obese because there is an imbalance to the energy equation. The amount of energy taken in is greater than the amount of energy going out. There are three ways to begin to balance this equation:

- ☉ Increase energy-out through activity,
- ☉ Decrease energy-in by limiting calories, or
- ☉ Both increase energy-out through activity and decrease energy-in by limiting calories.

A focus on calories alone is not only risky for children's health, but it focuses too heavily on food. All children have great vitamin, mineral, protein, carbohydrate, and energy needs while they are growing. Limiting calories may cause children to get too few of what they need to develop well. An abnormal focus on food can also become an obsession over time. However, increasing activity not only burns more calories, but it has long-lasting health benefits such as increased muscle tone, increased metabolism, decreased resting heart rate, better sleep, and an overall sense of well-being. Therefore, the best approach is to focus on healthy food habits to fuel the body and to promote activity.

When working with overweight children with and without Down syndrome, the goal is to maintain the child's *current* weight while they grow rather than losing pounds. As they grow, their height will be more appropriate for their weight. With this in mind, let's look at some of the more important concerns in early childhood.

Ellyn Satter, a registered dietitian and certified social worker, has done significant work and research into the food choices, attitudes, and the feeding relationship between adults and children.<sup>4</sup> Her research found that over time, when taught to listen to their body regarding hunger and food, children chose foods that met their nutritional needs for calories *and* vitamins and minerals over time, just as the children with Down syndrome did in the study discussed earlier. The trouble is, parents have preconceived ideas about what, when, and how much a child should eat. Her recom-

mendation is to define the roles of the feeding relationship in the following way:

- ☉ Adults are responsible for what is presented to eat, where it is presented, and when it is offered.
- ☉ Children are responsible for how much and even whether they eat the food offered.

The only change to this philosophy for children with Down syndrome is the addition of an over-the-counter multivitamin to accommodate for potential micronutrient deficiencies. This philosophy is particularly helpful when dealing with overweight children or changing food habits. As the "food battle" begins, parents have a rule to follow rather than a situation to control.

The early childhood years (ages 2-6) are loaded with challenges for children with Down syndrome. Some transition from being land rovers (crawling) to running (what happened to walking?). Some will transition from using sign language as their primary communication tool to verbal approximations. Others will begin working with pictures and voice output devices. Most will discover the novelty of friends, experience their first preschool, and, to most parents chagrin, discover the word "MINE!" And they will **all** learn how to wrap Mom and Dad lovingly, but deviously, around their little finger.

What a busy life they lead. Regardless of their weight, the most important thing parents can do during this time and throughout their child's life that will affect their weight is to build their self-confidence and self-esteem. For the child who is overweight, this may be the most effective tool a parent has to offer. This is when the responsibilities of the feeding relationship mentioned above become an essential tool. The responsibility of parents is to feed children lovingly and responsibly. It is not to monitor how many servings of vegetables are eaten in a day, whether or not they cleaned their plate, or if they ate brownies over at their friend's house. It is the parent's responsibility to provide a structure for food choices and eating habits that is healthy, consistent, and without judgment.

Continued on page 12 

# Weight Management in Down Syndrome: The Early Childhood Years

↪ Continued from page 11

Some ways to create this structure include:

- ⊕ Providing scheduled meal and snack times. Children need to know that food is going to be provided. If meal and snack times are inconsistent, they may hoard food at mealtime or snack time because they worry about being hungry.
- ⊕ Limit eating to a few areas of the house. This keeps everyone from eating in front of the TV, and discourages grazing (constantly eating throughout the day). It also keeps the house cleaner!
- ⊕ Let kids help prepare meals and snacks. Meal and snack preparation are the perfect time for some fun learning experiences. Cooking provides many opportunities for grouping (group foods by size, color, or type), one-to-one correspondence (setting the table), and promotes lots of fine motor activities. Picking up nuts to put in the bread machine is just as much fun as putting Fruit Loops in an egg carton and the result is bread for dinner! The more comfortable kids with Down syndrome are around food, the more competent they will be at making their own food choices later in life.
- ⊕ Do not use food as a reward. This can be difficult for parents of kids with Down syndrome because of all the people involved in their lives. Discuss how to handle rewards without using food with school personnel, private therapists, and babysitters. If a child learns that certain foods are special by receiving them as a reward for good work, they will likely carry that into their adulthood.
- ⊕ Do not offer food unnecessarily. If a child falls off the swing at the playground or has his feelings hurt by a playmate, do not comfort him with freshly baked brownies. Also, do not offer high sugar drinks like soda and juice to quench thirst when water will do. Calories add up quickly when you drink apple juice whenever you're thirsty!
- ⊕ Remember there are some situations that are nutritional "goners." Sleepovers at Grandma's house, holiday gatherings, and birthday parties are situations where every child eats differently. If a child is

behaving like all the other kids and the only reason to step in is his weight, don't do it. Let him be a child. Food is one of the great social equalizers. Kids with Down syndrome need those moments to build strong friendships that will last when they get to elementary school.

In addition to these food-related goals, it is important to be active as a family. Find games and activities that can be done as a group such as tag, going for walks, swimming, or riding trikes and bikes. Being an active family will introduce activity to a child's life as a fun thing to do. Although activity plays an important role in normal eating patterns and overall good health, at this age, it is not imperative. For the overweight child with Down syndrome, the relationships that are built in the process are the most important part of the activity. This is another way to build self-confidence and self-esteem.

The most important thing to remember is that any changes made must be gradual, long-term, and for the entire family. Young children with Down syndrome who are overweight do not need to be put on diets. They do not need their food micro-managed. They need parents who set boundaries and provide the security of structure regarding food. They will be most effective at managing their food choices and many other choices in life if they believe in themselves and their abilities. It is in these early years that we, as parents, can build a strong foundation for all the challenges that lie ahead, including food.

*Next time: The School Age Child and Adolescent: The Battle for Independence Begins.*

#### References:

1. Luke, A., Rozien, N.J., Sutton, M., Schoeller, D.A. "Energy Expenditure in Children with Down Syndrome: Correcting Metabolic Rate for Movement." *Journal of Pediatrics*, Vol. 125, 1994, 829.
2. Luke, A., Sutton, M., Schoeller, D.A., Rozien, N.J. "Nutrient Intake and Obesity in Prepubescent Children with Down Syndrome." *Journal of the American Dietetic Association* Vol.96, 1262.
3. Stray-Gunderson, K. *Babies with Down Syndrome: A New Parents Guide*. Second Edition Woodbine House, 1995.
4. Satter, E. *How to Get Your Kid to Eat But Not Too Much*. Bull Publishing, 1987.



Joan E. Medlen, R.D., is a registered dietitian and the mother of two boys, one of whom has Down syndrome. Joan is on-call at a rural hospital, consults privately, and is an editor. She resides with her family in Portland, Oregon.

## Some Fun Nutrition Books & Activities for the Early Childhood Years

*How to Get Your Kid to Eat, But Not Too Much.* Ellyn Satter, R.D., ACSW. Published by Bull Publishing Co. 1987. ISBN 0-915950-83-9. \$14.95



*Eating the Alphabet: Fruits and Vegetables from A to Z.* Lois Ehlert. Published by Harcourt Brace Jovanovich, 1989. ISBN 0-15-224435-2. \$4.95.



*Kids Cooking: A Very Slightly Messy Manual.* The Editors of Klutz Press. Published by Klutz Press, 1987. ISBN 0-932592-14-7. \$13.95.



*Learning to Set the Table Placemats: Set of 4 and Matching Dish Set: Set of 4.* A set of placemats with outlines for where dishes go in a place-setting for a meal. The Dish set exactly matches the outline on the placemats. Available from Lakeshore Learning Materials. 800/421-5354. Item #LC64, \$14.95 and Item #LDA178, \$14.95.



*Vegetable Lotto.* A wooden lotto game for various vegetables. Available from Nasco Nutrition Teaching Aids. 4825 Stoddard Rd., Modesto, CA 95356-9318. 209/545-1600. Web: <http://www.nascofa.com> email: [info@nascofa.com](mailto:info@nascofa.com). Item # SB2536HR \$13.80.



*Yummy 5-A-Day Fruit and Vegetable Game.* A Lotto Game. Available from Nasco Nutrition Teaching Aids. 4825 Stoddard Rd., Modesto, CA 95356-9318. 209/545-1600. Web: <http://www.nascofa.com> email: [info@nascofa.com](mailto:info@nascofa.com). Item #WA17205HR. \$19.00.



*Classroom Cooking From A-Z.* An entire set of activities and tools (alphabet cookie cutters, measuring cups, and so on) for edible activities that teach the alphabet. Includes a recipe box with a recipe for every letter of the alphabet. Available from Lakeshore Learning Materials. 800/421-5354. Item LC622. \$49.95.



## Our New Team Member: Gretchen Koettters!



Gretchen Koettters, Office Assistant at Capabilities Unlimited, Inc. working on the Disability Solutions mailing list.

Have you noticed our new subscription form on the back cover? We have contracted our mailing list management to Gretchen Koettters at Capabilities Unlimited, Inc. in Cincinnati, Ohio. Gretchen is a skilled Office Assistant for CUI, and also works at Children's Hospital and Medical Center doing data entry for the Radiology Lab and making new patient kits for children entering the hospital.

The subscription form is designed to support Gretchen in her work. Often readers share their copies of *Disability Solutions* with friends so they may subscribe. When possible, it would be nice if the subscription box is copied and neatly filled in with **black ink**. When subscriptions are received, they are mailed to Gretchen in Cincinnati, where she adds them to our database. One week before *Disability Solutions* is mailed, Gretchen electronically sends the updated database to *Disability Solutions* for the mailing house.

We are excited about adding Gretchen to our team. Thank you for your assistance in supporting her!



Reviews



# Radiance Descending

Reviewed by: Emily Perl Kingsley

*Radiance Descending* by Paula Fox. Published by DK Ink Publishing, 1997. ISBN: 0-7894246-7-3. \$14.95.

*Radiance Descending* is advertised as a book for 10-12 year-olds about a “young boy taking the first steps towards understanding his younger brother who has Down syndrome.” Unfortunately, after reading the book a couple of times, I found no evidence of those first steps – or any steps – toward understanding.

Sadly, the book lays out 101 pages of uninterrupted negativity, bitterness, resentment, and actual loathing directed by Paul, the main character, towards Jacob, his younger brother who has Down syndrome. It reinforces a myriad of negative stereotypes, never provides the reader any insight into the reasons for all the venom and never moves towards resolution, insight, or any level of acceptance whatsoever.

I had hoped, by the end, for perhaps some minimal appreciation—or even, dare I say it, affection for Jacob—but I would have settled, reluctantly, for the most embryonic awakenings of plain basic acceptance. Unhappily, even that was nowhere to be found.

On the last page, in the very last paragraph of the book, Paul allows Jacob to “tweak his nose.” Perhaps the author intended that insignificant gesture to imply a beginning of relationship between the two brothers. Frankly, it was much too little and far too late. I seriously doubt that a single nose-tweaking in the final sentence of the book will signify the beginning of Paul’s emotional turnaround to the book’s readers. It certainly didn’t to me.

Without ever helping the reader understand why, Paul’s parents are portrayed as consistently unable or disinclined to be a support system for

him or to help him work through his hatred and his stubborn, purposeful unwillingness to relate to his brother who has Down syndrome. Even the sympathetic grandfather (an otherwise lovely character) seems willing to let seven whole years go by before he suggests that Paul deal with his problem. And when he does, finally, advise Paul that “it’s time to give it up,” he gives the poor kid no opportunity to express, examine or work through his seven years of unalterable animosity. Instead, Grandpa acknowledges that yes, Jacob is “eerie,” then drops the subject and hurries out of what might have been a nice moment of shared intimacy and possible enlightenment and growth.

The peculiar and unclear conclusion of the book, in which the child with Down syndrome comes down the stairs to his own seventh birthday celebration (where there are no other children present) dressed in a very bizarre get-up (a clumsily-sewn unraveling gold robe with paper cups sticking out from his head and falling in his eyes, etc.), gives an overall impression, not of Jacob’s integrity, dignity or worth, but of utter strangeness and differentness. It is an image that is as far as can be imagined from the kind of depiction of Down syndrome that we might hope for in literature. This is where the title “Radiance Descending” comes from, but I’m afraid that for me it was not radiant at all. Just weird.

All of this in the context of regressive and anachronistic detail (e.g., a child with Down syndrome who is seven years old but has never attended any school or program, who has absolutely no interaction with any other children, who is about to be sent to a separate segregated “special” school with “others like him,” etc., etc.) is very worrisome. How I wish this excellent renowned writer had done her homework and made the book more reflective of current attitudes and practices.

It makes me very unhappy to think about this book going out to an audience of young readers who, if anything, need more accurate and positive information about Down syndrome and more encouragement and reasons to understand, accept, and include their neighbors and classmates with developmental disabilities.



I urge all parents, teachers, and people concerned with promulgating up-to-date and positive information about Down syndrome to repudiate and avoid this dangerous book, *Radiance Descending*.



Emily Perl Kingsley is an Emmy-award winning writer for Sesame Street and author of the CBS-TV movie, Kids Like These. Emily is the mother of Jason Kingsley who is 23 years old and is now living on his own.



## Laying Community Foundations

Reviewed by: Jodi Reimer

*Laying Community Foundations for Your Child with a Disability: How to Establish Relationships That Will Support Your Child After You're Gone.* Linda J. Stengle, M.H.S. Published by Woodbine House, Inc. 1996. ISBN 0-933149-67-0. \$15.95. 800/843-7323. e-mail: info@woodbinehouse.com.

If there is one thing that can be said for parents of a child with a cognitive disability, it is that we have concerns for our child's future. We wonder many things such as: "Who will be here for our child when we are gone?" "Who will care for him and advocate for him like we do?" "Will someone be committed to making sure not only his physical needs are met but also to the need to be included and belong?" *Laying Community Foundations for Your Child with a Disability* is a book that reminds and challenges parents not to leave these questions to chance.

This book is a practical guide that encourages parents of children of all ages to proactively help their child establish committed relationships with people who are not paid to be in their life. All kinds of people from different walks of life who have one thing in common: caring about the person with the disability and are willing to be involved consistently in that person's life.



Initial chapters focus on why the subject of establishing relationships is important. It talks about our children's vulnerabilities and the problems with systems and services set up to help them without becoming a "pity party." Later chapters focus on assessing our child's strengths and abilities to determine what support will be needed in day-to-day living after we are gone. There is an invaluable description of how to go about finding people who are willing to help and asking them for a commitment to someone.

The strengths of this book lay in the author's ability to include real-life examples of these ideas at work for families. These stories give parents hope for our children's future and our ability to establish a fulfilling environment based on our child's desires. The author also does a wonderful job weaving in excerpts from other sources that add depth to the book. One section that I found particularly interesting was from a paper called *Common Assets of Mentally Retarded People That Are Commonly Not Acknowledged* by Wolf Wolfensberger. Mr. Wolfensberger reminds parents that we are sometimes conditioned to focus on our child's weaknesses and may have a hard time realizing what our child has to contribute to a relationship with a non-disabled person. This list of assets that a child may have includes "a strong tendency to relate to the 'heart qualities' of other people as opposed to their position or status" and "the ability to call forth tolerance, patience, and gentleness from other people." After reading this list of assets, I thought, "who wouldn't want to be friends with our children?"

My son is still in his early elementary school years and I am convinced that being included in his educational environment has been, and will continue to be, beneficial for him. The book, *Laying Community Foundations*, has helped to broaden my view of the concept of inclusion—inclusion in life and community. I am also more aware that belonging to a community will be beneficial to the quality of his life long after I'm gone.



Jodi Reimer is a mother of two children, one of whom has Down syndrome. She is a mother at home and a professional volunteer. She and her family reside in Federal Way, Washington.



Reviews

Reviews

Reviews

Reviews



