



# Finding Balance

Obesity and Children with Special Needs



A Report and Guide from AbilityPath.org



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*Obesity and Children with Special Needs*





“Health risks and the threat of obesity are huge concerns for families of children with disabilities and special needs. The issue goes **beyond food and portion control** for these families. **It’s a balancing act:** working with behaviors and aversions, medications and mobility challenges while exploring available community opportunities for participation. Finding the right balance is a family issue that starts in the home and quickly reaches out to schools, childcare centers, recreational and sports organizations. **So we all have a role to play** in combating obesity and building healthier communities. It requires a commitment from each one of us and **this report shows us the way.**”

-Sheryl Young, CEO, AbilityPath.org



“Anything you do with a best friend or a best buddy is more fun –and that includes getting healthy. For a person with intellectual disabilities who craves social relationships, inclusion and friendship, **exercising and eating right with a buddy are critical first steps** to improving the quality of their lives. Companionship helps to relieve some of the **tremendous pressure on parents** and is a valuable resource for stressed families seeking the balance that comes from improving the health and self-image of their special needs child. **This report is a critical guide** for families and professionals seeking to make change.”

-Anthony K. Shriver, Founder and Chairman, Best Buddies International



“As a society, **we have to do a much better job** of building community for people who have some challenges but still have the capacity to be healthy. We have **an epidemic of low expectations and social isolation** and the resulting health and emotional problems that ensue from that. Balance is about finding a sense of self-worth and social engagement so that you can feel good about yourself and valued by others. Everybody will have a different pathway to achieving that sense of balance. **This is not just about our bodies. It’s about our values.**”

-Timothy Shriver, Chairman and CEO, Special Olympics



## *Table of Contents*

<b>Overview:</b> Obesity and Children with Special Needs .....	6
<b>Four Stories:</b> Parents and Children Working Towards Healthy Weight .....	8
<b>Problem:</b> High Incidence Among Children with Special Needs .....	10
<b>Impact:</b> Consequences for Children's Lives .....	12
<b>Risk Factors:</b> Obstacles to Healthy Weight for Children with Special Needs .....	14
<b>Profiles:</b> Obesity Profiles for Particular Special Needs Groups.....	21
<b>Solutions:</b> The Five Spheres of Influence .....	25
<b>Programs:</b> Examples of Anti Obesity Programs for Children with Special Needs .....	29
<b>Resources</b> .....	31
<b>Parent Toolkit:</b> Tips for Parents Working Towards a Healthy Weight.....	32
<b>Parent Toolkit:</b> Tips for Creating Healthy Food Relationships .....	33
<b>Parent Toolkit:</b> Strategies for Eating in Restaurants .....	34
<b>Parent Toolkit:</b> Strategies for Introducing New Foods to Children with Very Limited Diets .....	35
<b>Parent Toolkit:</b> Food Chaining .....	36
<b>Parent Toolkit:</b> Healthy Snacking .....	38
<b>Parent Toolkit:</b> Healthy Snacking Grocery List .....	39
<b>Parent Toolkit:</b> Replacing Food Rewards.....	40
<b>Parent Toolkit:</b> Tips for Introducing Exercise .....	41
<b>Parent Toolkit:</b> Resources for Adapted and Inclusive Fitness Activities .....	43
<b>About AbilityPath.org</b> .....	46
<b>Special Thanks and Contributors</b> .....	47
<b>Articles and Studies</b> .....	50

## Overview

# Obesity and Children with Special Needs

Sam, a 19-year-old with Down syndrome, struggles to stay fit and healthy, despite an active schedule that includes yoga, bowling, swimming and drama. At 5 feet 6 inches, he weighs about 190 pounds and while he likes to stay active, Sam has health challenges that make this difficult— his poor vision makes him worry about his balance, and his flat feet make running difficult. When he was 15, Sam’s parents saw that he was becoming overweight and enrolled him in Health U., a program created by an interdisciplinary research team at the University of Massachusetts Medical School Eunice Kennedy Shriver Center. There, Sam learned about the importance of fitness and how to prepare and eat healthy foods.

Four years later, Sam’s weight is stable and he has found a variety of ways to stay active, although it’s not always easy for him to put the dietary lessons into practice. “I love eating junk food,” he says. “I want to make good choices like eating bananas, grapes, strawberries, broccoli and celery. My mom makes me eat salad. It’s not my favorite at all.”

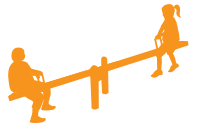
Sam sometimes calls his mother the “food police,” but he offers sound advice to other young people with special needs. “I would tell them to stay healthy and stay strong and stay active,” he says. “Tell them to exercise and work out with me and put their fears aside.”

Sam’s story is unusual in the special needs and disabilities community. His parents intervened early and they now spend hours driving him to his many inclusive activities. He leads a very active life. But many, if not most children with special needs face multiple challenges when it comes to maintaining a healthy weight. Food aversions, the side effects of medications, and mobility limitations make these children even more susceptible to being overweight or obese than other children, who are already facing a nationwide epidemic of obesity. One study found that among teens with Down syndrome, 86 % were either overweight or obese. Those figures are just as startling for children with other disabilities.

*Many, if not most children with special needs face multiple challenges when it comes to maintaining a healthy weight.*

According to the Centers for Disease Control and Prevention (CDC), children with disabilities are 38 % more likely to be obese than their counterparts. “As a community, we must recognize the special dangers obesity presents to our children,” says Sheryl Young, CEO, AbilityPath.org, an online resource and social community for parents and professionals serving the needs of adults and children with disabilities and the organization sponsoring this report. “This is an epidemic in our own homes and we can and must find solutions.”

Thirteen percent of U.S. families have a child with a disability. Yet too often, children with special needs have been left out of the obesity discussion. To help families, schools, physicians, service providers, policymakers and journalists understand both the severity of the problem and the range of solutions, AbilityPath.org interviewed physicians, psychologists, public health experts, dieticians, researchers, advocates



and parents. Over the years, the staff at AbilityPath.org have heard many parents of children with special needs talk about how hard it is to keep their children at a healthy weight. “How can they help them make healthy food choices? How can they have weight control, especially for those who are on medication? How can they have more movement that’s fun for them and safe?” They ask.

*Over the years, the staff at AbilityPath.org have heard many parents of children with special needs talk about how hard it is to keep their children at a healthy weight.*

While children with special needs are children first, and disabled second, they require an extra level of thoughtfulness, advocacy and attention in order to maintain a healthy weight. Solutions that work for typically-developing children may not work for them without modification, and those solutions that do work may not be available in their community.

This report has four goals:

- To **initiate** a conversation about the problem of unhealthy weight among special needs children.
- To **inform** families about the extent of the obesity problem, its causes, and the risks it poses to children’s health and well being.
- To **empower** parents and caregivers with tools, resources, and solutions so they can help their children be fit and healthy.
- To **inform** policy makers, school administrators and medical professionals about the importance of including children with special needs in their efforts to combat obesity.

## *Four Stories:* Parents and Children Working Towards Healthy Weight

**Alex** is a 12-year old-boy with autism who seemed to be a typically developing child until about age 4, when, his mother says, “He kind of fell off the planet.” As Alex grew older, he became more aggressive and when he turned 8 his mother, Elisa, put him on the drug Abilify. “It saved our lives in terms of him being able to live with the family,” she says. But the drug had some potent side effects. Alex gained 45 pounds the first year he was on it. “At age 6 he was wearing a size 6 and by 9 ½ he was a size 12,” Elisa recalls. “He also became calmer, more relaxed and more sedentary and he didn’t know what to do with his new body. Since then, he’s definitely had a weight issue.”

While Alex likes fruits and vegetables, since being on the drug he has had trouble controlling his intake of carbohydrates, sometimes binging on things like french fries or packaged hot dog buns. “If he’s at a party and that stuff is available, he will not stop eating it. He will take it off other people’s plates,” Elisa says.

Over time, Alex’s blood sugar rose dangerously high, to the point where he was considered pre-diabetic. With the help of an endocrinologist, Elisa was able to retool Alex’s diet to bring his blood sugar down, but the scare was enough to keep her vigilant about Alex’s eating habits, while also reducing the amount of Abilify he takes. “I can’t imagine my life with his challenges plus having to deal with insulin shots and monitoring his sugar,” she says. “It would just be a nightmare.”

Alex is now 5 foot 3 inches and weighs about 135 lbs. He can run a mile with his Adapted Physical Education coach, plays soccer on weekends and he loves to swim. Still, he’s no longer the active runner and jumper he was before the medication. “It’s hard to get him to move whereas before it was hard to get him to sit still,” Elisa says. “He’s easier to live with but there’s been a cost to his health.”

*“There’s not that self-regulation of hunger and fullness that typical kids will have.”*

**Mason** is a bubbly, outgoing 4-year-old with Down syndrome who loves to play with balls, to swing and slide and swim. His mother, Anne, says he’s “all boy.” But because she is a registered dietician, she knows that even her active, playful son is at high risk for obesity. “With Down syndrome, overweight is more likely to hit at puberty, but of course I’m doing my best to keep that from happening,” she explains. “There’s not that self-regulation of hunger and fullness that typical kids will have. With typical patients, I teach them to listen to how they feel – ‘Are you eating slow enough to realize your body is full?’ With Mason, I frequently have to cut him off – he would go back for seconds, or thirds. I have to do some kind of distraction technique to get him thinking of something else – ‘Let’s go play cards. Let’s go on the swings.’”





**Lottie** is a tiny 4-year-old with many medical and developmental challenges, including spina bifida, hypothyroidism, and microcephalus. As a baby she was diagnosed with a failure to thrive and at 3, she was still taking a bottle and would only eat a very smooth pureed soup. After intensive therapy, she has learned to sit at a table with other children and will eat crackers, bread, yogurt and cereal. Yet despite her many food aversions, her Body Mass Index or BMI is now in the 95th percentile.

*“Your first instinct when your child is asking for food is to give it to him. But I can redirect him to an activity that makes him feel safe and secure.”*

**Judge** is an 11-year-old with autism. At 4, he had a variety of sensory issues and would only eat yellow foods. Today, after intensive feeding therapy, he eats a relatively balanced diet. But he still loves fast food and like many of us, he associates food with comfort – particularly fresh-baked cookies. His requests can be hard to resist.

“He does perseverate on food sometimes,” observes his mother, Barbara. “He loves cookies baked in the oven, the whole process of buying them, cooking them and eating them. He’s so happy the whole time, he’ll say, ‘I love you, I love you, I love you,’ so it’s very easy to get caught up in it and want to do it all the time. It just makes him so happy.”

Over time though, Barbara has learned that food requests can be an indication of anxiety rather than hunger. “When he’s nervous or anxious he’ll start asking for food,” she explains. “Your first instinct when your child is asking for food is to give it to him. But I can redirect him to an activity that makes him feel safe and secure. I’ll say, ‘Let’s go play chutes and ladders.’ We do something else that brings him the comfort that the food does.”

*Problem:*

## High Incidence Among Children with Special Needs

“We feel that the healthy weight issue for people with disabilities is every bit as serious as it is in the general population. There’s an epidemic, an endemic of unhealthy weight in this population.”

Stephen Corbin, D.D.S., M.P.H.

Senior Vice President, Constituent Services and Support  
Special Olympics

### What is Obesity?

Obesity is defined using body mass index (BMI), which is an estimate of the amount of body fat a person has based on his or her height and weight.

- A child is considered overweight if he or she has a BMI at or above the 85th percentile and lower than the 95th percentile for children of the same age and sex.
- A child is considered obese if he or she has a BMI at or above the 95th percentile for children of the same age and sex.

The Center for Disease Control and Prevention (CDC) offers a BMI calculator for children and teens on its website that also factors in gender: <http://apps.nccd.cdc.gov/dnpabmi/Calculator.aspx>

Obesity is a global problem. Overweight and obesity are the fifth leading risk factors for global deaths and the problem is increasing. Worldwide, obesity has more than doubled since 1980. In the U.S., more than one-third of all adults are obese. But while obesity affects much of the developed world’s population, it is of special concern for those with disabilities. Research has demonstrated conclusively that both adults and children with disabilities are significantly more likely than their peers to be overweight or obese. “We found enormous differences between adults and children with and without disabilities across numerous surveillance tools,” reports Michael Fox, Sc.D., Associate Director for Science, Division of Human Development and Disability, National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention.

### The Statistics

Special Olympics is the largest recreational program in the world for people with intellectual disabilities. Each year, as a part of its screening process, its Healthy Promotion program measures the BMI of about 5,400 of its youth athletes (under age 22) in the United States. Despite their involvement with sports, Stephen Corbin, D.D.S., M.P.H., Senior Vice President, Constituent Services and Support at Special Olympics reports that 16.1 % of these screened athletes are overweight and 32.9 % are obese. All together, nearly half of these athletes are at an unhealthy weight. “This is quite alarming to us,” Dr. Corbin says. “Once people get very heavy, they tend not to want to do physical activity. So it’s almost a self-fulfilling death sentence.” In fact, the CDC estimates that health care costs of obesity related to disability reach \$44 billion each year.



But while people tend to get heavier as they get older, obesity is not restricted to disabled adults. It's a growing concern among children with special needs. According to data from the National Health and Nutrition Examination Survey (NHANES), 22.5 % of children with disabilities are obese compared to 16 % of children without disabilities. The problem is more pronounced among girls than boys:

- Among girls with disabilities age 2-17, the prevalence of obesity is 23 %. Among their peers without disabilities, the prevalence is 14 %.
- Among boys with disabilities age 2-17, the prevalence of obesity is 21 %. Among their peers without disabilities, the prevalence is 17 %.

The problem is particularly acute among young teens and “tweens.” The CDC has found that while 18 % of children age 10-14 without disabilities are obese, the rate for children in the same age group with disabilities is 30 %. “That’s the time in early adolescence when children generally look at themselves and become more self-conscious,” explains Dr. Fox. But while children without disabilities have many options for controlling their weight through team sports and other activities, children with disabilities often have fewer choices.

Different kinds of disabilities provide their own particular challenges. An analysis of NHANES data from 1999-2002 produced striking results:

- 80.6 % of children with functional limitations on physical activity were either overweight or obese.
- 50.8 % of children receiving special education services were either overweight or obese.
- 44 % of children with attention deficit disorder (ADD) were either overweight or obese.

In 2010, researchers measured the BMI of 461 adolescents aged 12-18 with physical, intellectual or behavioral disabilities. The findings were startling:

- 67.1 % of the teens with autism spectrum disorder were either overweight or obese.
- 86.2 % of the teens with Down syndrome were either overweight or obese.
- 18.8 % of the teens with cerebral palsy were either overweight or obese.
- 83.1 % of the teens with spina bifida were either overweight or obese.
- 39.6 % of the teens with intellectual disability were either overweight or obese.



*Impact:*

## Consequences for Children's Lives

“Childhood obesity, because it tends to track into adulthood and is itself a risk factor for the most prevalent chronic diseases, may represent a particular threat to the long-term health of many children with special health care needs.”

Paula M. Minihan, Sarah N. Fitch, and Aviva Must

“What Does the Epidemic of Childhood Obesity Mean for Children with Special Health Care Needs?”

Children with special needs and disabilities already work harder than their counterparts just to accomplish everyday tasks. Obesity adds an additional layer of difficulty for both children and their caretakers.

Here's how:

- Obesity can make movement more difficult and curtail a child's ability to participate in leisure activities ranging from playground games to amusement park rides.
- Obesity adds an added stigma for children who may be already stigmatized because of their disability.
- Obesity makes it more difficult for caretakers to help their children with daily tasks like bathing and toileting.
- Obesity puts children, adolescents, and adults at a higher risk of secondary health problems like type 2 diabetes, asthma, cardiovascular disease, orthopedic problems, sleep apnea, breast, colon, and endometrial cancers, stroke, osteoarthritis, and gynecological problems.
- Obesity incurs additional health care costs.

Knowing these facts and learning techniques that other parents are using will help reverse these numbers and improve the lifestyles of children with disabilities and special needs. This report is intended as a guide to action and as a resource for families, caregivers, professionals, and policy makers committed to fighting the obesity epidemic.

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*Risk Factors:*

## Obstacles to Healthy Weight for Children with Special Needs

“ There are so many factors that have to be dealt with, particularly when you get into the more severe level of disability where there are physical, sensory, cognitive and behavioral issues. There are financial issues. There are sibling issues, other children that need attention. Unfortunately health promotion is not something that gets to a high enough level of urgency in many families, not because it isn't important but because of all the other necessities that are essential to sustaining all the other parts of that child's life and the family's life. ”

James Rimmer, Ph.D., Director  
Center on Health Promotion Research for Persons with Disabilities  
University of Illinois at Chicago

### Risk Factors for Obesity in the General Population

The causes of obesity are no mystery, and yet, paradoxically, its precipitous rise is not fully understood. In simplest terms, people gain weight when they consume more calories than they expend. But the root causes behind the calorie/activity imbalance are the subject of some debate. Is it our sedentary lifestyles? Is it our highly processed foods? Or are there other factors to consider?

### Commonly Cited Reasons for Obesity Include:

- The higher price of healthy foods compared to unhealthy foods
- Increased portion sizes
- Increased availability of processed foods
- Increased consumption of sugar-sweetened drinks
- Decreased physical activity
- Increased screen time



A 2006 study published in the International Journal of Obesity listed some other possible causes that are less frequently cited. They include:

- Inadequate sleep that has been tied to weight gain.
- Increased exposure to endocrine-disrupting chemicals in food and the environment, which may alter metabolism.
- Climate controlled environments that reduce the calories burned by sweating and shivering.
- Women giving birth at older ages, which correlates with heavier children.

### Risk Factors for Obesity Among Children with Special Needs

Children with disabilities face the same obesity risks as other children. But they also have a large set of risk factors particular to their disabilities. We have identified seven unique obesity risk factors faced by children with disabilities. While not every child contends with every risk factor, many children face multiple challenges when it comes to maintaining a healthy weight.

#### Risk Factor 1: A More Complex Relationship with Food

A healthy diet is high in fruits and vegetables, whole grains, and proteins and low in sugars and fats. But children with disabilities may have physical or behavioral barriers to a healthy diet. Children with Down syndrome and cerebral palsy may have trouble chewing or swallowing, which can lead them to eat softer and more processed foods. Children with autism spectrum disorders may have an intense aversion to certain textures, flavors or colors, leading them to eat a very limited assortment of foods. “You may have a parent saying, ‘All he eats is peanut butter and jelly sandwiches’,” says Paul Carbonne, M.D., Assistant Professor of Pediatrics at the University of Utah, School of Medicine.

*“And it’s not as easy as saying, ‘Don’t give them that stuff.’”*

Parents of children with special needs often are reluctant to clash with their children over food, either because they are already fighting enough behavioral battles or because they don’t want to remove a source of pleasure for a child who has many challenges. “Sometimes the one thing families can do to make [their children] feel better is to feed them,” observes Verna Baker, M.S., R.D., L.D., a dietician who works with children with special needs through a program called KIDS FIRST at the University of Arkansas for Medical Sciences Department of Pediatrics.

Another factor is peer influence. The desire to fit in is strong for any child, particularly one with a disability. If other kids are eating candy and drinking soda, trying to avoid these foods becomes even more difficult, especially if these choices are widely available on school campuses. The other





food challenge is the fact that parents, therapists and teachers alike may be in the habit of using food for behavior modification, rewarding desired behavior with sweet treats or – less frequently – punishing undesired behavior by withholding them. Both approaches tend to make these foods more desirable.

Sometimes food is simply used to express affection or win compliance. “Parents tell us all the time that it happens in schools,” says behavioral psychologist Richard Fleming, Ph.D., M.S., M. Ed., of the Eunice Kennedy Shriver Center at the University of Massachusetts. “School staff wink and put an extra serving on their plate. I’ve heard it so many times – they think they’re doing a sweet thing by putting an extra cookie on the plate. It’s a strange form of discrimination.”

### **Risk Factor 2: Barriers to Exercise**

Exercise is vital not just for maintaining a healthy weight, but also for muscle tone, circulation and mood. When children with disabilities exercise regularly, they are helping to control the progression of chronic disease and functional decline while improving their overall health. But 39 % of youth with physical disabilities report never exercising at all, according to one study.

The reasons are many. Children with cardiac or respiratory conditions tend to tire more easily, making it harder for them to participate in physical activity. Children with cerebral palsy, spina bifida or muscular dystrophy may have significant mobility issues. Many children with disabilities need modifications to be able to participate in fitness activities but may not have access to adaptive equipment or to inclusive recreation classes. For example, while children with a wide variety of disabilities enjoy playing in the water, that option may not be available to them if the pool does not have a lift for getting in and out. One study of the factors affecting recreation and leisure participation of children with disabilities found that the top three barriers were the child’s own functional limitations, the high cost of specialized programs and equipment, and a lack of nearby facilities or programs.

*Many children with disabilities need modifications to be able to participate in fitness activities but may not have access to adaptive equipment or to inclusive recreation classes.*

### **Risk Factor 3: Medications**

Seventy-five percent of children with a special health care need take at least one prescription drug. Many medications, particularly certain antipsychotics, antidepressants, anticonvulsants, neuroleptics and mood stabilizers, are associated with weight gain. “From what we see happening, it seems that physicians don’t necessarily look that closely at the consequences of prescribing those types of medications in terms of it being detrimental to a child’s health in other ways,” says Dr. Fox.





#### **Risk Factor 4: Family Stress**

Parents of children with special needs often have schedules crowded with medical and therapeutic appointments, extra transportation responsibilities as they shuttle children to activities and services, and a variety of extra care-giving duties at home. With so much to do, high calorie prepared or packaged food may seem like a more viable option than cooking meals from scratch. By the same token, exercise may have fallen into the category of “maybe someday, when we have time.”

*With so much to do, high calorie prepared or packaged food may seem like a more viable option than cooking meals from scratch.*

In addition, 21 % of families of children with special needs report that their child’s disability has caused financial burdens either because it has made it difficult to work fulltime or because of out-of-pocket expenses not covered by insurance. Healthy food, inclusive fitness classes or professional consultation may simply be financially out of reach. “Reimbursement for nutritional counseling and services is non-existent in some cases and low in others,” says Baker.

Taken together, the extra financial and caretaking burdens can make weight management initiatives seem overwhelming. As one study points out, “Time and money needed to arrange for healthy meals, increasing physical activity and reducing screen time may be harder for families also struggling with finances, caretaker time and energy, and pressures associated with employment.”

#### **Risk Factor 5: Genetic Disorders**

Certain genetic disorders have obesity as clinical features. Those include Prader-Willi syndrome, Bardet-Biedl syndrome, Cohen syndrome, Borjeson syndrome, Carpenter syndrome, and MOMO syndrome. Other conditions, like Down syndrome, spina bifida, and autism spectrum disorders have characteristics that place children at particular risk for obesity.

#### **Risk Factor 6: Perceived Risk**

Children with special needs are often eager to participate in fitness activities. But parents, teachers, pediatricians and coaches may feel that the activity will be too difficult, too dangerous, or too disappointing for a child with a physical, intellectual, or behavioral disability. “Some of this has to do with stereotypes – the idea that kids with disabilities are ‘too sick’ to engage in physical activity,” says Dr. Fox. One study has found that pediatricians frequently underestimate the benefits and overestimate the risks of physical recreation for children with chronic health issues.

*Children with special needs are often eager to participate in fitness activities. But parents, teachers, pediatricians and coaches may feel that the activity will be too difficult, too dangerous, or too disappointing.*

Parents tend to worry both about their child experiencing failure when they attempt a physical challenge, and that the child will get hurt. In a study of 11 to 16 year olds with physical disabilities, 68 % felt that “their parents stop them from doing what they want to do because they worry too much.”

“Parents don’t want their kids to get hurt or to put them into a situation where they’re vulnerable,” says Dr. Nancy Murphy, M.D., Department of Pediatrics at the University of Utah School of Medicine. “All kids are going to fall and skin their knees and sprain their ankles. It’s OK. The benefits so outweigh the risks, it’s worth taking the risks.” In fact, athletes with disabilities have rates of injury that are similar to other athletes. “Everything’s a risk in life,” agrees Dr. Rimmer. “But it’s a greater risk to sit and do nothing. Because in the long run that’s not going to prevent a child from developing obesity or diabetes.”

Parental concern about their child’s safety should not be dismissed. For some children inclusive sports are a possibility, while for others they are not, but that is why options like Special Olympics, AYSO’s VIP soccer program for kids with disabilities and Little League Baseball’s Challenger League exist; they are all designed to support and encourage kids of varying ages and abilities to participate in team sports. “We’ve got to get them moving. We have to challenge kids to enjoy it and luxuriate in the fun and the physical health and the emotional health that comes from exercise,” says Timothy Shriver, Chairman and CEO, Special Olympics. “Sports and fitness and nutrition are part of a piece that goes together.”



*“Who doesn’t remember being picked last for the team? We need to model sports and recreation that are inclusive and find sports and fitness programs that are for all ability levels, not just the best ability levels.”*

Children whose abilities or temperaments don’t lend themselves to team sports still have many options for being active safely with the help of adaptive equipment and protective gear. Often, says Timothy Shriver, parents’ fears are “rooted in a bad sports model” based on winners and losers. “We need positive sports models,” he says. “We need parents to ask their parks and recreation departments, their YMCAs to create participatory models that help people feel fit and healthy and not feel excluded or rank-ordered.”

### **Risk Factor 7: Social Isolation**

Children whose special health care needs may have fewer friends than other children their age and thus may miss out on the chance for free play in an outdoor setting. At the same time, they may also be excluded from team sports because others believe they won’t contribute to victory. “Who doesn’t remember being picked



last for the team?” says Timothy Shriver. “We need to model sports and recreation that are inclusive and find sports and fitness programs that are for all ability levels, not just the best ability levels.” Unless given a chance to engage in either structured or unstructured physical activity, children with special needs are likely to be inactive. Special Olympics research shows that the social aspect of sports is one of the main reasons athletes become involved. In addition to its programming for athletes with intellectual disabilities, the organization developed Unified Sports, providing its athletes with the opportunity to play on teams with “partners” or athletes without disabilities.

### **Risk Factor 8: Screen Time**

Most children in our culture have access to a mind-boggling assortment of sedentary diversions like television, video games and computers. Those amusements can feel heaven-sent to families whose children are prevented from participating in other activities and they are often used to provide “down time” for overstressed parents and children alike. At the same time though, screen time is strongly associated with obesity. “If a child is less engaged in physical activity than they’re more engaged in sedentary behavior. It’s an either/or. The more you get them on the side of activity, the less time they have for screen time and other sedentary behaviors,” says Dr. Rimmer.

While the reasons for this are not fully understood, studies have found that television viewing lowers the rate of children’s metabolism more than resting does. At the same time, television viewers are exposed to a steady bombardment of advertisements for soda, snack foods, fast foods, and candy, which is one reason people tend to snack while in front of the television. “Childhood obesity is almost directly correlated with the amount of time children spend in front of computers and televisions,” says Dr. Fox.





*Profiles:*

## Obesity Profiles for Particular Special Needs Groups

“ We find that many of the children who are overweight are still malnourished. They have sufficient caloric intake but not sufficient nutrients.”

Verna M. Baker, M.S., R.D., L.D.  
Clinical Services Director of Nutrition,  
KIDS FIRST/UAMS Department of Pediatrics

### Down Syndrome

Children with Down syndrome tend to be shorter than other children, and studies indicate that their basal metabolic rate – the amount of calories the body burns at rest – is lower. At the same time, several aspects of the condition contribute to obesity:

- Hypothyroidism, which affects 30-50 % of children with Down syndrome.
- Increased leptin, a hormone that regulates food intake and correlates with obesity.
- Poor mastication, or chewing, which makes it difficult to eat raw fruits and vegetables.

In addition, children with Down syndrome often have sensory deficits that make balance and coordination more difficult, leading to decreased physical activity. They may also have poor impulse control and a tendency to be oppositional or noncompliant when a parent attempts to push exercise or healthy foods.

While estimates vary, one study found that between 30 % and 50 % of children with Down syndrome were obese. Children with Down syndrome are also at increased risk for developing Type 2 diabetes both due to their propensity for obesity and their large abdominal fat stores.

### Autism

Children with autism often have sensory issues that affect their acceptance of healthy foods, sometimes exhibiting aversions to specific textures, smells, colors, temperatures, or brand names. “Often parents and caregivers give in to their preferences, which a lot of the time may be the high calorie items,” explains Baker. “We’ve had children who will only eat McDonald’s french fries and it had to be in the McDonald’s package.”

*Children with autism often have sensory issues that affect their acceptance of healthy foods, sometimes exhibiting aversions to specific textures, smells, colors, temperatures, or brand names.*

Even children who do not have specific aversions may find certain foods, particularly starches, so pleasurable that they have difficulty controlling their intake. “He loves fruits and vegetables but the pizza and the white bread and the fries, he cannot stop eating that stuff,” says the mother of a 12-year-old with autism. “He will eat a whole large pizza if it’s accessible to him.”

Studies have found that:

- Children with autism are 40 % more likely to be obese than children without autism.
- Children with autism refused foods more than twice as frequently as their typically developing counterparts.
- Children with autism consumed more sugar sweetened beverages and snack foods than their neuro-typical counterparts.

There are other factors as well. Children on the autism spectrum may be taking medications that lead to weight gain. They may also have motor impairments that may make it difficult to play sports, in addition to social skill impairments that make participation in structured activities with peers challenging. Additionally, behavior modification using candy or other treats is a common strategy for therapists working with children with autism as they usually don’t respond to social motivation. “A lot of kids are trained not to do anything unless you have M&Ms and jelly beans in your pocket,” observes the mother of a child with autism.

### **Cerebral Palsy**

Children with cerebral palsy (CP) are obese at about the same proportion as other children, but the percentage of children with CP who are obese has more than doubled since 1994, an alarming trend. Because children with cerebral palsy may have started out with feeding problems, their families may have gotten in the habit of relying on high calorie, nutrient dense foods that are no longer appropriate as their child’s health stabilizes. Some research also indicates that children who were ill or undernourished in utero may have metabolisms that cling assiduously to any available calories, making it easy for them to put on weight. At the same time, children with cerebral palsy may find it difficult to chew and swallow fruits and vegetables, leading them to rely on soft, less nutritious foods that are also high in calories.

### **Prader-Willi**

Children with Prader-Willi syndrome (PWS) are typically plagued by a chronic feeling of hunger and an inability to feel satiated that can lead to chronic food seeking and binge eating. In addition, children with PWS have lower caloric needs because of their slower metabolisms and short stature. They also frequently have intellectual and behavioral disabilities that make fitness activities more challenging and sleep disturbances that leave them sleepy and low-energy during the day. The combination of these factors makes PWS the most common genetic cause of life threatening childhood obesity.





## Spina Bifida

Children with spina bifida, especially those who also have hydrocephalus, are at high risk for obesity. The Spina Bifida Association reports that at least half of the children over age 6 with spina bifida are overweight, and in adolescence and adulthood, more than half are obese.

Contributing factors for obesity in children with spina bifida include:

- Neurological impairments that lead to mobility problems.
- Short stature, which leads to lower caloric needs.
- Slower metabolic rate resulting from a higher proportion of fat cells.







*Solutions:*

## The Five Spheres of Influence

“It’s not just a matter of the individual making the right choices. We need public policies that support physical activity programs for people with disabilities. We need more investment in programs both public and private. And we need private sports and fitness clubs to offer choices for people with disabilities.”

Stephen Corbin, D.D.S., M.P.H.  
Senior Vice President, Constituent Services and Support  
Special Olympics

In writing about the impact of the obesity epidemic on children with special health care needs, the researchers Paula M. Minihan, Sarah N. Fitch and Aviva Must deployed an ecological model describing five overlapping spheres of influence that impact each individual child. A child’s weight is impacted by a variety of factors, some close to home, others influenced by public policies made hundreds or thousands of miles away. Just as each sphere of influence can be part of the problem; it can also be part of the solution.

### Individual

Children have to be involved in decisions about their own health and fitness. Parents can talk with them about healthy eating and the importance of physical activity and engage them in the quest for enjoyable healthy foods and pleasurable fitness activities. Children can set goals for themselves. These should not be weight loss goals, but goals for new behaviors – “eat fruit and vegetables every day” or “go to a yoga class once a week” or “learn how to swim.” As the mother of a young man with Down syndrome observes, “The most important thing is you have to get the ‘want to’ in them for it to work. You have to talk with them and not preach at them and tell them what to do.”

### Interpersonal (Family, Friends, Peers)

Families must be committed not just to changing their children’s habits, but to changing their own, buying, preparing and eating healthy foods as a family and incorporating pleasurable fitness activities into family life. “You have to change the home environment,” says Dr. Fleming. “That means both parents and siblings. It sure makes it easier if everyone’s on board.”

The upside of this approach is that everyone reaps the benefits by feeling healthier and more energetic. Children also learn that healthy weight is part of healthy living, not something that is being imposed on them because of their disability.

Elisa, a mother whose 12-year-old son has autism, is determined to lose 100 pounds herself, while also getting her son Alex to a healthy weight by maintaining his current weight as he grows. To that end, she has made some changes. The family, including Alex's younger brother, tries to go for a walk after dinner every night instead of watching a movie and Elisa makes sure to keep the house stocked with only healthy foods. "We haven't won the battle," she says, but she feels the whole family is now focused on being fit.

As children get older, peers are often more effective motivators than parents. "Everything you do with your friends you want to do more often," says Anthony K. Shriver, Founder and Chairman, Best Buddies International, a program that fosters one-to-one friendships between people with and without intellectual disabilities. "If the person is involved in sports, the person with special needs will want to do it just to be with them." Josh, a young man with Down syndrome who had never ridden a bicycle, has been doing 20 mile tandem bicycle rides with his friend Alice through Best Buddies. Neither one had much cycling experience when they started, but together they've completed three 20 mile fitness rides sponsored by Best Buddies and are getting ready for a 100 kilometer challenge in Washington DC. To train, they sometimes take spin classes together at the local YMCA. In the process, Josh has lost 30 pounds and has also learned how to ride his own bike, which he uses to get to church. His mother, Kay had wanted Josh to learn to ride a bicycle without much success. "He rode with Alice on the tandem bike and then he got the 'want-to' to ride a regular bike," she says.

*"Whether it's taking a class, joining a team or league, or just having a friend to do things with, interpersonal relationships can be key to developing healthy habits."*

### **Organizational: Schools and Health Care Sites**

Parents need to make sure that all the people in a child's life are working together to promote healthy weight. In schools, that means educating teachers and staff about not using food for behavior modification and advocating for Adapted Physical Education (APE) at school. APE is a federally mandated component of special education services which ensures that physical education is provided to students with gross motor delays as





part of that child's special education services. Parents should make sure to address physical education in their child's Individual Education Program (IEP).

Physicians may also need to be educated, as many are unfamiliar with the distinct needs of children with disabilities or the weight-gain consequences of prescription drugs. "On average, a person with intellectual disabilities would have to go to 50 different physicians before finding one with experience and training in intellectual disabilities," says Dr. Corbin. Often children with special needs see a variety of specialists but don't have a primary health care provider who can work with them on preventative weight management strategies.

### **Community: Neighborhoods, Municipalities, Counties**

Many of our choices are determined for us by the built environment without our realizing it. Seemingly minor details like an absence of curb cuts, crosswalks, sidewalks, or working elevators are major impediments for people with disabilities who may be trying to go for a fitness walk or reach a swimming pool or inclusive exercise class. "The way communities are constructed right now, it's a perverse incentive towards sedentary lifestyle," says Dr. Fox.

*Recreation centers, health clubs, and sports groups also need to make accessible and inclusive fitness activities part of their regular offerings so that parents can bring the entire family to one place.*

But physical accessibility is only the first step. Recreation centers, health clubs, and sports groups also need to make accessible and inclusive fitness activities part of their regular offerings so that parents can bring the entire family to one place and have something that everyone can do. Playgrounds need accessible play structures. Parks should have accessible trails. "Beyond the Americans with Disabilities Act is the whole area of program accessibility," says Dr. Rimmer. "We've gotten to the first level which is access. The next level is participation which is a much different animal."

### **Society: National and State Policies, Laws and Regulations**

Researchers and policy makers looking to understand and combat childhood obesity must make sure to include children with special needs in their studies, plans and policies. The Americans with Disabilities Act was a major first step, but only a first step towards better access for people with disabilities. Other policy initiatives must focus on improving the availability of healthy foods in schools and neighborhoods and decreasing the amount of junk food advertising and marketing aimed at children.







### *Programs:*

## Examples of Anti Obesity Programs for Children with Special Needs

### Special Olympics Health Promotion

[http://www.specialolympics.org/healthy\\_athletes.aspx](http://www.specialolympics.org/healthy_athletes.aspx)

Health Promotion, part of the broader Special Olympics Healthy Athletes initiative, seeks to improve the quality and length of life for Special Olympics athletes by encouraging and enhancing positive health behaviors, reducing risky ones, and improving self-efficacy and self-advocacy. Health Promotion provides free screenings to Athletes for body mass index, bone density and blood pressure, as well as education in a range of topics, including both nutrition and physical activity. In addition to screening events, Health Promotion messaging is also integrated into the broader year-round programming of Special Olympics, including coaches training, sports resources and materials, and family education. Through Health Promotion, healthy lifestyle messaging is seamlessly interwoven with sports programming so that health is an equal, necessary component to helping athletes achieve their fullest potential both on and off the field.



### Health U.

<http://www.umassmed.edu/shriver/Service/communityFamilyServices/Health.aspx>

Dr. Richard Fleming and an interdisciplinary research team at the University of Massachusetts Medical School/Eunice Kennedy Shriver Center have developed an educational program called Health U. The Health U. curriculum consists of 16 sessions that focus on nutrition and physical activity, with materials and activities modified to meet the cognitive needs of the participants. Health U. is currently being conducted as a randomized controlled trial to determine the best approach for promoting weight loss in adolescents and young adults (ages 13-26) with Down syndrome.

### Kids First

<http://www.uamshealth.com/kidsfirst>

University of Arkansas for Medical Sciences operates 11 KIDS FIRST sites in centers strategically located around Arkansas, serving 750 children with special healthcare needs ranging in age from 6 weeks to 5 years. In their pediatric day healthcare clinics, children diagnosed as having a medical condition known to place them at risk for developmental delays and disabilities receive intensive intervention from an interdisciplinary team that includes nutritional counseling, occupational, speech and behavioral therapy, parent meetings and support groups, and family consultation.

## U-Fit

<http://www.health.utah.edu/outreach/UFIT/index.html>

U-FIT is a family-centered, family-friendly program based at the University of Utah College of Health designed for children and youth with special needs. By working alongside skilled volunteers, the program is designed to build friendships, increase self-esteem, and improve motor skills and levels of physical fitness while ultimately having fun in a nurturing environment. The key to the success of the U-FIT Program is through family involvement of those who participate. U-FIT tries to meet the goals and needs of the families that are as diverse as those of the participants.

## Nickelodeon's World Wide Day of Play

[www.nick.com/thebighelp/worldwide-day-of-play](http://www.nick.com/thebighelp/worldwide-day-of-play)

The World Wide Day of Play is a part of Nickelodeon's "The Big Help" campaign, which focuses on engaging kids for positive change in four key issue areas: health and wellness; the environment, education and community service. Now in its 8th year, Worldwide Day of Play is an entire day dedicated to active play. On the World Wide Day of Play, the network goes "dark" for three hours, turning off programming to encourage kids to get up, get out and go play! Each year, World Wide Day of Play is celebrated with more than 3,500 local events in all 50 states and in 13 countries. This year, in partnership with AbilityPath.org, Nickelodeon published the How iPlay guide to encourage children of all abilities to get out and play. This guide can be downloaded at [www.abilitypath.org/wwdop](http://www.abilitypath.org/wwdop).

## Best Buddies

<http://www.bestbuddies.org>

Best Buddies® is a nonprofit 501(c)(3) organization dedicated to establishing a global volunteer movement that creates opportunities for one-to-one friendships, integrated employment and leadership development for people with intellectual and developmental disabilities. Founded in 1989 by Anthony K. Shriver, Best Buddies is a vibrant organization that has grown from one original chapter to almost 1,500 middle school, high school, and college chapters worldwide. Today, Best Buddies' seven formal programs – Middle Schools, High Schools, Colleges, Citizens, e-Buddies®, Jobs and Ambassadors – engage participants in each of the 50 states and in 50 countries, positively impacting the lives of nearly 700,000 people with and without disabilities around the world. As a result of their involvement with Best Buddies, people with intellectual and developmental disabilities secure rewarding jobs, live on their own, become inspirational leaders, and make lifelong friendships.



## Let's Move

[www.letsmove.gov](http://www.letsmove.gov)

Let's Move! is a comprehensive initiative, launched by the First Lady Michelle Obama, dedicated to solving the challenge of childhood obesity within a generation, so that children born today will grow up healthier and able to pursue their dreams. Combining comprehensive strategies with common sense, Let's Move! is about putting children on the path to a healthy future during their earliest months and years. Giving parents helpful information and fostering environments that support healthy choices.

## RESOURCES

### Obesity and Children with Special Needs



## PARENT TOOLKIT

### TIPS FOR PARENTS WORKING TOWARDS A HEALTHY WEIGHT

#### 1. Start Early.

Preventing unhealthy weight is easier than losing it and bad habits can be hard to break. “There’s not a doubt in my mind that doing this early in life and getting conditioned to do it will have a better outcome for that individual when they reach adulthood,” says Dr. Rimmer.

#### 2. Make Change as a Family.

Everyone in the family benefits from a healthy diet, clear limits on screen time and sweets, and regular exercise – including parents and siblings. Consider committing to a half day a week of family-based activity, whether it’s going swimming or visiting a park or zoo that requires walking.

#### 3. Use What You Know.

Chances are, you have already been using many of the techniques that are key to weight loss: goal setting, feedback, positive reinforcement, and control of triggers and environmental stimulus. Rather than thinking of weight management as an additional challenge, think of it as just another example of the limit-setting and behavior modification you do already.

#### 4. Start Small.

Routines are important to all families, and particularly ones with children with special needs. Instead of turning them all upside down at once, introduce changes slowly. A few places to start: turn off the TV during dinner, eliminate soft drinks from the shopping list, or institute a once a week family walk. “A little bit gives you enormous benefits,” says Dr. Rimmer. “Just getting off the couch. A little bit more gets you more.”

#### 5. Recognize Triggers.

Some situations tend to make everyone fall into old, unhealthy habits. Barbara, whose son Judge has autism, knows that he will not eat foods that are too complex, so if he is going to be eating away from home, she brings simple, healthy food for him to eat. Sam, who has Down syndrome, will eat all the food on his plate in a restaurant so his parents privately arrange for the servers to bring him a smaller portion.

#### 6. Set Goals.

Encourage your child to have his or her own health and fitness goals and celebrate when he or she meets them. Achievable goals might include eating vegetable and fruit every day or walking all the way to the library.



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## PARENT TOOLKIT

### TIPS FOR CREATING HEALTHY FOOD RELATIONSHIPS

- Avoid food wars. Keep your healthy food efforts fun and friendly.
- Keep mealtimes pleasant and free from distractions like TV.
- Encourage your child to savor food by eating slowly.
- Model good eating habits.
- Don't use food for rewards or punishment.
- Don't let your child skip meals, as this leads to snacking.
- Learn appropriate serving sizes for your child's age.
- Serve vegetables and fruits raw when possible, as they are more filling.
- If chewing and swallowing are issues, serve healthy but easily masticated healthy foods like yogurt, steamed vegetables, and pureed fruits.
- Learn to read food labels to understand sugar, fat and sodium content.
- Allow occasional treats so that sweets and junk food don't become forbidden fruit.
- Offer a variety of foods – it takes many introductions of a food for it to be accepted.
- Make sure to always have one food on the table with which a child feels comfortable.
- If your child usually wants seconds, make the first portion smaller.
- Allow seconds of starches only after seconds of fruits and vegetables.
- Involve kids in planning, shopping and cooking. Also, plan and shop for the week's meals ahead of time.
- Only eat at the dining room or kitchen table. (No car snacking or walking around snacks)
- Don't drink your calories – avoid sweetened drinks.
- Keep junk food and soda out of the house.
- Choose whole grains over refined grains.
- Bake, roast or poach instead of frying.
- Choose cereals and other foods with low or no added sugar.
- Eat at home whenever possible.
- If grazing is a problem, set times when kitchen is closed.
- If your child eats out of boredom, redirect him or her to other pleasant activities.

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## PARENT TOOLKIT

### STRATEGIES FOR EATING IN RESTAURANTS

Portion control is easy at home, but it can be difficult when you go out to eat. Here are four strategies for eating out without creating a feeling of deprivation or conflict.

1. When placing orders, ask for a dish to take food home in. When the food is brought to the table, put some aside saying, “This is for later” or “Tomorrow’s lunch.” This helps diffuse the quantity situation right away.
2. Discuss the menu and healthy food choices before ordering but then let your child order what they want.
3. If your child orders food that is particularly high in calories like french fries, talk with the server privately and ask them to cut the portion in half before bringing it to the table.
4. Avoid “all you can eat” restaurants or buffets.



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## PARENT TOOLKIT

### STRATEGIES FOR INTRODUCING NEW FOODS TO CHILDREN WITH VERY LIMITED DIETS

At the KIDS FIRST program, the staff is used to working with children who have strong food aversions. Here are some of the steps they suggest when introducing new foods to children with sensory issues:

- Read books about food.
- Play with food, being as silly as you want.
- Make art with food.
- Talk about food in the grocery store – what it is, where it comes from, and what it's used for.
- Encourage your child to pretend to eat toy food or real food.
- Use pictures, grocery store ads, food magazines pictures, plastic foods, cans and boxes of foods to talk about foods.
- Use a rolling pin or mallet to crush dry items. Remember to always be talking with your child about the food in a positive manner.
- Use cookie cutters to cut bread, Jell-O, pancakes, lunch meat or whatever he or she will touch.
- Use frilly toothpicks or utensil with one-to-one supervision and allow him or her to arrange items they will not touch. Make circles, squares or just play with foods i.e. cheese cubes, cheerios, gold fish crackers, etc.
- Allow your child to pour, stir and scoop foods. Use small amounts so as not to overwhelm or cause too big a mess.
- If a child won't allow a food on the plate, put it to the side of the plate. Aim to slowly move it onto the plate over time.
- Encourage your child to touch, smell and play with food even if he or she won't eat it. If a child won't try food, see if he or she will kiss the food, thus bringing it closer to the nose and mouth.
- If a child is willing to taste the food, allow your child to spit it out if they want.

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## PARENT TOOLKIT

### FOOD CHAINING

Children with food aversions may benefit from a technique called food chaining, which has the goal of preventing children from sensory overload. The goal is to start with a food that the child accepts, then progress from that food to another one.

#### Considerations:

- A child struggles to just prepare for the task of eating. He or she is affected by all surroundings. For example, when your child sits down, their body is assaulted by sensory input from all sides: lights, number of people sitting at the table, noise, feeling of the chair beneath them, clothing, aromas, of foods, taste when they first put food in their mouth and then the changes that occur when they crush the food with their teeth.
- Some kids prefer foods whose texture does not change when they chew. For example, your child may not be able to predict the texture of a food before they bite into it so they may freeze with the food on the tongue. Your child might respond by spitting the food out of their mouth.
- If your child continues to be pushed to eat foods they cannot tolerate, eating will become something that they fear and avoid.
- Kids seek food they feel safe with and do not always eat or drink for reasons of hunger.
- Children may find comfort and emotional well-being in seeking out predictable foods that are familiar to them. It is their way of protecting themselves from being overwhelmed by the sensory properties of “new” foods. Mealtimes may be overwhelming to them.

#### Example of Food Chaining:

McDonald’s French Fries > Different sizes > Different brands > Homemade French Fries > Other food items in same shape > Breaded vegetables like zucchini > Sweet potato fries > Tater tots > Potato wedges > Baked potato > Mashed potato

- Consistently try the same variation of the food item for several meals/days before giving up i.e. 15-25 times.
- Once the item is accepted, continue to gradually change accepted items in this format.
- Keep trying! Don’t give up! It will work.

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## PARENT TOOLKIT

### FOOD CHAINING (CONT.)

#### Important Things to Know:

1. New foods are offered to problem eaters based on a “sensory hierarchy.” Your child must first be able to tolerate being in the same room with the food, the sight of the food, aroma of the food, the feel of the food on their hands and finally the taste by licking and then biting/chewing the food.
2. Never overwhelm your child by changing all or too many foods at once.
3. If a new food is unsuccessful, consider whether you can modify it. Adults can look at a food and predict how it will taste and feel in their mouths, but children cannot.
4. Recognize that some foods are more challenging i.e. meats or vegetables.

#### More Tips:

1. Give your child warning as to timing of meals or snacks.
2. Give your child choices.
3. Not every meal has to be part of the food chaining process.
4. Time meals and snacks wisely.
5. Make the mealtime setting fun and keep it simply.
6. Keep distractions and noise to a minimum.
7. Make sure your child is comfortable at meals. Positioning is important.
8. Motivate child to succeed. Reward small progress.
9. Shift focus off your child at mealtime as much as possible.
10. Don't reward negative behavior.

Adapted from a handout by Verna M. Baker, M.S., R.D., L.D.  
Clinical Services Director of Nutrition,  
KIDS FIRST/UAMS Department of Pediatrics

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## PARENT TOOLKIT

### HEALTHY SNACKING

“I keep fruit for him all the time and make sure it’s all cut up. If you have fruit around he will eat fruit. If you have chips around, he will eat chips. So we try not to have them available.”

Kay, mother of a son with Down syndrome

Snacks aren’t bad in and of themselves – they can be useful for keeping children from overeating at mealtimes.

Here are some tips and suggestions for healthy snacking:

- Serve snacks that contain at least two food groups, like protein and carbohydrates.
- Keep a container in the refrigerator with healthy snack choices like cut up veggies.
- Keep a box on the kitchen counter with other healthy snacks like whole wheat crackers and nuts.
- Bring snacks with you when you go out to avoid vending machines or emergency snack stops.
- Keep junk food and soda out of the house.



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## PARENT TOOLKIT

### HEALTHY SNACKING GROCERY LIST

- ☐ Apples and peanut butter
- ☐ Yogurt with granola or fruit
- ☐ Cheese and crackers
- ☐ Oatmeal cookies and milk
- ☐ Fruit and cheese kabobs
- ☐ Cut up vegetables and a low fat dip
- ☐ Hardboiled eggs
- ☐ Lean ham or turkey slices
- ☐ Trail mix of nuts, dried fruit, pretzels
- ☐ Air popped popcorn
- ☐ Unsweetened apple sauce
- ☐ Homemade popsicles made from fruit juice or non-fat yogurt
- ☐ Smoothies made with frozen fruit, non-fat yogurt or tofu and water
- ☐ Rice cakes, whole grain crackers or whole grain bread with low fat cheese, fruit spread, peanut butter, almond butter, or soy nut butter
- ☐ Low fat cottage cheese and peaches canned in light syrup
- ☐ A light or reduced fat string cheese with fresh berries
- ☐ Apples or celery with peanut butter or soy butter



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## PARENT TOOLKIT

### REPLACING FOOD REWARDS

Consistent use of food rewards for good behavior or hard work teaches your child that when he or she does something well they should get something to eat. It also teaches them to value the types of foods used for rewards- usually high sugar or high fat treats -more than other foods.

If you would like to begin to change your practices, here are some ideas you can try:

- Make a list of all the times food rewards are used. You may be surprised at how often your child is eating in the course of a day.
- Make a list of nonfood “motivators” for your child that are currently meaningful, such as stickers, stamps, Pokemon cards, Barbie accessories, sports stuff, verbal praise, “high fives”, or doing something special with you or a friend.
- If your child is attached to the food reward system, begin by having him or her earn one sticker or check mark on an incentive chart before receiving the food reward. As they become familiar with the system, increase the number of stickers to two, then three, then five and so on. When you increase the number of stickers needed to earn a reward, especially for tasks they mastered well, tell your child you are doing that because he or she is growing up fast or doing it well. Make it a goal to earn more stickers.
- Once you increase the number of stickers or checkmarks to earn for a reward, discuss changing the reward from food to something more tangible. For instance, after earning ten stickers, they can get a dollar for a trip to the toy store. They can save their money or spend it right away.
- When you begin this process, it is important to have a visual way for your child to follow his or her progress so they stay motivated. Use incentive charts to help track progress.
- Some examples of non-food rewards include: a trip to a special park, playing a favorite game, or having a friend over.

Changing how you entice your child to do his or her work or behave the way you want is difficult. Also, sometimes children need to do their work or behave a certain way without a reward. Your child needs to learn to do something because it is what is expected in a certain situation, not because he or she is going to get something from it.

Source: The Down Syndrome Nutrition Handbook, Joan Medlen

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## PARENT TOOLKIT

### TIPS FOR INTRODUCING EXERCISE

#### 1. Make It Fun.

Choose activities your child enjoys, whether it's swimming, dancing, jumping on a trampoline, yoga, basketball, bowling, or a trip to a climbing gym. Many children with special needs are likely to have more fun with individual and non-competitive sports, but others love being part of a team. Ask your child what he or she might enjoy and if undecided, give four options to choose from.

Sam, for instance, loves to sing and dance and can happily work himself into a sweat rocking out to Elton John. "It's unconventional, but it works," his father says.

#### 2. Plan for Safety, Then Relax.

Parents should perform due diligence by making sure their child is wearing appropriate safety gear like helmets or shin guards and checking that the environment is free of obstacles or hazards. Then they should relax and allow their child to experience the bumps and scrapes of childhood.

Josh, for example, recently fell off his bicycle for the first time. "His mom was really worried and he was kind of sad," says his Best Buddies friend Alice. "I have a major major boo boo on my elbow from flying off my bike. I was excited to say to Josh, 'Welcome to the club – real bikers have battle wounds and this is your battle wound.'"

#### 3. Allow Kids to Fail.

Your child may not be successful when starting an activity – he or she may tire quickly or have trouble doing the activity. That's OK. Set realistic goals at the outset – completing the class for instance. Then work with him or her to set new goals that are achievable.

#### 4. Reduce Sedentary Time.

Any time you reduce the amount of time spent sitting in front of a screen, you will find that it increases the time spent being active.

#### 5. Involve Peers and Community.

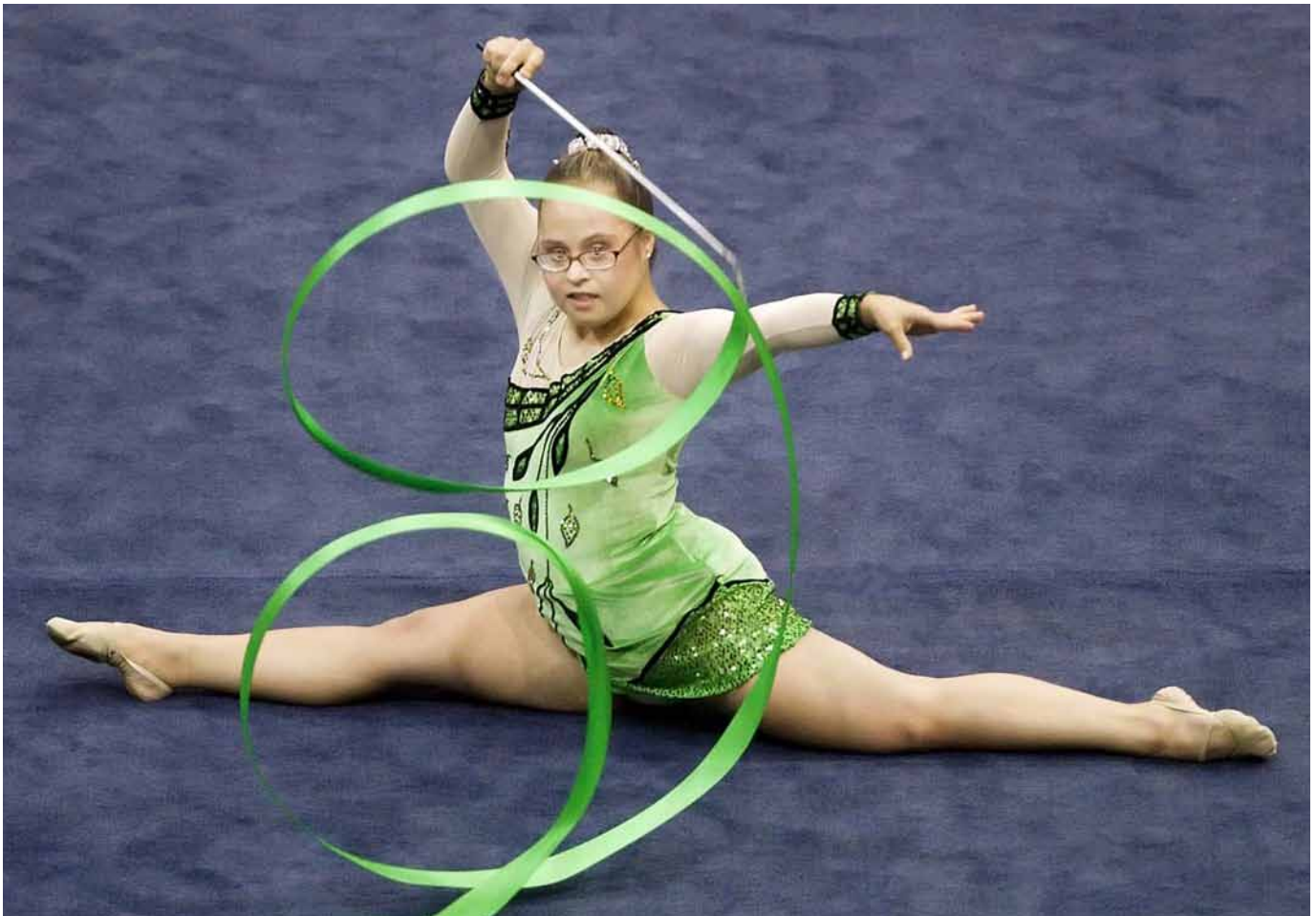
Children are often more motivated when they are doing things with others, and those personal connections can be profound for parents as well. Caregivers whose children participate in Special Olympics, for instance, have been found to have lower rates of depression and more feelings of participation. Organizations like Special Olympics, Best Buddies International and a variety of other inclusive fitness programs can forge meaningful connections for children while motivating their fitness activities. AbilityPath.org developed the How iPlay guide with Nickelodeon that demonstrates the many ways kids with special needs are playing in their communities; resources for getting involved are included. Visit [www.abilitypath.org/wwdop](http://www.abilitypath.org/wwdop) to download a copy of the How iPlay guide.

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## 6. Build Activity Into Daily Life.

Rather than piling on new fitness commitments, start small by walking to school or to do errands, parking farther from your destination, and taking the stairs rather than the elevator. Including children in household tasks like walking the dog, washing the car, working in the garden or cleaning the house is another way to get everyone up and moving.



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## PARENT TOOLKIT

### RESOURCES FOR ADAPTED AND INCLUSIVE FITNESS ACTIVITIES

#### **AbilityPath.org**

[www.AbilityPath.org](http://www.AbilityPath.org)

AbilityPath.org is an online hub and special needs community for parents and professionals to learn, connect and live a more balanced life - through all phases of a child's growth and development. The website combines social networking features with expert content from AbilityPath.org's team of educators, parents, therapists and medical professionals.

#### **How iPlay**

[www.abilitypath.org/wwdop](http://www.abilitypath.org/wwdop)

How iPlay was developed in partnership with AbilityPath.org and Nickelodeon to illustrate the power of play for ALL children. Kids with special needs play in their communities every day with the support of families, teachers, and organizations. This playbook includes amazing stories of athleticism, victory, and most importantly FUN.

#### **Special Olympics**

[www.specialolympics.org](http://www.specialolympics.org)

The mission of Special Olympics is to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community.

#### **Best Buddies**

[www.bestbuddies.org](http://www.bestbuddies.org)

Best Buddies is dedicated to establishing a global volunteer movement that creates opportunities for one-to-one friendships, integrated employment and leadership development for people with intellectual and developmental disabilities (IDD).

#### **The Medical Home Portal**

[www.medicalhomeportal.org](http://www.medicalhomeportal.org)

Type "recreation" into the search engine and select your state to find adapted and inclusive opportunities near you.

#### **The National Center on Physical Activity and Disability**

[www.ncpad.org](http://www.ncpad.org)

Comprehensive resources for every imaginable kind of activity, including the ability to develop adaptive tools through rectech.org, create instructional and exercise videos.

Learn More At



## **The National Ability Center**

[www.nac1985.org](http://www.nac1985.org)

Adapted recreation activities and summer camps in Utah.

## **American Association of Adapted Sports Programs**

[www.adaptedsports.org](http://www.adaptedsports.org)

AAASP uses the adaptedSPORTS® Model, an interscholastic structure of multiple sports seasons that parallels the traditional interscholastic athletic system and supports the concept that school-based sports are a vital part of the education process and the educational goals of students.

The sports featured in the adaptedSPORTS® Model have their origin in Paralympic and adult disability sports, however, they are innovative in that they are cross-disability in nature. AAASP has adapted these sports for the student-athlete based on their functional ability. By providing standardized competition rules, it is possible for the widespread implementation of an interscholastic adapted athletic system.

## **Boundless Playgrounds**

[www.boundlessplaygrounds.org](http://www.boundlessplaygrounds.org)

Boundless Playgrounds has developed nearly 200 truly inclusive playgrounds in 31 states and Canada and has over 100 projects under development.

## **BlazeSports America**

[www.blazesports.org](http://www.blazesports.org)

Driven by a desire to provide all children and adults with physical disabilities the chance to play sports and live healthy, active lives, BlazeSports is dedicated to offering programs, education, and tools worldwide.

## **AYSO VIP Program**

[www.ayso.org/programs/vip.aspx](http://www.ayso.org/programs/vip.aspx)

The AYSO Very Important Players (VIP) Program provides a quality soccer experience for children and adults whose physical or mental disabilities make it difficult to successfully participate on mainstream teams.

## **Little League Baseball the Challenger Division**

<http://www.littleleague.org/learn/about/divisions/challenger.htm>

The Challenger Division was established in 1989 as a separate division of Little League to enable boys and girls with physical and mental challenges, ages 4-18, or up to age 22 if still enrolled in high school, to enjoy the game of baseball along with the millions of other children who participate in this sport worldwide.

## **Special Olympics: TRAIN program**

The Special Olympics TRAIN program is a health and educational program designed to assess Special Olympics athletes' sports skills and to provide them with nutritional information. The TRAIN placemat (see page 45) provides Special Olympics athletes with a tool that can be used during mealtimes. The front features an example of a healthy plate, sample foods in each food group and an explanation of how food fuels the body. The back is a calendar to track daily physical activity as well as fruit, vegetable, and water consumption.

Learn More At





## MEATS AND BEANS

- Make your muscles and body strong.
- Try to eat a variety of foods from this group: meat, fish, eggs, and beans.



## GRAINS

- Give your body energy.
- Instead of only eating white bread, white rice, and regular pasta, try to get half your grains each day from whole grains. Whole grains are usually brown in color and have more vitamins.

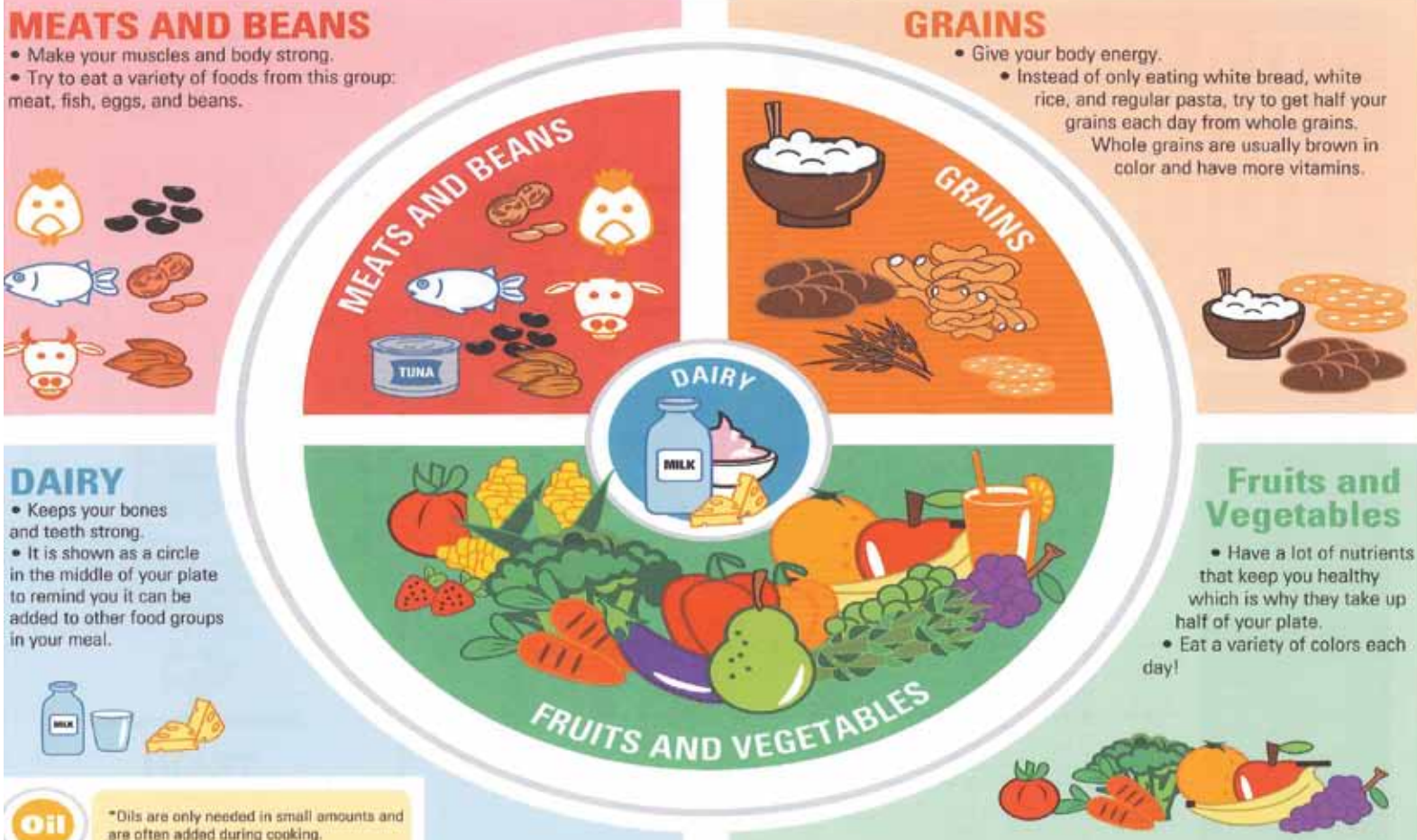


## DAIRY

- Keeps your bones and teeth strong.
- It is shown as a circle in the middle of your plate to remind you it can be added to other food groups in your meal.



\*Oils are only needed in small amounts and are often added during cooking.



## Fruits and Vegetables

- Have a lot of nutrients that keep you healthy which is why they take up half of your plate.
- Eat a variety of colors each day!



# TRACK YOUR SUCCESS

## WHAT DID YOU DO TODAY?

- Mark each way you chose to be healthy.
- Use the two blank boxes to track other ways you chose to be healthy.

**#1. Be more active**  
Try to exercise at least 30 minutes a day.  
Play a game outside instead of watching TV.



**2. Eat more fruits and vegetables**  
Eat at least 5 a day.  
Eat fruits and vegetables for a snack instead of junk food.



**3. Drink more water**  
Carry a water bottle throughout the day.  
Drink water instead of soda.



For more ideas on how to become a healthier athlete, look at the TRAIN@Home nutrition and exercise guide books.

TODAY I CHOSE TO

SUN MON TUES WED THUR FRI SAT

Be More Active

Eat More Fruits and Vegetables

Drink more water



Special Olympics

**TRAIN**

1133 19TH STREET NW  
WASHINGTON, DC 20036 • 360.411.1154

# About AbilityPath.org

**AbilityPath.org** is an online hub and special needs community for parents and professionals to learn, connect and live a more balanced life - through all phases of a child's growth and development. The website combines social networking features with expert content from AbilityPath.org's team of educators, parents, therapists and medical professionals. Content is available in English and Spanish and features advice, tool kits and other practical day to day living tips so families can learn, laugh and live a more balanced life. AbilityPath.org's community blogs, forums, events and groups allow parents to connect and share experiences and stories, providing an outlet of support and encouragement throughout their parenting journey.

AbilityPath.org was created by Community Gatepath, a nonprofit with over 90 years of experience serving families and children with special needs. Community Gatepath fosters hope, dignity and independence among children and adults with disabilities. It is one of the largest providers of services for people with disabilities in the San Francisco Bay Area. Over 8,500 individuals annually receive support or direct care through Community Gatepath and its comprehensive menu of services including: childhood early intervention, a Family Resource Center, inclusive preschool, transition for young adults services, employment services and social business enterprises. AbilityPath.org is funded through private donations, foundation grant support and corporate partnerships.

## Our Partners

### Best Buddies

Best Buddies® is a nonprofit 501(c)(3) organization dedicated to establishing a global volunteer movement that creates opportunities for one-to-one friendships, integrated employment and leadership development for people with intellectual and developmental disabilities. Founded in 1989 by Anthony K. Shriver, Best Buddies is a vibrant organization that has grown from one original chapter to almost 1,500 middle school, high school, and college chapters worldwide. Today, Best Buddies' seven formal programs – Middle Schools, High Schools, Colleges, Citizens, e-Buddies®, Jobs and Ambassadors – engage participants in each of the 50 states and in 50 countries, positively impacting the lives of nearly 700,000 people with and without disabilities around the world. As a result of their involvement with Best Buddies, people with intellectual and developmental disabilities secure rewarding jobs, live on their own, become inspirational leaders, and make lifelong friendships. For more information, please visit [www.bestbuddies.org](http://www.bestbuddies.org) or [www.bestbuddieschallenge.org](http://www.bestbuddieschallenge.org).

### Special Olympics

Special Olympics is an international organization that changes lives through the power of sport by encouraging and empowering people with intellectual disabilities, promoting acceptance for all, and fostering communities of understanding and respect worldwide. Founded in 1968 by Eunice Kennedy Shriver, the Special Olympics movement has grown from a few hundred athletes to more than 3.7 million athletes in over 170 countries in all regions of the world, providing year-round sports training, athletic competition and other related programs. Special Olympics now takes place every day, changing the lives of people with intellectual disabilities c all over the world to community playgrounds and ball fields in every small neighborhood's backyard. Special Olympics provides people with intellectual disabilities continuing opportunities to realize their potential, develop physical fitness, demonstrate courage, and experience joy and friendship. Visit Special Olympics at [www.specialolympics.org](http://www.specialolympics.org).



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Obesity and Child with Special Needs



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