



99 Bald Hill Road
Cranston, RI 02920

DSSRI NEWS

Winter/Spring, 2005

SUPPORT
•
EDUCATION
•
ADVOCACY
•
PUBLIC AWARENESS

President's Message

Is Spring around the corner? As I write this message it is snowing, again; schools are delayed if not closed. We are still deep into this winter mess.

We are working on our Comedy Night fundraiser for Friday, May 13, 2005 at the Providence Marriott. Mike Petit and friends will be the MC/entertainment for the evening. It should be a lot of fun. I hope to see many of you there! We are looking for raffle prizes; if you would like to help out with the raffle, please call the office.

Our Events/Hospitality Committee is planning our 3rd Annual Member Luncheon. Please watch your mail for more information.

Elections to the Board will be held at the

May Meeting. Anyone interested in joining the DSSRI Board of Directors should call the office at their earliest convenience.

We are looking forward to spring and planting our gardens. It is also IEP season and time to look into summer programs for your children. Shop around for just the "right" one for your child. Don't wait too long; summer will be here before we know it!!! Believe it or not!

If anyone needs support with IEPs or related issues, do not hesitate to call the office.

Sincerely,
Marilyn Blanche

President

Down Syndrome Society of Rhode Island

Vice President's Message

I think we can all agree that DSSRI has been a tremendous support for those of us whose lives have been touched by a friend or family member with Down syndrome. In addition to having the most current medical information available, the society also has many resources for us to advocate, educate, and celebrate the obstacles and opportunities ahead of us. In the past year, our society has also donated a number of books to libraries so that important resource information is available to individuals through any library participating in the CLAN system.

DSSRI also hosts a number of social gatherings such as the "New Parent Get Together's", the Annual Holiday Party, and the Buddy Walk. All of these functions give us the opportunity to welcome the newest little guys and gals into our group and to share our visions and journeys parent to parent.

We all know the benefits to being a member of DSSRI but the most benefit can be realized by volunteering on the DSSRI Board. As a board member, you have the opportunity to lend your expertise, talents and voice to organization. It is a rewarding experience and by networking with other members you develop a wealth of resources that will prove to be invaluable. We have four terms expiring in 2005 and a vacancy for term expiring in 2006 and one in 2007. If you are interested, please call the DSSRI office and speak to Claudia or contact me directly at (401) 683-0650.

Robin Pacheco
DSSRI, Vice President

In Appreciation

Derek Cicerone
Microsoft Giving Campaign
Family & Friends of the late Helena
Degnan
Family & Friends of the late Arlene
Sullivan-Conley
Family & Friends of the late John Jollie

Family & Friends of the late Florence
Pellegrino
Representative Al Gemma
Rhode Island House of Representatives
Joanne MacDonald
Santa & Mrs. Claus
IBEW Local #99

Members and friends of DSSRI for your help and support all year long!

CONFERENCES

MDSC Conference, April 2, 2005.

See flyer in this issue of DSSRI News for further information.

NDSS Conference, "IMAGINE" will take place July 7-10, 2005 at the Fairmont Hotel in Chicago, IL. More information available in the Events and Conferences section of www.ndss.org in the coming months.

NDSC Annual Convention will be held in Anaheim, CA at the Hyatt Regency, Orange County, near Disneyland® July 29-31, 2005. For more information contact Denise Dreyer @ 1-800-232-6372.

Calendar of Events

March 28, 2005:	Board Meeting	July 25, 2005:	Board Meeting (only if needed)
April 13, 2005:	General Membership Meeting "Wills & Trusts" <i>MetDESK</i>	Aug. 27, 2005:	Board Meeting
April 25, 2005:	Board Meeting	Sept. 14, 2005:	General Membership Meeting (speaker to be announced)
May 11, 2005:	Medical Panel (speak- ers to be announced)	Sept. 26, 2005:	Board Meeting
May 13, 2005:	Comedy Night	Oct. 2, 2005:	Buddy Walk
May 23, 2005:	Board Meeting	Oct. 24, 2005:	Board Meeting
June 27, 2005:	Board Meeting	Nov. 27, 2005:	Holiday Party
		Nov. 28, 2005:	Board Meeting

Disability

From *RIDING THE BUS WITH MY SISTER: A TRUE LIFE JOURNEY* by Rachel Simon. Copyright (c) 2002 by Rachel Simon. Used by permission of Houghton Mifflin Company

"Where are we?" I ask.

"We're at Tenff and Main," Beth says definitively.

"We can't be. We're walking down a street, between two corners."

"Tenff and Main."

"But look: this is a street. The corner's up there. Maybe you mean *that's* Tenth and Main. If so, then we must now be on Tenth Street. Is that right?"

"What *diffrence* does it make? I get where I need to go."

"Because there's a difference between a street and a corner. You're smart.

You can see that."

"Yeah."

"And we can't be at Tenth and Main until we reach the corner. Do you understand that?"

"I *guess*."

"So what street are we on?"

Silence.

"Do you know what street we're on?"

"I don't *know*."

"Yes you do. What *street* are we on?"

"Broad?"

For six months I have, for the most part, consigned my older, more disgruntled feelings about Beth to some remote corner of my heart. But now they are squirming out, as Beth's mood seems to shift toward, being more self-absorbed and contrarian - or perhaps as we become so well reacquainted that she reveals these hidden sides and I, in turn, rediscover my impatience. I want to blurt at her, "Stop being so dense!" I want to shake her and cry out, "Don't close your mind so fast to every new concept just because it's new, or because someone thinks you might benefit from it. Try to get it!" I want to chase away what I increasingly suspect is Beth's habitual defiance or laziness.

I struggle to speak with kindness, but it's getting increasingly difficult. Why can she not learn the simplest things? Is it that she can't, or that she won't? Does the problem lie entirely in her disability?

And - while I'm railing on - why doesn't she notice that anyone else has needs? Lately, she's entered a phase where she won't listen to other bus riders, not even her most adored drivers, when they talk about anything not bus-related. Me, too: I always arrive in town with my own food, knowing it has never occurred to her this entire time to stock even a single slice of bread for my visits. I ask for nothing except to be part of her life, accept her bawd expression if I dare mention anything about myself, and affirm and admire and truly like her. Yet she still resents giving me any help at all, even in carrying my bedding to the car.

I don't get it. Especially because Beth is smart and acutely aware. She can also be outgoing and generous; she's started joining the retirees in her high-rise for Tuesday-night Bingo, and she routinely purchases and hand-delivers postage stamps to drivers with utility bills to pay. But every time she complains about the nasty drivers, sometimes even attempting to incite impartial drivers to war against their crustier colleagues, every time she pays no heed to a drowsy shift worker

Policy Disclaimer

The Down Syndrome Society of Rhode Island, Inc. (DSSRI) was formed by people with a common interest - improving the lives of people with Down Syndrome and their families. It is for this reason that we welcome input from various parents and professionals.

We do not, however, as an organization, support or endorse any particular treatment or therapy. The purpose of this newsletter is to provide a forum for an exchange of ideas.

Please submit information or articles to:

DSSRI
99 Bald Hill Road
Cranston, RI 02920

DSSRI reserves the right to edit any submissions for appropriate and "person-first" language.

Disability

—continued

who has asked her to lower her voice, and every time she brags about how she barged into the drivers' room even though one of her enemies was there on his break, a feral feeling rears up within me, and it's all I can do to hold back my words.

How much is Beth, and how much is Beth's brain?

What is mental retardation, anyway?

I call Olivia at her office. We have been doing this every month; she brings me up to date on Beth's medical developments, I acquaint her with events on the buses. Sometimes, we allow ourselves to slide off course. We talk about long-beached romances; we offer wisdom from books. She refers to the Bible and Edgar Cayce, I talk about Toni Morrison and Benjamin Franklin.

This day, two beats before our goodbye, I try to sound casual: "Oh, by the way, what, uh, did you think mental retardation was before, you know, you studied it for your career?"

She says, "People who couldn't do what I could do, because they were born that way."

"When did you understand... what did you learn when you entered the field?"

"Well, one of my big moments came during my training, when I saw this movie about babies with a type of MR. Their brain wants to process information about learning to crawl, but it doesn't coincide with how their body responds. Eventually it happens, but it takes longer than with other babies. That was when I saw that what I'd need to deal with these people is patience, patience, and more patience."

Good, I think. Perhaps she'll understand the return of my negative feelings and help me reach a calmer place. "Is that... what you find most... difficult about working with Beth?"

She thinks for a minute. "The worst part of it is the way the people around Beth deal with her: talking about her like she's not there, looking down their noses at her. I deal with this every day in my job, and not when I'm hearing about strangers, but sometimes families, too. One person I know was visiting her

family, and became talkative during dinner. When the family got fed up, instead of saying, 'Can you give someone else a chance to speak?' someone actually said, 'Maybe we should stick a pacifier in your mouth, and everyone laughed. It's so demeaning! People treat their pets with more respect.

"I don't have any trouble with Beth," she concludes. "I think she's a joy to work with."

"Me, too," I say, half-truthfully, and change my mind about asking my question. I hang up in a swirl of relief and shame. I have lived with mental retardation for thirty-nine years, and I have never asked anyone what it really is. In the interest of raising four equal children, our parents almost never uttered the words except in private and never added books about mental retardation to our shelves. In fact, I'd read about this disability only in works of fiction - *Flowers for Algernon*, *Of Mice and Men*, and *The Good Earth*, when I was younger; when I was older, *The Sound and the Fury* and the Flannery O'Connor short story "The Life You Save May Be Your Own." And none of them answered the questions that I hadn't thought to ask. But why should it have occurred to me to do so? Mental retardation had just always been my sister, and my sister had always been it.

I am glad Olivia had to get off; I am not prepared for her to see my ignorance.

Then, on my next visit, which falls right after Beth's birthday, when we are now officially "twins," I drag through a day that sits especially heavy in my heart. On seventeen buses, over twelve hours, Beth's talk brims with spite about the brutes she encounters in the drivers' room. Her babble is unceasing, booming, and unvarying from bus to bus. People glare. An elderly man with a cane, who evidently assumes I sat beside Beth without knowing what I was getting into, leans close to me and says, "She sure does run her mouth, that one." While we're waiting at the terminal for a bus, I'm accosted on the sidewalk by a mother and her teenage daughter. The mother, who grasps immediately that I'm Beth's sister, ignores Beth while shouting at me that I

Disability

—continued

need to control her: she picks fights with them on the bus, I'm told, as she's jealous when they speak with the drivers, and plays her radio because she knows it irritates them. Beth shrugs. Late, in our day, when I suggest that she at least speak more softly on the bus, she says to driver after driver, "Rachel thinks I'm talking too loud. The last driver didn't think I was talking too loud, he sez I should do what I want, and thaz right, I don't talk too loud, do you think I talk too loud, do you, do you?" I tell myself to let it roll off me, that it's none of my business if she's as loud as a foghorn. I don't want to intrude like her nosy coriders. Live and let live. Right?

Then that evening, as we rest on her love seat watching *Diff'rent Strokes*, my head splitting despite my relief that I finally got to the end of this day, she gives me her slyest smile and says, "I'm gonna tell that fat girl off tomorrow. I'm gonna tell her like it is."

I look at her.

"Who are you talking about?"

"Just somebody. She wants everyone to treat her special, she wants the bus to leave her at her house instead of the stop, and the drivers are sick of it, and now she wants *my seat*, and I told her she couldn't have it, and she yelled at me. So I'm gonna tell her off. *Now you know.*"

"What do you mean, tell her off?"

She laughs. "I'm gonna tell her that she stinks!"

In a different mood I might laugh, too, then calmly discuss civility. But I'm already too worn out and perturbed to control myself, and my feelings suddenly break loose. "Beth, why don't you try being nicer to people?!"

"I'm nice to people who are nice to *me.*"

"Telling people they stink isn't being nice."

"It don't matter."

"It *does* matter. You don't need to be nasty to anyone."

"I don't *care.*"

I take a few deep breaths; I know it's just a petty conflict. But it's at least the tenth one

today, and dammit, I'm not just another busy-body passenger, I'm her sister, and the bus isn't a military theater, it's just a city bus and she's just another rider, and - and - and I just can't stand it anymore! "Why can't you ever notice when you upset people!" My voice is rising; I can hear my angry, righteous tone. I look away, pretending I don't want an answer, telling myself that everyone has feelings like Beth's sometimes. *But*, the dark voice retorts, *most of us manage to keep them to ourselves.* I peer back at Beth and force my words into an approximation of composure. "Beth. Really. You could just keep your mouth shut."

"She'll get over it."

"But think about what Jacob says: do unto others. You could just share your seat."

"Iz not her seat."

"It's not *yours*, either."

"And she *does* stink. And I can say what I want. Iz a free country. Louie the driver sez so, and that new driver, Rita -"

"Sure, you can say what you want. But you don't have to say things that hurt."

"I don't have to be polite to her."

"Look, I don't have to be nice to everybody, but I try, even when people act badly, because there's no need to make bad situations worse. And if I hurt people's feelings by accident, I apologize."

"I'm not gonna apologize."

"That's what we do when we hurt people."

"Thaz what *you* do."

"But other people have feelings, right?"

"I don't *know.*"

"What do you mean, you don't *know!*" I explode. "Other people matter! We can at least try to get along with each other!"

I flee into her bedroom.

Out in the living room, she turns her television up higher. I stay where I am, steaming at her window, clenching my fists. I will not go back out. I cannot. I breathe hard at my reflection, and past it, to the valley of row houses, their chimneys spiking up like fangs. I glance

Disability

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at her desktop and its feast of stickers waiting to decorate envelopes - teddy bears in tutus and smiling hearts and Beauty and the Beast - and I hate them all. I hate her Donald Duck sheets. I hate the Care Bear Christmas ornaments in the bathroom. This year is spreading out endlessly. Why bother? Why not just give up? I should just throw myself in my car and go home.

But she's my sister, I remind myself, closing my eyes, and under all this anger, I do love her. And I promised her a year. Stupid! A stupid promise! I am not up to this task at all.

I gaze out to the horizon, thinking, once again, How much is Beth, and how much is Beth's brain? Maybe it's time that I tried to find out.

Late one afternoon at home, seven hours before I will be leaving our annual twinness behind to turn forty, I shut off my fax machine, turn off the phone volume, close the computer file of my latest writing project, boil water for peppermint tea, and go online. Of course, I encounter many sites related to mental retardation. I wend my way through them, so caught up that I miss the sun's departure and the day passing into night. In the dark hours, I learn at last about my sister.

First I come upon The Arc of the United States at thearc.org, one of the leading advocacy organizations for people with mental retardation. I discover that 2.5 to 3 percent of the American population has mental retardation, which, based on the 1990 Census, means between 6.2 and 7.5 million people. That's a lot of Beths out there - twenty-five times as many people as those who are blind. One out of ten American families has intimate experience with mental retardation. That's a lot of me's.

I learn that my old nemesis, the term "mental age," does have some merit. "The term mental age," The Arc's site says, "is used in intelligence testing. It means that the individual received the same number of correct responses on a standardized IQ test as the average person of that age in the sample pop-

ulation. Saying that an older person with mental retardation is like a person of younger age or has the 'mind' or 'understanding' of a younger person is in-correct usage of the term. The mental age only refers to the intelligence test score. It does not describe the level and nature of the person's experience and functioning in aspects of community life."

In other words, "mental age" does not mean, as some erroneously believe, that the clock stopped ticking in some people's minds when the hands reached two or seven or fifteen. Mental retardation is not a childhood that has simply gotten stuck.

I observe that I too must alter my vocabulary. No longer is it proper to say, as I have all my life, that someone "is mentally retarded." As I discover on other websites, by using the new "People First Language," one focuses on the person first, the disability last, as in "a woman who has mental retardation" or "a man with mental retardation." The analogy is that people with cancer have cancer, they are not cancer itself; the disability is only one aspect of who they are. In addition, with People First Language, one can avoid using the word "retarded," which is too close to the familiar slur. In fact, some websites minimize the use of "mental retardation" by using as synonyms terms such as "developmental disability," "intellectual disability" and "cognitive disability." As I scribble down this People First Language, I realize that many of my acquaintances might disparage such linguistic changes as mere nods to political correctness, and for a moment I do, too. But then how many cultural barriers Beth has had to deal with throughout her life - and how many physical barriers people with other disabilities experience: sidewalks without curb cuts, restrooms lacking accessible facilities, cabs that refuse guide dogs. Altering the way I speak is nothing compared to what she, and they, go through almost all day, almost every day. And it is such a simple way to help transform the cultural landscape that it seems arrogant and misguided to resist doing so.

Back at The Arc of the United States, I learn

Disability

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about the causes of mental retardation, a broad category that includes anything that impairs the development of the brain in utero, during birth, or in childhood. Among the causes that have been identified are fetal alcohol syndrome, childhood diseases, and genetic conditions such as Down syndrome. But, surprisingly, in one-third of all cases the cause of mental retardation remains a mystery, as it does for Beth. That figure swells to three-quarters when you're focusing on individuals with retardation that is considered mild.

Ah! Here it is: *mild*. I dig in deeper and turn up delineations so fundamental that I am embarrassed to be just discovering them. I learn that mental retardation is classified in four levels: mild, moderate, severe, and profound. Mild, which accounts for about 87 percent of all people with mental retardation, my sister among them, refers to an IQ of about 50 to 75. To supplement my understanding, I go to a psychology database. Among the books I am referred to is *Abnormal Psychology and Modern Life*, by Robert C. Carson, James N. Butcher, and James C. Coleman. The title is familiar; I turn to my dust-lined bookshelves and there it is, one of the textbooks I picked up at the end of a recent school year, on the "Take Me" shelf in the building where I work.

Here, I learn that people with mild mental retardation are considered educable, as Beth was, after my mother pressed the issue, and that "their intellectual levels as adults are comparable with those of average 8- to 11-year-old children." Wait a minute! I thought that whole mental age stuff was nonsense - but I read on. "Statements such as the latter, however, should not be taken too literally. The mildly retarded individual with a 'mental age' of, say, 10... is not in fact comparable to the normal 10-year-old in information-processing ability....The social adjustment of such persons often approximates that of the adolescent, although they tend to lack the normal adolescent's imagination, inventiveness and judgment....Often they require some measure of supervision because of their limit-

ed ability to foresee the consequences of their actions" (Carson, Butcher, and Coleman, Scott Foresman, 1988, p. 475).

I find this explanation wonderfully clear. Would that I'd had this textbook when I was in college. No - when I was in first grade. I'd like to memorize those lines so I could repeat them in any conversation I have about my sister.

As for the other levels, this book continues, people with moderate mental retardation, which refers to IQs between 36 and 51, were those I saw in the Trainable classes at school, and would have been Beth's classmates had the school system placed her where her IQ tests initially (and apparently shortsightedly) suggested she should go. Many cannot read or write, have very limited conceptualizing skills, and have poor motor coordination, which is evident in their clumsy movements; they can become partially independent in a sheltered environment. People with severe mental retardation, with an IQ between 20 and 35, have major problems with motor and speech development; and, although they can develop some hygiene and self-help skills, they will always be dependent on others for care. Lastly are people with profound mental retardation, which means an I.Q. under 20. Given their extreme deficiencies in adaptive behavior, their inability to master anything beyond the simplest tasks, their very basic verbal communication (if there is any speech at all), and their often severe physical disabilities, they need custodial care for life.

A charge races under my skin. I am a detective on a trail. I am amassing a profile of what might as well be a missing person.

Almost on a high as I pore over this book, and circle round and round the Internet, I lose myself for hours until - *how had I failed to see that?* - I spy the definition of mental retardation. It's right there, on The Arc's website. Not only that, but it is at the top of the very first page I discovered this evening; it was staring me in the face from the start.

Disability

—continued

There are three criteria:

1. IQ is below 70-75.
2. Significant limitations exist in "two or more adaptive skill areas," which means "those daily living skills needed to live, work and play in the community. They include communication, self-care, home living, social skills, leisure, health and safety, self-direction, functional academics (reading, writing, basic math) community use and work."
3. The condition manifests itself before age eighteen.

I find myself holding my breath in amazement, staring at 2: "adaptive skill areas." Shaking my head, I gaze at the list, as certain characteristics trigger specific associations for me:

Communication: The many times when "I don't know" indicates that Beth truly has no idea what she thinks; Beth muttering to herself during conversations.

Self-care: Her insistence on tempting pneumonia with shorts and sandals in cold conditions; her unbalanced diet, despite everyone's efforts to educate her about healthful eating and the harm that can come from ignoring it.

Social skills: The way she resorts to nasty verbal attacks rather than diplomacy with the fat girl on the bus; her inability to read Henry's nonverbal and even verbal cues.

Health and safety: Her reluctance to allow medical examinations; her denial of any possible medical consequences with "Thaz not gonna *happen*."

Of course, anybody could have one of these behavioral traits, but there have to be two or more of these adaptive deficiencies, and there has to have been a pattern of these from childhood on, and -though it can't be known definitively without a test - there has to be the lower IQ. Beth meets all three criteria.

I get it. This new information means that when I tutor Beth about street corners, or

nudge her toward more appropriate attire for the weather, I should not expect instant assent or feel irate when I don't receive it. Indeed, anger is a foolish and pointless response when I should actually expect limitations. Especially when I factor in her stubborn personality. And even more especially when I consider that she's in a society that careens between bullying her and seeing her as a perpetual child.

I look up. I am in my dark apartment, and it is midnight, and I think, how could I have known Beth for all these years, and just come to this realization now?

I stare into the unlit room. I still have not untangled how much is Beth and how much is Beth's brain, nor whether, when she does not welcome new conversations, fashions, manners, boundaries, or concepts of space, it is because she cannot, or will not, or is simply not in a mood to open her mind at a given moment. I also have not ascertained how much, if any, of her self-centeredness is a result of her mental retardation. And, given the inextricable weave of nature and nurture, of self and society, that exists in all of us, it seems unlikely that I ever will.

But now I do know that, like me, and the drivers, Beth is on a journey. It's just that Beth's bus chugs along a lot more slowly.

I am shaky with insight. I want to tell someone; I need to. The first minutes of my fortieth birthday have already ticked by when I call Olivia's voicemail and leave her a message. I confess my ignorance. I spill out my relief. I tell her I have chased my loathsome feelings back into their pit.

When I hang up, I expect to relish this triumph. Oddly, though, as I rise to microwave my late dinner, I feel only queasy. Yes, there was a missing person here; we were twins thirty-nine times before I even started to find out about Beth. I turn off my computer, and watch the screen go dark.

Note: *Olivia*, mentioned in this article is Beth's case manager.

Mothers Have Spoken: Physicians Need to do a Better Job in Delivering a Postnatal Diagnosis of Down Syndrome

—by Brian Skotko

Two years ago, I asked 2,945 mothers who have children with Down syndrome to participate in a research study that examined how doctors deliver a diagnosis of Down syndrome. Your responses poured in, and your stories were poignant and sensitively honest. I am happy to report that you now have a voice in a national medical journal. The results of your opinions—and your frustrations—have been published in the January issue of *Pediatrics*.

This research study asked mothers to reflect on a central question: How could medical support have been better when you received the diagnosis of Down syndrome for your child? To answer this, mothers completed an 11-page survey, which included a variety of topics: How did your physician deliver the diagnosis? Were the verbal explanation adequate, the setting appropriate, the language sensitive, and the printed materials helpful? What was it like to receive the diagnosis?

Five parent support groups—the Massachusetts Down Syndrome Congress (Massachusetts), the Mile High Down Syndrome Association (Colorado), the Triangle Down Syndrome Network (North Carolina), the Down Syndrome Association of Los Angeles (California), and the Down Syndrome Society of Rhode Island (Rhode Island)—distributed copies of the research survey to all of the mothers on their mailing lists. In total, 1,250 responses were received, making this the most comprehensive and robust study on the topic, to date.

The majority of mothers reported being frightened or anxious after learning of the diagnosis, and very few rated the overall experience as a positive one. Among the words that were used were *shocked, angry, devastated, overwhelmed, depressed, stunned, and helpless*. The statistics revealed that mothers were more apt to be fearful and anxious if their physicians emphasized the negative aspects of Down syndrome when

first delivering the diagnosis. Physician behaviors did improve with time, although very slowly. Definitively positive comments did not seem to be included in mothers' responses until the late 1990s and 2000s. Mothers were most optimistic when their physicians talked about the positive aspects of Down syndrome and provided them with up-to-date printed materials.

Through their collective responses, mothers have called upon physicians to adopt 10 recommendations when delivering a postnatal diagnosis of Down syndrome:

(1) **The person to deliver the news should be a physician.** Mothers in this study received the diagnosis from a variety of health care providers: pediatricians, neonatologists, obstetricians, genetic counselors, nurses, and in two cases, the lactation specialist and the candy-striper volunteer. Mothers felt that a physician was the person most knowledgeable to present the diagnosis.

(2) **Obstetricians need to coordinate their messages with neonatologists and pediatricians.** In many hospitals, mothers suggested that there was confusion and, at times, disagreement over which physician was responsible for delivering the news. Physicians from various specialties need to work collaboratively.

(3) **The news should be delivered once the mother is settled and as soon as a physician suspects the diagnosis.** Some mothers were upset that they received the news immediately, particularly while episiotomies were still being sutured. Most mothers, however, were worried during what was described as a silence period, where no health care professional would give them an honest answer about what was going on. A physician should not wait until a diagnosis is confirmed through karyotyping; mothers prefer to be aware of the physicians' thought process, no matter how difficult the news might be.

Mothers Have Spoken: Physicians Need to do a Better Job in Delivering a Postnatal Diagnosis of Down Syndrome

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(4) **Whenever possible, the physician should make the announcement with both parents present, in a private setting.** As the diagnosis of Down syndrome is just as novel to the father as it is to the mothers, physicians should not expect that fathers should be the ones to share the news with the mothers.

(5) **When delivering the news about Down syndrome, the physician should first congratulate the parents on the birth of their child.** Mothers have recommended that physicians include the positive aspects of Down syndrome in their first descriptions of the condition. Many mothers mentioned that the best words used by their physician during this initial explanation were, “Love your child like any other child.”

(6) **Health care professionals should keep their personal opinions to themselves.** Mothers have asked physicians to offer sound medical advice based on up-to-date information, but not personal opinion.

(7) **Mothers should be provided with up-to-date printed materials.** Most new parents were frustrated at either receiving outdated information or no information at all. Mothers requested receiving complimentary copies of books on Down syndrome that included positive imagery; or, in the cases where hospitals were financially unable to do so, a bibliography listing the most current resources for new parents.

(8) **Parents should be provided access to other families who have children with Down syndrome.** First call programs—that is, support programs in which a parent of a child with Down syndrome visits or phones one of the new mothers—were mentioned as invaluable sources of help to the new parents. Hospitals and parent support groups should work collaboratively to provide this requested outreach to new parents.

(9) **After the initial diagnosis or suspicion is shared with parents, they should be offered a private hospital room.** As mothers respond to the diagnosis with a variety of emotions, many requested that they have a private space to express those emotions.

(10) **Physicians should be cognizant of the realities and possibilities of growing up with Down syndrome.** Simply put, Down syndrome is not just what was taught in medical school. Mothers considered it the responsibility of doctors to stay informed about the educational and social potentials of children with Down syndrome.

The time for change is long overdue. These recommendations offered by mothers are by no means revolutionary and could be easily implemented by all physicians responsible for delivering diagnoses of Down syndrome. You can continue to effect change by sharing the full study with the hospitals in your surrounding area. (The complete report is available online at www.ndss.org or www.ndscenter.org.)

Also of note: Many of the mothers who responded to the survey received the diagnosis of Down syndrome through prenatal testing. These results were analyzed separately and will be published in an upcoming issue of the medical journal, *American Journal of Obstetrics and Gynecology*. I will be sure to submit to you another report when I am able to release these results.

Financial support for this research was provided by the Tim White Fund from Children’s Hospital Boston and a part-time research grant from Harvard Medical School.

Brian Skotko is a joint-degree student at Harvard Medical School and Harvard John F. Kennedy School of Government. He has a 23-year-old sister with Down syndrome and has co-authored the book, Common Threads: Celebrating Life with Down Syndrome. He can be contacted at Brian_Skotko@student.hms.harvard.edu.

School Accommodations and Modifications

Some students with disabilities need accommodations or modifications to their educational program in order to participate in the general curriculum and to be successful in school. While the Individuals with Disabilities Education Act (IDEA) and its regulations do not define accommodations or modifications, there is some agreement as to what they mean. An accommodation as used in this document allows a student to complete the same assignment or test as other students, but with a change in the timing, formatting, setting, scheduling, response and/or presentation. This accommodation does not alter in any significant way what the test or assignment measures. Examples of accommodations include a student who is blind taking a Braille version of a test or a student taking a test alone in a quiet room.

A modification as used in this document is an adjustment to an assignment or a test that changes the standard or what the test or assignment is supposed to measure. Examples of possible modifications include a student completing work on part of a standard or a student completing an alternate assignment that is more easily achievable than the standard assignment. Needed modifications and accommodations should be written into a student's Individual Education Program (IEP) or Section 504 Plan. These changes should be chosen to fit the student's individual needs. It's important to include the student, if appropriate, when discussing needed accommodations and modifications. Asking the student what would be helpful is a good first step.

Here are some ideas for changes in textbooks and curriculum. (Additional suggestions for the classroom, instruction and assignments will be in a future issue of D.S.Press.) When reviewing these ideas, keep in mind that any accommodations or modifications an IEP team chooses must be based on the individual needs of students, and the changes must be provided if included in the child's IEP.

Textbooks and Curriculum Books

Provide alternative books with similar concepts, but at an easier reading level.

Provide audiotapes of textbooks and have the student follow the text while listening.

Provide summaries of chapters.

Provide interesting reading material at or slightly above the student's comfortable reading level.

Use peer readers.

Use marker to highlight important textbook sections.

Use word-for-word sentence fill-ins.

Provide two sets of textbooks, one for home and one for school.

Use index cards to record major themes.

Provide the student with a list of discussion questions before reading the material.

Give page numbers to help the student find answers.

Provide books and other written materials in alternative formats such as Braille or large print.

Curriculum

Shorten assignments to focus on mastery of key concepts.

Shorten spelling tests to focus on mastering the most functional words.

Substitute alternatives for written assignments (clay models, posters, panoramas, collections, etc.).

Specify and list exactly what the student will need to learn to pass. Review this frequently.

Modify expectations based on student needs (e.g., "When you have read this chapter, you should be able to list three reasons for the Civil War.")

Give alternatives to long written reports (e.g., write several short reports, preview new audiovisual materials and write a short review, give an oral report on an assigned topic.)

Reprinted from D.S. Press, newsletter of the Down Syndrome Association of Greater Cincinnati and The Alliance (Technical Assistance Alliance for Parent Centers) Pacer Center, Inc. (952-838-9000) Minneapolis, MN

The Language of Feelings

—by Ann Nobis

Our goals for our children often include improving vocabulary, sentence structure, academic concepts, and following directions, as well as numerous other speech, language and communication skills. But what about the language needed to understand and express one's feelings? So often the feeling responses I get from the children and young adults I meet are just "good", "happy" and "mad".

Feelings are so personal to the individual and to the situation. How does one even begin to "teach" feelings vocabulary? Happy and mad are so much more concrete and visible than are feelings such as confused, disappointed, concerned, proud, embarrassed, interested, bored, excited, nervous, scared, sad, etc. Think about how often, as language models, we even openly talk about our feelings to our children. As parents we want to show our children we are in control and can do it all! I don't know about you, but, as a parent, I am far from knowing it all and from being in control all of the time!

I do want my daughter and the children I work with to be able to express their true inner feelings so I can help them understand

them and deal with them. Feelings are real and need our attention. Following are some suggestions:

Choose a few feeling words a month to focus on.

Role play personal situations while talking about them.

Label the feeling word and simply describe how it feels to you.

Use exaggerated facial and body expressions.

Demonstrate how you might solve your problem in a positive way if dealing with a negative feeling.

Use feeling words in conversations you have as a family, during discussions with friends and with your child so he/she has the opportunity to "see" your feelings as well as "hear" what they are called.

Provide language for your child to describe how they appear to be feeling... "You look confused, I guess you didn't understand. I will try again".

Pictures, photographs, icons, signs are also helpful in reinforcing what feelings mean and how to express them.

Reprinted from www.aim-high.org.

FROM OUR MEMBERS:

Mom seeking playmate/playgroup for 11 year old boy with Down syndrome. Interested persons may e-mail reynajarred@cox.net

Mom interested in a playgroup for a 8 month old girl with Down syndrome in the Tiverton, Little Compton, Aquidneck Island area. If interested, contact the DSSRI office at 463-5751.

"Since there is nothing so well worth having as friends, never lose a chance to make them." Francesco Guicciardini

Physical Education Classes can be Adapted for Children with Disabilities

—by Beth Casper

Tom Kobelinski's ideas have pioneered a whole new way of thinking about physical education and physical fitness. He finds the most creative ways for students with disabilities to perform successfully in physical education classes. He never assumes that a child can't be involved or would be better off without attending gym. "I believe that all students belong and can be successful in a regular physical education setting," said Tom, an adapted physical education instructor. "I am not a believer that students have to earn their way into least restrictive environments. They are students of the school, and they are welcome. I've never removed the opportunity for a student to participate in regular physical education."

That doesn't mean that Tom hasn't found challenges. One day, a fourth-grade boy with autism sat down on the track at the start of the class's mile run test. Tom decided that he would sit down next to the boy and talk to him about the mile run. Tom found out that the boy was frustrated because even at the beginning of the run, he was behind the rest of the classmates. Tom and the boy discussed why the students run for a mile, and they watched the other students complete each lap. Afterwards, Tom asked the boy if he would like to run around the track when the other students were gone. Tom let the boy pick the direction if the boy promised to keep moving for at least one entire lap. The boy completed the task successfully and felt so confident about his abilities that he played dodge ball with the rest of the students for the second half of the class.

In another situation, Tom worked with Marc, a student who screamed every time he entered the gym and for as long as he was in the gym. The previous year, teachers

decided to pull Marc out of the physical education classes because of his behaviors. Tom played a game with him in the hallway while another class was in the gym. Eventually Tom and Marc stood at the door to the gym and watched the other students doing calisthenics to music. Upon Tom's cue, Marc ran into the gym and ran laps around the other students - stopping every time the music stopped. Since then, he has attended physical education class with the rest of the students in his grade.

"It's these kinds of interventions that really speak to a child's abilities, not their disabilities," Tom said. "I believe that there is optimal performance and functional performance, and I want to shorten the gap between those two."

Tom's success can also be attributed to his partnership with LeMoyne Corgard, the elementary physical education specialist at Oxbow Creek Elementary School in the Anoka-Hennepin School District. LeMoyne and Tom have developed a model curriculum for inclusionary practices, which can be used by the school district. For the model to be successful, Tom and LeMoyne spend many extra hours together and with para-professionals planning for specific classes with specific children.

"I don't ever see any barriers for kids with disabilities- I look for solutions," LeMoyne said. "When I see students in first through fifth grade, I see kids of all abilities."

LeMoyne said that the model that he and Tom developed for their school district is helping many children be successful and learn new skills. "I have a unique perspective because I have to look at the needs of anywhere from 20 to 32 of my students in the physical education class," LeMoyne said.

Physical Education Classes can be Adapted for Children with Disabilities

—continued

“That really breaks the barriers down. When I see a child truly included, the message that sends to the other kids is the most powerful thing I’ve seen as a teacher. We have students who by the fourth grade expect that a

child with cerebral palsy will go around the track with them. They see that this child is capable of many things.”

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After School Program Inclusion

—by Maggie Kolk

Most schools advertise after school programs for their students. These programs may range from 2 to 4 hours after school. They usually have goals of a homework period time and then some supervised free time. Students with disabilities are allowed to sign up for these programs and cannot be discriminated against because of their disability.

School personnel may state that they don’t have to make accommodations for students with disabilities or that they don’t pay for the program or it isn’t funded through another source. The school administrators may also state that the accommodation costs too much for the program. Finally they may also claim that the accommodation will substantially change the program.

The following are some basic facts for your use.

School personnel who say that the program does not have to make accommodations are wrong. The Americans with Disabilities Act (ADA) pertains to all agencies that receive federal funds. Schools receive federal funding. If they are allowing the school building to be used, the ADA applies. Also, a public accommodation has to follow ADA rules and guidelines. A public accommodation means a private entity that owns, leases (or leases to), or operates a place of public accommodation. This means that if they allow the public to participate then

they are considered, under Title III of the ADA, to be a place of public accommodation.

It matters how funds are received and spent. Find out who receives the payment for the program and who keeps track of the hours and pays the employees. The school system usually handles both. If this is the case, the cost of accommodation is compared to the complete budget of the school system not just the amount allotted for the after school program.

The program personnel may say that if they accommodate your child they will have to raise the fee. Raising the fee for all students is fine, but they cannot tell the parent of the student with the disability that the parent has to pay the entire cost. The program personnel cannot tell other parents why the fee is increased without violating federal and state confidentiality laws. Program personnel are not allowed to divulge “personally identifiable information to anyone.” Since the child with a disability may be “readily identifiable,” the school cannot tell other parents that they are accommodating a student with a disability and that is why the fees are increasing.

Accommodations must be reasonable. To determine if the accommodation is reasonable look at whether the accommodation will substantially change the program. If it does then the accommodation would be found to be an unreasonable accommoda-

After School Program Inclusion

—continued

tion. “Substantially” in this instance means not achieving what the program was set up to achieve.

The program may have to change their policies and procedures to accommodate students with disabilities. They cannot discriminate against a student with the policies and procedures if reasonable accommodations can be made for the student. The student’s disability also has to be taken into consideration before any disciplinary measures are carried out. The program cannot hold a student with a disability to a standard that the student could not possibly meet because of the disability.

I suggest that parents view the program to see what type of accommodation would best meet their child’s needs and then sit down with staff and administration and work out a plan for the accommodations

that are needed. This way all involved are comfortable with the accommodations and the inclusion of the student with a disability into the program. Be aware that the school cannot place unreasonable expectations on parents. Parents of a student with a disability should provide the same information for their child as any other child in the program. Timelines for pick-up should be the same for everyone in the program.

Remember, it is not discrimination if there are age limits and no one past a certain age is allowed in the program. It is also not discrimination if, when you register your child, the program staff inform you that the program is full. You should ask if they have a waiting list. If they do, request that they put your child’s name on the list.

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Health Issues for Adults with Down Syndrome

—by Brian Chicoine, MD & Dennis McGuire, PhD

Health is more than the absence of disease. Health is a sense of physical, mental and spiritual well-being. It is a process that involves health promotion, health monitoring, and early intervention for health problems. Understanding what is typical or in the normal range for a person with Down syndrome is essential for providing health care.

Understanding Normal/Typical Adults with Down syndrome have a number of typical behavioral issues that are important to understand so as not to over-diagnose disease states.

- **Self-talk and imaginary friends** – These appear to be developmental stage-appropriate behaviors that are used as coping strategies, defense mechanisms, and to alleviate boredom.
- **The Groove** – People with Down syndrome often show a tendency towards needing sameness, repetition and order in their lives. It can be very functional.

- **Grief** – A delayed response to grief is often seen and it may be demonstrated in alternative ways.
- **Pain Tolerance** – People with Down syndrome may have an increased tolerance to pain. However, limited communication skills may also limit the ability to express/convey pain that can lead to the pain being expressed in alternative ways.

HEALTH PROMOTION

- **Regular Exercise** – We have found that adults with Down syndrome are more likely to be closer to their ideal body weight if they have opportunities for recreational and social activities (not necessarily exercise). We generally recommend 20-30 minutes of exercise 3-5 times per week. In addition, (or alternatively) social activities like shopping, visiting museums, etc. that involve walking can be very beneficial. Increasing energy expenditure by

Health Issues for Adults with Down Syndrome

—continued

parking a little farther away, taking the stairs, and working in the house and yard are all beneficial. Generally, turning off the television and being more active is beneficial.

- **Recreational Activities** – As noted above, recreational activities can have a benefit for physical health. In addition, they are an important part of mental health as well as part of life's enjoyment. Sometimes as parents naturally slow down with age or the adult with Down syndrome ages out of the school system, fewer activities are available. That is a particularly important time to seek other reliable people who can assist in participation in recreational activities.
- **Nutrition** – Obesity is the most common nutrition-related disorder. It has been demonstrated that children with Down syndrome have a basal metabolic rate that burns 200-300 calories less per day. The study showed that if reducing calories was the only way used to prevent obesity, essential nutrients were excluded from the diet. Therefore, increased activity had to be part of the solution.
- **Opportunities for Accomplishment and Sense of Worth** – Adults with Down syndrome have the same need as others to feel a sense of accomplishment and worth. For some, that may be a repetitive job that fulfills their need for order and regimen. For others, it may be a particular sense of being needed achieved through doing for others. An assessment of what the individual would like to get from a job, as well as what his skills are to do the job is encouraged.
- **Immunizations** – (These recommendations assume all childhood immunizations were given appropriately.)

Diphtheria-Tetanus – recommended every 10 years

Influenza – consider annually each fall especially if exposure to many people. Recommended annually for persons with certain other health problems.

Pneumonia – We recommend considering the pneumonia vaccine at age 50 for adults with

Down syndrome. Recommended at a younger age for persons with certain other health problems and then repeat in 5 years.

Varicella (Chicken Pox) – recommended testing for immunity by blood tests if there is no history of having had chicken pox. Recommend the 2-shot series if not immune.

Hepatitis B – recommended for people living in group facilities. We also recommend it for persons working in a group setting (e.g. workshop) and considering it for all others. We recommend a blood test before administering the vaccine for adults with Down syndrome to see if they have immunity (thus, they do not need the vaccine). In addition, we recommend drawing a blood test (hepatitis B surface antibody) to document attaining immune status 4 to 6 weeks after the third shot.

- **Osteoporosis prevention** – Osteoporosis is more common in adults with Down syndrome. Adequate calcium intake throughout life is essential. Recommend 1000 mg a day of calcium for men and non-menopausal females and 1500 mg a day for menopausal females (by diet or supplement). Recommend taking Calcium with vitamin D to promote absorption. Consider bone density scanning to screen for osteoporosis. Consider appropriate medical therapy for prevention or treatment of osteoporosis.

HEALTH MONITORING

- **Health Screening** – History and Physical exam recommended annually.
- **Some important aspects of the history:** – Decline in skills; Memory impairment; Swallowing difficulties, choking; Change in gait, unsteadiness; Incontinence of urine and/or stool; Change in appetite Change in weight; Behavioral issues; Psychological concerns; Change in mood; Change in interest in life
- **Thyroid** – Recommended annual thyroid blood testing.
- **Celiac Disease** – Consider blood testing (anti-endomysial antibody or anti tissue-transglutaminase antibody).

Health Issues for Adults with Down Syndrome

—continued

- **Neck x-ray** – once in a lifetime; (additional neck x-ray if previous abnormal or symptoms develop).
- **Cancer of the cervix** – Recommend pap smear every 3 years (after two annual tests normal) if not sexually active and asymptomatic. If sexually active, may want to do annually.
- **Breast cancer** – Recommend mammogram once between 35-40 and annually starting at age 40. Annual breast exam and teach/encourage breast self-exam (if possible).
- **Cancer of the testicle** – Recommend annual testicular exam and teach self-exam (if possible).
- **Vision** – Recommend exam every 1-2 years.
- **Hearing** – Recommend audiogram every 1-2 years.

*By Brian Chicoine, MD & Dennis McGuire, PhD, Adult Down Syndrome Center of Lutheran General Hospital, www.advocate-health.com/adultdown Steffi Gratigny, MD, The Denver Adult Down Syndrome Clinic, March 2003. Reprinted from **D.S. Press**, newsletter of the Down Syndrome Association of Greater Cincinnati*

HIPAA Gives Reasons to Rethink Guardianship

— from the MetDESK

All of us are familiar with HIPAA. Or, at the least with some of the ways it has impacted our lives from forms and clearances at doctors' offices, to an array of other ways in which it aims to protect privacy.

HIPAA regulations, which became effective in April 2003, represent a federal effort to set national minimum standards for the confidentiality of medical records. Many of you might know that under the new HIPAA rules, doctors are not allowed to talk freely about a patient's medical condition, and they can be fined, and even jailed, for dissemination of any private health information without consent. This applies to all individuals.

While privacy is a well-intentioned objective, it can have implications for the medical care of individuals with special needs if you choose not to appoint a guardian for your child after he or she turns 18.

A parent, by definition, is an interested person concerned with the total well being and care of a child or other dependent. If you as a parent have any feeling at all that your child or other dependent could possibly lack significant understanding or capability to make or communicate responsible decisions for him or herself, as related to health care, you may want to consider a lim-

ited guardianship. Under HIPAA, if some guardianship steps are not taken, another person may not be able to act on the person's behalf to obtain medical care.

In some states, disclosure of medical information can be authorized by a health care agent or other person recognized by HIPAA regulations as the "personal representative" of an individual in need of a guardian. This could happen if a situation arises where an individual is not capable of handling a medical decision on his or her own but does not have a guardian. As the saying goes, the best offense is a good defense and that advice seems to apply well here. For this issue, that means obtaining as much information as possible related to your child and HIPAA from various folks within your community. Some suggestions include a special needs attorney, your family physician and perhaps expert resources who are familiar with your child's situation and possibly potential capabilities.

If you need help or any additional information on the right resources to help you, contact MetDESK at 1-877-MET-DESK or www.metlife.com/desk.

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