



99 Bald Hill Road  
Cranston, RI 02920

# DSSRI NEWS

November, 2006

SUPPORT  
•  
EDUCATION  
•  
ADVOCACY  
•  
PUBLIC AWARENESS

## President's Message

**H**ello Everyone!

There is a hint of Autumn in the air already. The nights are cooler and it is apparent that summer is on the wane. I trust that everyone took advantage of the hot days of summer and enjoyed all the benefits the season offered. As the beach weather fades,

I'd like to welcome you to our busy fall schedule. I anticipate a great turn out of family and friends at our scheduled events for fall 2006. Listed below is our Calendar of Events which brings us to the end of 2006.

- *Buddy Walk, September 17, 2006. 10:00 at Goddard Park, Warwick, RI*
- *New Parent Gathering, September 30, 2006. East Providence, RI*
- *General Membership Meeting, Medical Panel, October 16, 2006. NEA RI Conference Center, Cranston, RI*
- *Holiday Party, November 26, 2006. IBEW Local #99, Cranston, RI*

I appreciate all your efforts to ensure the success of these programs. As always, if you have any suggestions for speakers or topics contact the office (401) 463-5751 or [coordinator@dssri.org](mailto:coordinator@dssri.org).

### Here's an overview of the past few months activities.

Our spring conference, Toward a Brighter Future, was packed with information for attendees. In fact, in lieu of a newsletter this spring we published a compendium for the conference which contained all the handouts from every speaker at the conference! There was a dinner dance for interested attendees who danced the night away with friends and family!

Our annual fundraiser, Night of 1000 Laughs, was a tremendous success! Thanks again, Phil and Tracey Rizzuto! We have already made plans for next year; May 4, 2007; Charlie Hall and the Ocean State Follies will be our entertainment at the Crowne Plaza at the Crossings.

This past July, several of our members attended the National Down Syndrome Congress (NDSC)

Convention in Atlanta. Claudia attended for DSSRI attending variety of workshops from, adult health issues to sibling issues; Katie Lowe presented a workshop, "Cooking with Katie" sponsored by DSSRI. Katie has agreed to present this workshop for interested self advocates within the next few months. Stephanie & Diane Cerep also attended the conference and attended many workshops addressing a variety of topics.

DSSRI has been very busy and we don't plan on stopping! Please take a look at the article "Parent Support" We are looking to offer topics on inclusion, siblings, adult issues and new parents. Again, contact the office with any suggestions.

Happy Fall!  
Marilyn

### 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.

## Stress: Kids get it too

(The following is a review of a workshop presented by Barbara Tien, B. Sc. SLP, at the Up Side of Downs teacher's conference. It is reprinted from the newsletter of the Calgary Down Syndrome Association, February 1998)

"Children may not always understand our words, but they always experience what's going on."

### Holmes and Rache life and event scale

Death of a spouse	100	Change in responsibility at work	29
Divorce	73	Son/daughter leave home	29
Marital separation	65	Trouble with in-laws	29
Jail term	63	Outstanding personal achievement	28
Death of a family member	63	Wife begins or stops work	26
Personal injury/illness	53	Begin or end school	26
Marriage	50	Change in living conditions	25
Fired from job	47	Revision of personal habits	24
Marital reconciliation	45	Trouble with boss	23
Retirement	45	Change in work hours	20
Change in family health	44	Change in residence	20
Pregnancy	40	Change in schools	20
Sex difficulties	39	Change in recreation	19
Gain of new family member	39	Change in church activities	19
Business readjustment	39	Change in social activities	18
Change of financial state	38	Small mortgage	17
Death of a close friend	37	Change in sleeping habits	16
Change to a different work place	36	Change in number of family get togethers	15
Change in number of arguments with spouse	35	Change in eating habits	15
Large mortgage	31	Vacation	12
Foreclosure of mortgage	30	Minor law violations	11

If your total is between 150-199 you have Moderate Stress

If your total is between 200-299 you have Medium Stress

If your total is over 300 you have Severe Stress with the potential of serious health problems.

### Stress is part of life

Each person has a tolerance level for stress. In life some people are just better at coping than others. Emotional stress occurs when an individual's tolerance level is exceeded.

Stress can be manifested in many different forms. Adults tend to express themselves verbally; i.e., letting off steam is a very common and accepted behavior. It is important to "act like a man" or "deal with it" and "get on with life" and this is the extent of the advice many get to deal with stressful experiences.

However, children tend to act out their stresses. They lack the cognitive reasoning skills to express feelings and emotions and thus can either withdraw or lash out in many unique and unpredictable

ways. Children with cognitive impairment do not have the same level of language, memory of social skills to tell others what has happened or what is bothering them. Their behavior is misinterpreted, in particular when some adults automatically assume that it was deliberate.

Developmentally, all children are not at that stage of insight; i.e. that things are too tough, or too long. All they know is that they are tired, or bored, frustrated, or that people are mad at them. They don't know why. Problems escalate because they do not pick up quickly on social cues or problem-solve independently. Parents and educators must take particular care to teach them the skills needed to reach out for help in appropriate ways and learn to cope.

# Stress: Kids get it too

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## Actions speak louder than words

Children with Down syndrome are known (at times to their detriment) for their pleasant personality and eagerness to learn. What parent doesn't cringe when people assume all children with Down syndrome are such happy kids? They all have their ups and downs, just like any other child, coping with the stresses of everyday life. Pity the child who is not a happy camper. This child is not living up to the expectation of being a good child with Down syndrome. She/he is a disappointment her/his parents and her/his teachers. When you are a disappointment in the eyes of others, you learn to view yourself as a disappointment.

## Kids get angry too! Feelings are OK, aren't they?

One of the problems of dealing with stress in children is that they are not allowed the same options as adults.

1. An **open display of anger or frustration** is considered unacceptable and precipitates confrontations; for example, a teacher can be angry with a student but children do not have the same right. "Don't talk back."
2. Adults can **withdraw or walk out** but this freedom is not given to children; for example, it is considered alarming if a student leaves the classroom or does not maintain eye contact when being scolded.
3. **Daydreaming** is often very therapeutic and productive but it is reprimanded in school in often humiliating ways, for example, being asked a question when the teacher knows the student hasn't been listening.

It is very likely that, more often than not, children may be punished for using some of the same kinds of stress-coping techniques that are satisfactory for adults.

The goal is to keep like stresses in balance and to help children cope. To start, we must allow children to express anger or frustration. Second, it is critical to recognize the stresses a child may be facing and are carrying with them into the classroom.

## Life stresses

1. **Fatigue** (chronic or acute) – predisposes children to irritability
2. **Toileting** – especially in school age children
3. **Disability** – children with intellectual challenges have less emotional control due to lack of understanding of situations

## 4. Chronic health conditions

5. **Social need for mutuality** – wanting to be like peers and recognizing in many ways that they are different than peers
6. **Social environment** – crowding
7. **Family relationships** – neglect, over anxious parents, over-protective parents
8. **Aspiration levels** – of parents and teachers can be too high or too low

All of the above interact in different ways and at different times. When stress level is exceeded, behavior at home and school can become a concern.

## Signs of stress and changes in common behavior patterns ...

1. Withdrawal or refusal to participate in once – loved activities
2. Dysfluencies-stuttering
3. Separation anxiety
4. Self stimulation behaviors – rocking, tuning out, thumb sucking
5. Increase in refusals – "no" language
6. "I don't" syndrome
7. Unusually quiet
8. Hesitant to join in family routines; needs prodding
9. Failure to follow regular, daily routines
10. Distractible – difficulty sustaining attention to tasks
11. Irritable and moody; cries easily
12. Avoidance of eye contact; head down
13. Short fuse
14. Chronic fatigue
15. Lack of appetite or increase in appetite

For many children, attending school daily and performing poorly is a source of considerable and prolonged stress. For example, if children overreact with increased muscle tension performance on many tasks may suffer and further increase the environmental stresses (i.e. clutching a pen tightly for printing)

Another good example is when the frustration level is reached in reading. This is the level at which children evidence distracting tension, excessive or erratic body movements, nervousness and distractibility.

## Stress: Kids get it too

—continued

This frustration level is said to be a sign of emotional tension or stress with breakdown in fluency and a significant increase in reading errors.

Math anxiety is very common, and one most of us can relate to! There is a feeling of frustration and incompetence, the root of which is fear of making mistakes and appearing stupid in front of others.

### Sources of anxiety (in class)

1. **Time Pressure** – timed tests, flash cards, competitions
2. **Humiliation** – calling out marks highest to lowest, being called on by the teacher to perform in front of the class
3. **Emphasis on one right answer** – a student may work hard and still get the wrong answer. There is often no reward for effort or process of thought. Yet, that is how learning occurs: process vs. product.

Rewarding process as well as correct answers prevents students from becoming fearful of making mistakes and possibly getting angry with themselves. **It is important to call on all children to demonstrate their competencies, and their weaknesses.**

### Do's and don'ts of supporting a child experiencing stress

#### **Negative beliefs – doing things for the wrong reasons**

1. All kids with Down syndrome are the same
2. Big boys/girls don't cry
3. It's my way or the highway
4. If you take one you have to take them all
5. I go by the book
6. It's my duty as a parent, teacher, aide ...
7. he really wanted to, he could do it
8. I want more for you
9. We have standards
10. Super – parent – if we've gotten this far, there's no letting up
11. kid – “poster” kids can't let up

When we do things for the wrong reasons, we end up hurting the person we are trying to help and that includes children, parents and teachers.

If you want children to behave and be good, it is important to not have a black and white relation-

ship where people are judged as being good vs. bad. In coping with stress, we all try our best with the skills and resources we have at hand. The greater the individual and family resources, the greater the chance that children can cope.

### Don'ts: what teachers do to induce stress in children

The emphasis that teachers place on competition in so many school situations makes a child feel that he can't meet the expectation required to win his teacher's approval.

For children with special needs, the problem is compounded when you are always at the bottom of the class.

1. You are never student of the week
2. Your spelling test never gets a sticker
3. You never get to line up first
4. You never get a speaking role in class productions
5. You don't receive a report card with achievement ratings
6. You are always being pulled from the classroom

### You can't fool Mother Nature

Failure to identify and accept a child's individuality generates stress that unnecessarily makes life more difficult for child and adult. Demands may be made that are impossible to meet, owing to the child's basic makeup. Sometimes adults are oblivious to the child's basic needs.

A child's individuality is undeniable, but adults sometimes do not like what they see and, therefore refuse to acknowledge certain components of the child's disability, or they exert efforts to get the child in step. Anyone who has been around children knows some children are harder to deal with than others, but wishing the “Bobby” was more like “Andy” rarely serves any useful function.

### Words of wisdom

Following a crisis, the greater the individual or family resources, the less stress or impact will be experienced, and the greater will be the ability to cope internally with the crisis.

The idea that the parent can transmit to the siblings is one of acceptance of the child for what he is, sympathetic tolerance for his deficiencies, and expectations that he will contribute to the household activities in areas of competence.

## Stress: Kids get it too

—continued

The parents' attitudes towards the child and the parents' techniques of dealing with the child will be reflected in the child's self-attitudes and behavior towards others.

Self image is usually an outgrowth of how she or he is seen by others – most significantly the parents.

### The right amount of stress is good

For too long, children with special needs were protected from the real world. They were isolated from the stress and strain of daily life. They grew up under – challenged and under - achieving.

It is important for each teacher and parent to realize that we cannot divorce our stress from our

child's stress. The two are intertwined. It is important that we all recognize each other's stresses and the impact on our ability to interact with others. By talking about stresses openly and honestly, we can teach everyone coping skills that will help avoid crisis and confrontation.

References: **Controlling Stress in Children;** James H. Humphrey, Joy N. Humphrey, 1985; and, **Stress in Childhood;** edited by James H. Humphrey, 1984

*The above article was taken from Down's Update, newsletter of Mile High Down Syndrome Association, Inc. PO Box 620847, Littleton, CO 80162*

## Some Thoughts on Men and Grief

**G**entlemen, you are about to enter the pre-season of the big leagues. It is a period in ones' life called, "Grief." Some of you have experienced it before, and for others, this is the first time. It is a part of life, and for some reason you were selected. Don't ask me why: I don't have a clue!

When a tragedy or crisis occurs in our lives, we feel as though we have totally lost control. Men have had time feeling out of control; I know I do. We were raised to fix things, make them right. Dads, grief is normal and healthy. It either makes you bitter or better. Grief is a God-given emotion that allows us to empty out the deep feelings that must not be kept inside. Your choosing to endure this period in your life will make you a stronger and more mature man. Things to remember:

Your child being born with special needs has nothing to do with your manhood; leave the macho stuff behind.

Do not put distance between yourself, what happened, and your family.

Go through the grieving, deal with emotions, learn from them.

Men stay and find solutions; boys make excuses and forsake their commitments.

Your focus should not be on what has happened to you, but on what has happened to your child.

The fact that your child has been born with special needs is not going to change; you have to change!

Your spouse/partner needs your support on this one.

Your child needs a father, so, "step up to the plate."

Ask for help, it is a strength to do so. Join a support group, find another man who has a child with special needs because you need to learn about your child's disability and your new world.

You are now an exceptional father entering a higher level of manhood; take good care of yourself.

*By Ian John; reprinted from the DADS Newsletter, February 1998, Kindering Center, NFN, 16120 N.E. Eight St., Nellyue, WA 98008; The DS Press, Newsletter of the Down Syndrome Association of Greater Cincinnati, January/February 1999.*

## Parent Support Group

### Introducing "Support Connections"

Imagine gaining instant access to a group of individuals that share your common issues without leaving home!

With your help, the DSAGC (Down Syndrome Association of Greater Cincinnati) is launching a new email network called Support Connections. We will create several email networks of individuals (including parents, people with Down syndrome, families and/or professionals) sharing common issues so you will be able to connect with each other at anytime for sharing ideas, asking/answering questions, or getting support when you need it.

The need for these groups is clear. People are so busy that they don't have enough time or energy to attend a support meeting across town. We cover nine counties and the location of the meetings is not always convenient though we try to keep the meeting sites centrally located. But on the other hand, feedback from parents clearly shows that people are craving support from others in similar situations.

So, we have created this concept of email based Support Connections.

#### Participant's Role:

Inform us that you would like to share your email address on a list with others in a group that applies to you

Share information, experiences and knowledge to help others in your group

Ask for support when you need it

#### DSAGC's Role:

Share information specific to each group found on websites, articles, books and information obtained at conferences that might be helpful to the group

Periodically recruit "experts" in the particular area to address you group by email or by phone conference depending on interest. For instance, an expert on Section Eight Housing could be available for consultations with the Housing Options group at a set time and date. You would call and 800 number and be able to speak with the expert and the other group members on the phone at the same time and get all your questions answered.

Help assist, if the group chooses to, face-to-face meetings for social or informational purposes

The options for support and information sharing are limitless and we will do whatever we can to support the groups!

#### Six Different Groups:

At this time, the groups we are forming include the following but if you identify further groups in the future, please let us know and we can work with you to start a group that meets your unique needs!

*families involved in major medical needs*

*Adult siblings of adults with Down syndrome and their specific concerns: he/she moved last month ... now what do I do?*

*families needing help with behavior issues*

*families looking at housing options with the plan that one day their adult child will move out of their home*

*families working with people with the dual diagnosis of Down syndrome and Autism*

*families led by single parents and the unique needs that they have*

If you would like to be added to one of these email lists or just need more information contact Martha at the DSAGC or by email at: [Martha.dsagc@fuse.net](mailto:Martha.dsagc@fuse.net)

*Reprinted with permission from D.S. Press, the newsletter of the Down Syndrome Association of Greater Cincinnati; July/August 2006.*

After reading this article I thought it was a great idea! So, I thought, "DSSRI could do this too!" If anyone is interested in participating in "Support Groups" via email; send an email to me at [coordinator@dssri.org](mailto:coordinator@dssri.org) stating that: "you give DSSRI permission to distribute your email address to others for the purpose of sharing information for support groups." Topics we will start off with: Siblings for Siblings; Cardiac Issues; New Parents; Inclusion; Behavior; Support groups for parents of children with Down syndrome in the following age groups: 3-5; 6-12; 12-14; 14-21 and over 21.

If you have other suggestions for this project, please email the office. Thanks in advance for your participation!

# Transition Services: Communication is the Key to Success

By Kerry McKenna, reprinted from *Exceptional Parent Magazine*, September 1998 and *Down's Update*, October 1998

Okay, let's forget about education, schools, and regulations. Imagine you are taking a trip. Pick a place to go and depending on what you want to do, choose the route that best meets your needs. And if you want, you can change your route along the way to adjust to road hazards, weather, or take local roads to enjoy the scenery. But no matter what route you choose and end up taking, you know where you are heading before you leave.

This is what transition services are all about. A destination that not only provides you with a route to get there, which meets your needs and choices, but one which can be altered, to deal with changes in plans. It is about preparing for change by planning ahead. The most important questions that transition services planning tries answering include:

1. **How am I going to use the information and skills I have learned from school?**

For most students, the answer lies in joining the work force or proceeding with further education.

2. **What supports do I need to be successful?**

A diploma does not remove a disability. Some of the supports and accommodations that were an essential part of a student's success in the school environment are probably going to be needed for success in the post school environment. Identifying where those supports will come from then on becomes critical.

3. **What makes the transition services process different from preparing for graduation activities?**

The most noticeable difference is that transition services look at the student as a whole person who will be involved in the community, not just their accumulation of credits. Areas that may be addressed in the process include:

- Employment/continuing education
- Instruction/credit accumulation
- Community experiences
- Activities of daily living

- Functional vocational evaluation
- Specific topics that are examined can include:
  1. Looking at transportation
  2. Medical/mental health needs
  3. Housing
  4. Recreation/leisure
  5. Financial /legal issues
  6. Social needs.

Though a student will probably not have needs in all areas, each topic should be examined to ensure that supports and skills needed for success are in place.

Besides an understanding of the IEP portion of transition services, there are other topics that are critical for successful, quality transition service planning: a Person-Centered Planning Process, knowledge of outside resources, and advocacy.

4. **Person-centered planning process:**

Though there are many variations of this planning style, most models deal with the following.

What are the student's hopes and dreams for the future?

What are possible stumbling blocks?

What are the student's strengths, talents, abilities?

What supports are necessary to be successful?

The Person-Centered Process keeps the focus on the student. Districts that use Person-Centered Planning, rather than System Centered Planning, generally hold the planning meeting several months before the IEP annual review to allow time to incorporate the information into the IEP development process.

5. **Knowledge of outside resources:**

After the student graduates from the school system, who will provide the services the young adult with a disability will need to be successful? In most counties, agency guides exist which should be available to schools and parents. There are also Central information and "referral" sources. For instance, the United Way's referral database and Office of Collaborative Special Services may be of some assistance. Also, the local independent living center, your state's Vocational Rehabilitation Office, the Arc, and your local library's community reference section may be of some help. All of

## Transition Services: Communication is the Key to Success *—continued*

these resources can be found in your area telephone directory.

### 6.. **Advocacy:**

The effectiveness of the whole transition services process depends upon advocacy. Whether the student learns to become an effective self-advocate or has a parent, guardian, or friend to assist them, it is critical that advocacy issues be addressed as part of the transition services process. One of the keys to effective advocacy is knowing what is critical; that advocacy issues be addressed as part of the transition services process. One of the keys to effective advocacy is knowing what is needed. This is where Person-Centered Planning activities can have a positive impact. Many students and families have found that this process helped them identify the real needs and prioritize their activities as they work toward a clearly-stated future outcome. In instances where the student is not an effective self-advocate and no other person has stepped forward to advocate with the student in the transition services process, the school can perform a great service by helping the student identify someone to advocate with and for him or her. It is in the best interest of all that the identified advocate not be a member of the school staff, but rather someone who will continue to be available to the student after he or she graduates from the school system. Students oftentimes can identify someone they can talk to or confide in. Also, clergy familiar with the student may help identify an appropriate person.

### 7. **Approach**

How the issue of transition services is approached can also have a strong impact on how effective it is to the student, parents, and the school. A process designed around documentation and forms yields a transition services process that is sterile and devoid of relevance but may meet legal requirements as far as paperwork is concerned.

Transition services works when it is designed as a communications-based process; where the goal is focused dialogue about and with the student. That dialogue needs to focus on the student having a positive future in his or her community, the skills, interests, talents, and abilities that the student brings to that future, and identifying the supports that lead to success. It requires that all parties involved contribute to the process and listen to what others have to say. In districts that have adopted this style of transition services planning, a focused, streamlined, efficient process has

evolved that is high in quality and meaningful to all the key participants (students, parents, and school).

### **Students Should Graduate with a Resume, Not an IEP.**

#### **A Resume is:**

1. *Based on the individual's experiences that supports the job being sought.*
2. *Future Based. Most good resumes include a five-year goal; something the individual aspires to do.*
3. *A marketing tool. A good resume markets the individual's strengths, talents, and abilities as they relate to a goal.*
4. *Tells a story. Enumerates what this individual has done to prepare to achieve his or her goal.*
5. *A resume shows relationships, in the form of references, which uses references, to assist the career path. References are names of people who can vouch for the individual's ability to achieve his or her goal.*

#### **An IEP is:**

1. *Based on the individual's experiences that support being in special education.*
2. *Often is a 1 year document.*
3. *Usually relies on tests and assessments which identify why a person belongs in special education.*
4. *Does not always reflect positive things that have occurred as a student matures.*
5. *Identifies professionals who interact with students, their purpose, and contact time.*

*Kerry McKenna is the facilitator for the Hudson Valley Transition Coordination Site at the South Westchester (NY) Board of Cooperative Educational Services (BOCES)*

**15** **DEVELOPMENTAL AGE** **7**  
**12** **VS.** **24**  
**6** **Chronological Age** **10**  
Revolutionary Common Sense  
by Kathie Snow

The “developmental (or functional) age” concept is a disability-world paradigm that should make us halt in our tracks. Many children and adults with disabilities are routinely graded against a “developmental scale.” If a person’s abilities are substantially lower than the “norm,” he may be saddled with a “developmental age” (DA). His chronological age (CA)—his real age—is dismissed as irrelevant. From that point on, services, education, and even the way he’s treated by family members may be based on his DA. Yikes!

What happens when, for example, a 15-year-old (CA) is *treated* like a 10-year-old (DA)? He’ll probably *act* like a 10-year-old! Do we wonder why so many people with disabilities are considered “behind” or “not ready?” *Duh!*

During my son’s kindergarten IEP (Individualized Educational Program) meeting, the physical therapist shared her report with the IEP team. When she read, “Benjamin functions at the level of an 8-month-old,” I thought the kindergarten teacher was going to faint. I, on the other hand, was horrified that my son was portrayed this way. Luckily for us, 5-year-old Benjamin was present, and his presence refuted this testimony! He was sitting in a little chair at a little table, “reading” a book out loud (one of many he had *memorized*). When the kindergarten

teacher heard the “8-month-old” level, she looked from the therapist to Benjamin and back again several times.

After being questioned about her statement, the therapist revealed this assessment described his “gross motor” skills. Since Benjamin had never crawled, his “development” (gross motor) was—and would be forever, I suppose—“fixed” at the level of an infant. If Benjamin had not been in attendance at that IEP meeting so that the teacher could see who he *really* is, his opportunities for inclusion would have been diminished. The teacher would have probably insisted that he not be in her classroom that year. But his physical presence at the IEP meeting demonstrated that he was definitely not like an 8-month-old!

While doing presentations around the country, I routinely meet parents who describe their children by their disabilities, and include a statement like, “Brian is eight, but he functions at the level of a 4-year-old.” Egads! Who made this ridiculous presumption? And why would anyone believe it?

Brian might have “tested” at the level of a 4-year-old on one type of assessment or another, but he has double the life experience of a 4-year-old, so how in the world can we say he “functions” like a 4-year-old?

## 2 - Developmental Age vs. Chronological Age

Let's use our common sense here! Children who *do not* have disabilities are all over the map in their development! A 10-year-old (without a label) may read like a 13-year-old, play soccer like a 16-year-old, and behave like an 8-year-old—and he's considered "normal!" Then there are adults *without* disabilities, like myself: at the age of 52, I routinely vacillate between acting like a 10-, a 20-, and an 80-year-old. But no one ever puts a developmental or functional age on me! Why, then, do we do this to people with disabilities?

We have mistakenly assumed that treating a person as if he were his developmental age is a good thing. We may even believe, for example, that (1) a child could not be successful if he was educated in a classroom with others of the same chronological age or that (2) an adult could not do a certain type of job because of his developmental age. If you're concerned about a person with a disability "not being at age level," look carefully at his environment and how he's treated by others. Perhaps he's not "acting his age" because he's not being treated as the age he really is! *Duh!*

Routinely, young children (with and without disabilities) are held back in kindergarten and the primary grades because it's believed they're "not ready" for one reason or another. But many people are recognizing the dangers of this practice. Adults, with and without disabilities, who were held back in school painfully reveal the years of stigma attached to being older than their peers

**Treat people as if they were  
what they ought to be and you  
help them to become what they  
are capable of being.**

Johann von Goethe

in school. It can become a lifelong legacy of perceived failure that crushes a person's soul.

So what can we do when someone isn't "at the same functional level" as her chronological age? In some cases, the answer is nothing! In other cases, we can provide accommodations, supports, and/or assistive technology devices!

When deciding whether to do nothing or something, we once again need to use our common sense. If a child, for example, is not quite as mature as his peers, so what? Give him time to mature. If he's six, he needs to be surrounded by other 6-year-olds so he'll learn how to be a six. Keeping him with 4-year-olds will only encourage him to remain like a four.

If, however, a 6-year-old is thought to be like a 2-year-old because he's not talking, he needs a communication device! If a student isn't reading "at grade level," she needs modified reading materials and/or opportunities to learn through methods other than reading.

If a teenager or young adult doesn't "behave" at an "age-appropriate" level, he needs to be with others of a similar age, in positive, supportive environments where he can learn "how to be" that age. People around him need to have high expectations for him, as well as patience. And he may also need behavior supports.

Let's dump the developmental (functional) age concept once and for all! Let's treat people with disabilities with the respect and dignity they've earned for the number of years they've lived on this Earth!

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## Hailey's Hair

by Jeannie Reedy  
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It was funny how a compliment turned into an opportunity to do something really special. While enjoying the dinner at this year's Tearing up the Turf for Timothy golf tournament, a gentleman approached my daughter, Haley, and said, "My daughter would love your hair." I learned that his daughter, who also has Down syndrome, had Alopecia. This started me thinking about the possibility of Haley donating her hair. Haley was blessed with beautiful, thick, straight hair. I had heard of an organization, Locks of Love, several years ago, that makes wigs from hair that is donated for children who have lost their hair.

To preface the situation: you should know Haley LOVES her hair, and I don't blame her. In fact I would always tease her and say, "Haley, can I have your hair?" I always got the same response, "NO!!" So now that I was really going to want her hair, I wasn't sure how she would react.

We talked about what it would be like to not have hair. Though Haley said it would be sad, the discussion did not fully explain what it must be like to not have hair. Talking only went so far because all of the people we know without hair are older men. She thought they would look silly with her hair.

Thank God for the Internet – I was able to show Haley pictures on the Locks of Love website to make the process clearer to her.

With the help of a friend, I was able to find out who the little girl was that had started our "ball rolling". Her mother expressed how touched she was by Haley's gesture, but she had great news! We were happy to hear that over the summer her daughter's hair had started growing on its own. How exciting!! But we were a little disappointed that Haley wouldn't be able to see this through to the end.

The next day in the mail we received a letter from our parish about honoring the anniversary of September 11th with a weekend of service projects. On the list of ways to perform an act of service was, you guessed it, Locks of Love. We knew that this must have been meant to be. On September 17th Haley had eleven inches of her hair cut off to donate. According to our pastor, she is the only person he knows about from Christ the King parish to make this sacrifice.

Haley loves her new style, and in her words she looks "gorgeous." I am so proud of her doing this. Eleven inches is a lot of hair, especially for someone so into their hair. Now Haley wants to work on growing her hair out and doing it again. Haley leaves something special with everyone who knows her. And now she has given a special gift to someone every time they put on their hair.

Due to increased costs, Down Syndrome Society of RI is not participating in the RI Area Combined Federal Campaign or the Rhode Island State Employees Charitable Appeal. We are participating in the United Way of Rhode Island (#2790). We apologize for any inconvenience this may cause. Please call the DSSRI office with any and all questions (401) 463-5751.

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