

Hope or Denial?

How parents react to unexpected news

How parents react and learn to cope with having a child with a disability has been a topic discussed in professional literature for the past 20 years. For the most part, social workers and teachers were taught that parents go through stages of grieving as they mourn the loss of their “perfect child.” These stages, in order, are: denial (“This couldn’t be happening to me!”), anger (“Why is this happening to me?”), bargaining (“I promise I’ll be a better person if...”), depression (“I don’t care anymore”) and finally acceptance (“I’m ready for whatever comes”).

Over time, clinicians and parents have argued that this “stage” paradigm is too rigid and sequential. More realistically, parents often

experience a variety of feelings that come and go at expected and unexpected moments, some lingering, and some fleeting as they learn to “search and settle in.”

Of particular interest is the concept of denial. Do parents truly refuse to accept “the reality” of their child’s deficits? If a parent is hostile or uncooperative, is he or she “in denial?” What about the parent who puts away money every month in a college fund for her child with severe disabilities, noting she saves like this for all her children. Is this parent in denial of the severity of her child’s handicaps and what lies ahead in the future?

In a 2002 article, “Rethinking Denial,” published in the journal



Young Exceptional Children, the authors raise an important question: What is this concept of denial, and is it “maladaptive?” In reviewing the literature, these authors refer to other professionals who note the adaptive and positive aspects of being “in denial.” Nancy Miller, for example, in her book, *Nobody’s Perfect: Living and Growing with*

Children with Special Needs, notes that denial can be a protective device used by a parent when he or she is not ready to deal with a problem or its implications. She suggests that parents sometimes choose to put off dealing with issues even when deep down they know something is wrong.

Janice Fialka also notes
(Continued on page 8)



View Connections on the Web!

Thanks to our friends at Parent to Parent of New York State, *Preschool Connections* can be viewed online at the Parent to Parent Web site. Visit <http://www.parenttoparentnys.org/> Go to “Information,” then “Library,” and then “Newsletters”

In This Issue...

What’s Happening	page 2
“Celebrate Spring” Books	page 3
Resources	page 4
Health & Development: Obesity and more	page 5
Media: No More Meltdowns	page 6
Ask Nancy: Understanding Infants and Toddlers	page 7

About Helping Hands School

Helping Hands School is a private, nonprofit preschool for birth to 5 with special needs. Situated on 5 acres of rolling hills, woods, and fields in Clifton Park (Exit 9 off the Northway), Helping Hands School currently provides special education preschool and early intervention services to children from Saratoga, Rennselaer, Schenectady, Washington, and Albany counties. A nursery school for typically developing children is also offered.

Services

- A continuum of services for preschool children with disabilities, including various integrated and self-contained special education classroom models.
- Early Intervention home and community-based services for infants and toddlers with developmental delays.
- Intensive program options for children with a diagnosis along the autism spectrum.
- Developmental play groups for toddlers with special needs.
- Special Education Itinerant Teacher services provided in home, nursery school, daycare and community settings.
- Related services, including speech/language, occupational, and physical therapies.
- Comprehensive evaluations for preschoolers suspected of having a developmental delay or disability.
- Family support services available including parent support groups and social work services.
- Parent education workshops and newsletters for families of preschoolers and families of children with special needs, birth to 5.

About the Newsletter

Preschool Connections is a quarterly publication of Helping Hands School. The newsletter provides parents with up-to-date information about issues related to raising children of all abilities. Readers are welcome to copy and share information from this publication, but please credit Helping Hands School and *Preschool Connections*.

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Happenings

Family Events

Family Fun Time for Differently ABLED Children and their Families.

Enjoy the bounce house, inflatable obstacle courses, roller skating, and other fun motor activities at the **Fun Spot**, Route 9, Queensbury, May 23, 9:00-11:00am. This is a free event sponsored by Upstate NY Autism Awareness. *Visit the Web site or call Kristin Howarth at 791-2703 or Heather Walters at 761-0489.*

Special Story Time. In collaboration with the Upstate NY Autism Awareness, Crandall Library in Glens Falls has started to host a special story and art time for children with special needs on the second Thursday of every month at the library, 6:15-7:15pm. Ages 4 and older. *Contact Kristin at 791-2703 or Kristin@UpstateNYAutism.org*

Saratoga Springs Weekend Family Programs. Celebrate the Mexican holiday **Cinco de Mayo** with Don and Victoria Armstrong. Join in songs, games and stories, May 1, 11:00am... **Llamas in the Library** is May 9, 2:00-3:00pm. Meet live llamas upclose and personal from Dakota Ridge Farm. Ages 3 and older. *Call 584-1198.*

Children's Museum at Saratoga. The Museum will throw a **Picnic Party** at Congress Park with games, snacks, and crafts on May 5, 11:00am. (Call ahead for reservations.) On **Mother's Day**, May 9, mothers and grandmothers have free admission to the Museum. *Call 584-5540.*

Sundae on the Farm. Bring the family for a free tour of ArnoldHaven Farm in West Charlton on Father's Day, June 20, noon to 4:00pm. Visit the dairy facilities, and enjoy a horse-drawn wagon ride, live music, and ice cream sundaes at this Saratoga County annual event. *Call Cornell Cooperative Extension at 885-8995.*

Thomas the Train Returns! Upper Hudson Railroad offers rides on Thomas the Train, May 22, 23, and 29, 30. *Visit www.uhrr.com or call 251-5334.*

HCBS Waiver (What's that mean?)

The Home and Community-Based Services Waiver (HCBS) program is operated by the Office of Mental Retardation and Developmental Disabilities (OMRDD). This program enables qualified children and adults with developmental disabilities to live in the community as an alternative to institutional care, by providing services and supports individually tailored to meet each person's needs. Habilitation services, respite care, service coordination and adaptive technologies are services typically offered. Once a child is accepted into the Waiver program, the participant can generally retain the services until age 21 as long as he or she continues to meet eligibility. For more information, contact the Capital District Developmental Disabilities Service Organization (DDS) at 518-370-7370.

Special education jargon can be confusing. If school professionals use words or acronyms you don't understand, speak up immediately. Most people will be happy to slow down and explain anything that is unclear.





Celebrate Spring

Snow melts, robins return, and the ground grows soft and warm again---- it must be spring! These books will help you and your child usher in the season.



When Will It Be Spring?

by Catherine Walters (*Dutton Children's Books, 1997*)

Mother Bear and little Alfie need to sleep through the winter, but Alfie keeps misjudging clues and time and again wakes his mother long before spring has arrived. Alfie's eagerness and his mother's patience are shown in the beautiful illustrations as well as the text. This charming story will appeal to young and old.

It's Spring! by Linda Glaser (*The Millbrook Press, 2002*)

From the Celebrate the Seasons series, which includes *It's Fall* (2001), this brightly illustrated picture book portrays the wondrous workings of nature in springtime. Writing in first person from a boy's point of view, the author does a good job describing what spring

looks and feels like to a child: pussy willows soft against the cheek, birds that "cheep and warble and trill," and sunsets after dinner.

Susan Swan's eye-catching interesting cut-paper artwork will make you want to join in the celebration as new plant and animal life bursts out everywhere. A list of nature activities to do with your child is included at the end of the book.

Spring Things by Bob Raczka (*Albert Whitman & Company, 2007*) Springtime is full of happy activities. Nature is busy budding and flowering; baby animals are being born; gardeners are planting; and everywhere children are running and playing. The simple rhyming text only uses "ing" words to describe artist Judy Stead's vibrant illustrations.

Zinnia's Flower Garden by Monica Wellington (*Dutton Children's Books, 2005*)

Zinnia has a flower garden. She plans it out and plants her seeds. Then she waters, and weeds, and watches. First a seedling appears. Soon there are more. The little plants grow and grow until buds develop, and finally flowers bloom: sunflowers, sweet peas, and (of course) zinnias. The book boasts bright illustrations and simple text, but it's also filled with information about how gardens grow, making it appropriate for both older and younger children. This book is sure to inspire you and your youngster to start planting your own garden!

Sunflower House by Eve Bunting (*Harcourt Brace & Co., 1996*) Here's another book that will inspire you to grow a garden --especially one of sunflowers. A young child and his parents plant sunflower seeds in a big circle and watch the plants grow, and grow, and grow. The circle of gigantic flowers becomes a castle, a cage, a place to sleep in on summer nights. As summer wanes, so do the mammoth flowers, and the children's "house." They collect the seeds to plant the following spring and remember "it's neat to think when something's gone a part of it goes on and on..." This book beautifully shows the magic of nature *and* children's imagination.

Nature Activities to Do in the Spring

- * Plant beans in a pot on the windowsill. Water them and watch them grow.
- * Put up a bird feeder. Feed the birds. They can use the extra help in spring because very little food is left after winter. And there's not much ready to eat yet.
- * Take the hair out of your hairbrush and put it outside for a bird to use to line its nest.
- * Collect some earthworms. Put them in a large jar with moist (not wet) dirt. Wrap black construction paper around the jar. Each day unwrap the black paper and watch the earthworms tunneling. After a few days put the earthworms back outside.

Ideas from It's Spring by Linda Glaser



Parent Resources

Notables

EmFinders for Children who Wander

EmFinders EmSeeQ™ is a cellular-based emergency locator system that quickly finds an individual who has wandered off. Designed for children and adults with cognitive impairment and developmental disabilities, the watch-like device is worn by the individual who tends to wander. In emergency situations, caregivers make just two phone calls; the first is to 911 and the second is to EmFinders. The cellular network then provides 911 dispatchers the location of the missing individual. Learn more at www.emfinders.com

Walt Disney World (WDW) for Preschoolers

Planning a family trip to Disney? These two resources have loads of practical suggestions for visiting with children under five:

* *Beyond the Attractions: A Guide to WDW with Preschoolers* by Lisa M. Battista (2010). Paperback.

* "Tips for Taking Your Preschooler to WDW" Visit <http://allears.net/pl/kids.htm>

Stop Bedtime Battles

Your preschooler isn't sleeping through the night. He fights bedtime and refuses to nap. If this sounds familiar, try *The No-Cry Sleep Solution for Toddlers and Preschoolers* by Elizabeth Pantley (2005). The author does not advocate

any one method, but rather offers easy-to-use tools to identify sleep issues and an array of techniques from which you can choose, depending on your personal needs and lifestyle.

Apply Now for Your Access Pass

Offered by the NYS Office of Parks, Recreation and Historic Preservation, the Access Pass enables children or adults with a permanent disability free entry into State parks and swimming pools. The pass is good for four years. Allow 8 weeks for processing.

Download an application at <http://nysparks.state.ny.us/admission/access-pass.aspx> or call 474-2324.

NYACTS.ORG

It is estimated that more than 60,000 New York State residents have a diagnosis of autism or autism spectrum disorder (ASD).

In response, a Task Force has been created to help ensure that State agencies are working together to assist individuals and families struggling with ASD. A new Web site provides up-to-date information on detection, intervention and support services that are available through our State service systems. Visit <http://www.nyacts.org/> for more information.

Programs

Down Syndrome Resource Center (DSRC)

April 24: The Annual Beyond Our Wildest Dreams Conference. Featured speakers will be Dr. Brian Skotko and Susan Levine, co-authors of *Fasten Your Seatbelts: A Crash Course on Down Syndrome for Brothers and Sisters*. Keynote speakers will be Jason Kingsley and Mitchell Levitz, co-authors of *Count Us In: Growing Up with Down Syndrome*. Day-long conference in Albany begins at 8am. For more information, call 438-1113 or visit www.aim-high.org

Parents as Advocates

April 28: Protecting Their Future: Guardianship, Health Care and Financial Planning for Children with Disabilities. Presentation by Julie Michaels Keegan, Esq. Saratoga Springs Public Library, 6:30pm. Call Mary Fornabia, 588-3166.

Wildwood Programs

April 20: Functional Behavioral Assessment & Behavior Support Plans.

Presentation by Liz DeLibero. 9:00-11:30am, Latham.

April 27: How To Understand Your Child's Psychological Evaluation. Presentation by Dr. Alan Barnett. 9:00-11:00am, Latham. For more information, call 518-640-3300.

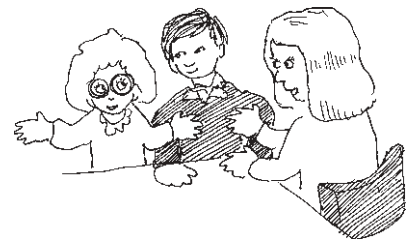
Parent to Parent of NYS

April 27: A Parent's Guide to Special Education. This training is designed for parents who are just entering the special education system to educate themselves on how to advocate for their child. This workshop will provide parents with an overview of the special education process. Registration required. Call: 381-4370.

Parent Groups

The Dad's Place at Parent to Parent NYS. Monthly meetings for dads, facilitated by Jim Swart of Parent to Parent. Network with outstanding fathers who have "been there;" share stories of success; share concerns or frustrations; refreshments, too! Contact Jim Swart at jmswart1@verizon.net or 381-4350.

Albany Chapter Autism Society of America. Gather information and support one another at monthly meetings: Saratoga Support Group meets at Saratoga Bridges in Ballston Spa; Albany Support Group meets at Macy's Colonie Center in Colonie. Call 355-2191.



What is...

Childhood Obesity?

Childhood obesity is a serious medical condition that affects children and adolescents. It occurs when a child is well above the normal weight for his or her age and height. Childhood obesity is particularly troubling because the extra pounds often start kids on the path to health problems that were once confined to adults, such as diabetes, high blood pressure and high cholesterol.

As part of regular well-child care, the doctor calculates your child's body mass index (BMI) and determines where it falls on the national BMI-for-age growth chart. The BMI indicates if your child is overweight for his or her age and height.

Using the growth chart, your doctor determines your child's percentile, meaning how your child compares with other children of the same sex and age.

Cutoff points on these growth charts, established by the Centers for Disease Control and Prevention define:

Overweight as a BMI-for-age between 85th and 94th percentiles

Obesity as a BMI-for-age 95th percentile or above

Because BMI doesn't consider things like being muscular or having a larger-than-average body frame, your doctor also factors your child's growth and development into the overall weight assessment. This helps determine whether your child's weight is a health concern.

Snacks appear to be one part of the problem. American kids snack three times a day, with chips, candy and other junk foods now accounting for more than 27 percent of children's daily caloric intake, according to a new study reported in *Health Affairs Journal*.

Another recent clinical study reported in *Clinical Pediatrics* says the "tipping point" for obesity may be as early as 2 years of age.

SOURCES: Mayo Clinic and Science Daily

Health and Development

Family Meals, Sleeping, and Screen Time. Preschool children exposed to three household routines -- regularly eating family meals, getting adequate sleep, and limiting screen-viewing time -- had a roughly 40 percent lower prevalence of obesity than those exposed to none of these routines. The study, "Household Routines and Obesity in U.S. Preschool-Aged Children," published in the March issue of *Pediatrics*, involved 8,550 4-year-old U.S. children. Among those exposed to all three household routines, the prevalence of obesity was 14.3 percent, compared with 24.5 percent among those exposed to none of the routines. Each routine by itself was associated with lower risk of obesity, and the more routines children had the lower was their risk for obesity.

Time to Toilet Train. Researchers at The Bristol-Myers Squibb Children's Hospital at Robert Wood Johnson University Hospital and Medical School have completed a study that pinpoints the period between 24 and 32 months of age as the most effective time frame for parents to begin toilet training lessons with their children. Additionally, the study indicates that the timing appeared to matter more than the specific training method used.

Serotonin and SIDS. The brains of infants who die of sudden infant death syndrome (SIDS) produce low levels of serotonin, a brain chemical that conveys messages between cells and plays a vital role in regulating breathing, heart rate, and sleep, reported researchers the February issue of *The Journal of the American Medical Association*, researchers theorize that this newly discovered serotonin abnormality may reduce infants' capacity to respond to breathing challenges, such as low oxygen levels or high levels of carbon dioxide. These high levels may result from re-breathing exhaled carbon dioxide that accumulates in bedding while sleeping face down.

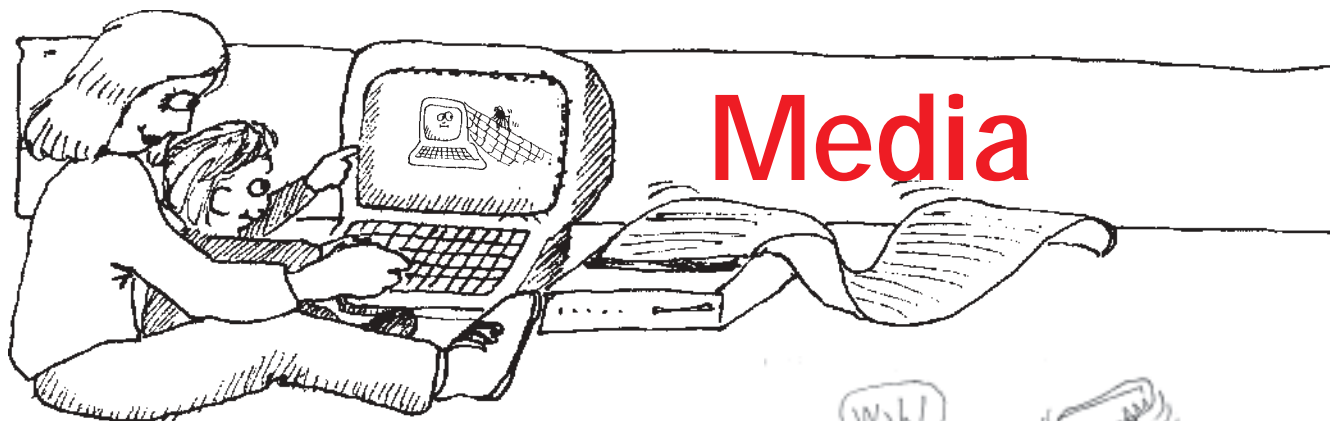
This abnormality appears to fit into the triple-risk model of SIDS, which holds that SIDS occurs only when three elements come together: an infant with an underlying vulnerability (i.e., low serotonin); a critical period of development (i.e., the first year of life when infants are stabilizing vital functions such as breathing); and an external stressor (i.e., perhaps, sleeping face down).

The Back to Sleep campaign urges parents and caregivers to place infants to sleep on their backs. Following the campaign's launch in 1994, the rate of SIDS dropped by more than 50 percent. Widespread adoption of back sleeping appears to have reduced the occurrence of SIDS, but has not eliminated it.

Choking Foods. The American Academy of Pediatrics recommends avoiding the following foods in children under the age of 4:

Hot dogs * nuts and seeds * chunks of meat or cheese * whole grapes * hard, gooey, or sticky candy * popcorn * chunky peanut butter * raw vegetables * raisins * chewing gum





Media

No More Meltdowns

A book about positive strategies for managing and preventing out-of-control behavior



Andrew bites his brother when he can't have the toy he wants. When he gets time-out for the biting, he completely "dissolves," and acts out even more with screaming and hitting.

Mark is not a "morning person." Every morning it's a battle for his mother, who needs to get him out the door to daycare. The more she hurries him along to eat, get dressed and brush his teeth, the more he resists. Invariably it ends in a meltdown.

Sound familiar? If you are a parent who tries consistent rewards and punishments, but still finds him or herself in a battle of wills with your youngster, then maybe it's time to try another strategy.

Author Dr. Jed Baker (who earned his clinical psychology degree from University of Albany) is a behavioral consultant in New Jersey schools. He lectures all over the world on social skills training and has 20+ years of experience working with children on the autism spectrum.

In his latest book, *No More Meltdowns*, Dr. Baker

offers a four-step program that can prevent meltdowns and make life easier.

The first step is to accept and appreciate your child. These "musts" in this first step are to control your own temper, create an atmosphere where the child feels competent, and avoid constant power struggles.

The second step is to de-escalate a meltdown with a distraction that will likely comfort the child. It might be another toy, a hug, or a bounce on your knee. Physical contact and playful movement deliver soothing sensory input that may be all you need to diffuse the meltdown.

The third step is to understand why meltdowns reoccur. Readers will learn the "ABC's" of behavior--Antecedent, Behavior, and Consequence--and determine the specific triggers of your child's meltdown.

The fourth step is creating logical plans to prevent meltdowns in the future. According to the author, most triggers for meltdowns can be grouped into one of four categories:

**Demands:* When children experience a new social situation, have to do a difficult task, or experience unpleasant sensory stimulation (such as trying a new food)

** Waiting:* When they do not get what they want immediately, or cannot get what they want at all, or have to stop doing something they like.

** Threats to self-image:* When situations cause children to feel ashamed or embarrassed, such as losing a game or making a mistake.

** Unmet wishes for attention.* When others refuse to play or interact with them, when they are jealous of others, or when they fear being alone.

The last chapters of the book show examples of prevention plans that were created for real children dealing with these types of situations.

The book is full of examples, extremely parent-friendly, and offers sound advice. It is intended for parents who have children with autism spectrum disorders, but the behavioral approach and principles are useful for parenting any child, with or without disability. Many of the examples are geared toward school-age children, but much of what's covered in the book can apply to younger children, as well.

Take Note! The author will be offering a workshop in our area on APRIL 23

No More Meltdowns: Handling Challenging Behaviors and Teaching Social Skills

With Dr. Jed Baker at the Desmond Hotel and Conference Center, Albany; 8:00am-3:30pm

For more information, fees, and registration, call Spectrum Training Systems, 920-749-0332, or visit www.spectrumtrainingsystemsinc.com/albany.html

Ask Nancy



Nancy T. Cupolo is a regular contributor to Preschool Connections. A popular educational consultant and training specialist, Nancy draws on 32 years of teaching and administrative experience in special education, elementary education, and early childhood education. She is currently the Department Chairperson of Teacher Preparation at Hudson Valley Community College. Nancy is owner of her own consulting business, Children First. E-mail your questions to Nancy at ncupolo@nycap.rr.com

Understanding Infants & Toddlers

"My baby is only 5 months old. Are there things I should be doing to help her with her development, or is it too early?"

It is never too early to interact with your baby and provide a stimulating learning environment. Even before she was born she was listening to you as her brain was developing in the womb. At five months of age your baby enjoys being held and cuddled; she looks at her own hands with interest and likes rhythmic activities. The synapses of the brain are making connections as you speak to her, touch her, and play with her. Her brain was only 25% "neuro-networked" at birth; 75% of her brain wiring depends upon you and her environment. So pick up on your baby's cues, sway her gently as you call her name, sing to her, point out things in her environment as you move about the house or grocery store, and use inflection in your voice as you speak. Provide toys that give feedback such as a rattle when shaken. She will love keys, measuring spoons, and squeak toys. Imitate her sounds and expand on them. Each day spend some "mirror time" together in which she looks at herself in the mirror along with you and you name her body parts as you point to them, or you dance together and vary the tempo and beat as you play music in the background. Read aloud often to her and she will begin to learn that words have meaning and the printed word has meaning. Water play is also important and can be very soothing if accompanied by soft music; bath time is a teachable time, to discuss hard/soft, stop/go, splash/splash etc. If you notice that by eight months of age that your baby is not sitting alone, reaching and grasping for objects or showing an interest in playing games such as pat-a-cake, please be sure to ask for a developmental evaluation.



"Joshua is almost 12 months old and he is not yet walking. Should I be concerned? How can I encourage him to walk?"

As children grow there is a window of opportunity for the development of many skills, however each child develops at his or her own pace. Some children walk by 9 months of age while others do not walk until 14 months of age. I always try to look at the "rate of acquisition of a skill" in relation to the "amount of exposure" that a child has had for developing that skill. For example, I once worked with a little boy who could not cut with scissors and he was five years old, however I quickly learned that in his house it was forbidden to use scissors at such a young age. Once he was exposed to cutting with scissors he acquired the skill very quickly because all of his motor skills were already developed and ready for this task. So think about providing a stimulating environment in which Joshua will have many opportunities to walk or attempt to walk. Provide large toys to push, pull, and stroll behind as he walks. Encourage him to pull to stand at the coffee table and walk around the table to retrieve a favorite toy. Place his favorite toy slightly out of reach and encourage him to walk to get the toy. Play a "go get it" game with him and sing as he retrieves the toy, "Joshua is stepping, stepping, stepping," and so on. Each new skill should be fun and motivating in the eyes of the child. Once given ample opportunity and your support he will gradually master the skill of walking.

(Hope or Denial? from page 1) **Hopes and Dreams Are Important**

that professionals may think of parents as being “in denial” when they seem hostile or uninvolved. But Beth Harry proposes that professionals sometimes use the term “in denial” when actually “the parent and professionals are in disagreement about the prognosis, diagnosis, program, or intervention strategy.” Unfortunately, when this happens, the phrase “in denial” is sometimes applied in a judgmental way towards parents. What is more to the point is that each party possesses a different perspective and may not be sharing the same vision of the child’s future.

As we “rethink denial,” two main points become clear about what it means for parents and the professionals who work with them:

As noted in the article, today more than ever, there is reason to be hopeful that your child, despite his or her difficulties, will achieve great things. Think about Helen Keller. Think about Temple Grandin, the autistic child who grew up to become a Ph.D. college professor, author, and distinguished authority on autism. People with disabilities, even severe disabilities, are living in their own homes, attending colleges, holding jobs, and starring in television shows. Just about anything is possible. Not everyone achieves their dreams, but dreams are worth having.

Hope may provide the emotional fuel to persevere. When a child is young and the future is uncertain, this is an important time for parents to believe in their child, be optimistic about the future, and muster up the energy to help their child reach his or her potential.

For many professionals, it’s important that they learn to reframe “in denial” as the parents’ way of “being in hope.” There’s a world of difference. Parents can be their child’s best advocate when they are armed with optimism, support, and information. Instead of judging parents, professionals can best support parents by sharing in this optimism and providing the encouragement parents need to be teacher, advocate, record keeper, and the many other roles that parents play.

Take the Time You Need

If we’ve learned anything over the past 20 years, it is that people need time to find their own personal ways through unexpected events. Some parents will appear to “adjust” immediately. Other’s may steadfastly appear to dig in their heels and refuse to “adapt.”

Professionals need to realize, as the authors noted

in the article, that sometimes parents attempt to slow down the speed of change, particularly when they are integrating new, and sometimes painful and uninvited, information about their child. Learning and understanding is a personal and private process that continues over time. Parents should not be made to think they have to progress according to someone else’s timetable.

Over time, researchers who have studied the impact of disability on families have noted that “most parents rebuild their hopes and dreams for their child, learn to adapt to the circumstances in their lives, and remain steadfast in their concern for and commitment to their child with disabilities.” The ways in which professionals understand and respect parents’ efforts can significantly contribute to this process.

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