

Dear Friends and Family, . . .The Family Visit for Someone with Autism

Continued from Page 1

private place set up to where I could retreat.

If I cannot sit at the meal table, do not think I am misbehaved or that my parents have no control over me. Sitting in one place for even 5 minutes is often impossible for me. I feel so antsy and overwhelmed by all the smells, sounds, and people--I just have to get up and move about. Please don't hold up your meal for me--go on without me and my parent's will handle the situation the best way they know.

Eating in general is hard for me. If you understand that autism is a sensory processing disorder, it's no wonder eating is a problem! Think of all the senses involved with eating: sight, smell, taste, touch AND all the complicated mechanics that are involved with chewing and swallowing that a lot of people with autism have trouble with. I am not being picky--I literally cannot eat certain foods, as my sensory system and/or oral motor coordination are impaired.



Don't be disappointed if mommy hasn't dressed me in starch and bows. It's because she knows how much stiff and frilly clothes can drive me buggly! I have to feel comfortable in my clothes or I will just be miserable! Temple Grandin, a very smart adult with autism, has taught people that when she had to wear stiff petticoats as a child, she felt like her skin was being rubbed

with sandpaper. I often feel the same way in dressy clothes.

When I go to someone else's house, I may appear bossy and controlling. In a sense, I am being controlling because that is how I try to fit into the world around me (which is so hard to figure out!) Things have to be done in a way I am familiar with or else I might get confused and frustrated. It doesn't mean you have to change the way you are doing things--just please be patient with me and understanding of how I have to cope...mom and dad have no control over how my autism makes me feel inside.

People with autism often have little things that they do to help themselves feel more comfortable. The grown ups call it "Self regulation," or "stimming". I might rock, hum, flick my fingers in my face, flap my arms or any number of different things. I am not trying to be disruptive or weird. Again, I am doing what I have to do for my brain to adapt to your world.

Sometimes I cannot stop myself from talking, singing, or partaking in an activity. The grown ups call this "perseverating" which is kind of like self-regulation or stimming. I do this only because I have found something to occupy myself that makes me feel comfortable, and I don't want to come out of that comfortable place and join your hard-to-figure-out-world.

Perseverative behaviors are good to

a certain degree because they help me calm down. Please be respectful to my mom and dad if they let me "stim" for a while, as they know me best and what helps to calm me. Remember that my mom and dad have to watch me much more closely than the average child. This is for my own safety, preservation of your possessions, and to facilitate my integration with you tippies (what we autistics fondly call you neurotypical folk!) It hurts my parents' feelings to be criticized for being overprotective or condemned for not watching me close enough. They are human and have been



given an assignment intended for saints. My parents are good people and need your support. Holidays are filled with sights, sounds, and smells. The average household is turned into a busy, frantic, festive place. Remember that this may be fun for you tippies but it's very hard work for me to conform. If I fall apart or act out in a way that you consider socially inappropriate, please remember that I don't possess the neurological system that is required to follow tippy rules.

I am a unique person--an interesting person. I will find my place at this celebration that is comfortable for us all as long as you'll try to view the world through my eyes!

Little Chair - Long Table

Remember that first IEP team meeting for your child? Let's see if we get this right. You're a young mother and you're probably alone. You're a little nervous, maybe even scared about what is supposed to happen at the meeting. You've been dealing with "experts" on other parts of your child's life as you've learned about the medical and community realities of having a child with a disability, and you haven't gained any measure of confidence in your abilities as a parent. You walk into the IEP team meeting room. You see the little chair and the long table. Across the table from you sit six or seven people

with degrees and titles who say they "know" your child. They hold your child's evaluations and other paperwork in front of them that you've never seen. During introductions it seems like everyone else has a title like Mister, Mizz or Doctor, while you're "just a mom."



Through the course of the meeting, while you squirm on the little chair - we call it the "mom" chair -- it seems to you that it doesn't take

By Tricia and Calvin Luker

long for everyone else to start calling you "Mom," while they keep the special titles for themselves. After all, they are the "experts." The meeting seems to run smoothly, with them doing most of the talking and you doing most of the listening. Before you know it, they thrust a multi-page document in front of you and insist you check "this box" and "sign here" so that they can be about the business of meeting your child's special education needs.

Tired, sore [from the "mom" chair] and confused, you follow their directions and the meeting concludes.

Continued on Page 3

Your child now has an Individualized Education Plan, and you have a headache, and a sinking feeling that - whatever happened - you've just signed away your child's future and you have no idea what you've just done. You leave the school in a fog, hoping that whatever you did was right by your child. After two or three of these IEP Team Meetings - and continuing doubt on your part about whether you've really made sure your child's educational needs are being met by the IEP -- you've finally connected with some parent groups and started to learn a little about the IEP process and you and your child's rights under the IEP. If you're somewhat lucky, you've even found a group or organization that has volunteer advocates available to help you prepare for IEP Team Meetings in advance. In some instances the volunteer advocates have even been able to attend the meetings with you. What relief this brings to you. Finally, you don't feel quite so small, inadequate or unprepared sitting in the "mom" chair, and the line of "experts" across from you aren't so daunting when you've got an advocate sitting in a little chair beside you.

Through the course of the meeting, while you squirm on the little chair - we call it the "mom" chair -- it seems to you that it doesn't take long for everyone else to start calling you "Mom," while they keep the special titles for themselves.

The volunteer advocates sitting next to you went through the same IEP growth process. They've learned the ropes from their own "mom" chair, and have made time to learn enough to help you and other parents through the process. They've carved out precious time to attend special education workshops. They've paid child care workers, paid their own transportation and preparation costs, and become an invaluable resource to you and other parents. They attend meetings for free, paying for copying costs out of their own pockets, along with the other costs associated with making sure their own child's needs are met while they are helping you. They've done this because of their own experiences in the "mom" chair, and their refusal

to see you and other parents go through the process without help. But wait. There is a sinister move afoot in schools across America. We're hearing stories about a new school trend. In school after school, volunteer parent advocates arriving to attend IEP Team Meetings with parents are being greeted at the meeting room door by school administrators. The administrators are telling the advocates that when they attend IEP meetings they are engaging in the unauthorized practice of law. They are telling the advocates that the school might have no choice but to report the advocate to the state agency that regulates lawyers.

The advocates, who already have overcome their own fear of being intimidated by the IEP process suddenly are confronting a new form of intimidation. Now what do they do? Attend the meeting and keep their mouths shut? Expose themselves and their families to the cost of fighting the school - and the state bar - over their right to help parents at IEP meetings? Leave the meeting - and the parent - so that they don't have to fight the battle?

The Senators and Members of Congress know little or nothing about your experience at that first IEP team meeting. They know little or nothing about what it is like to sit in the "mom" chair, across a long table from the school team. They also don't know what it is like for you - and for your child's educational programming - to have a volunteer advocate sitting with you, just to level the playing field a little, and to make the number of "experts" sitting across from you seem slightly less intimidating.

Our federal legislators also don't know how hard it is for parents to find good volunteer advocate help. They don't know how little information parents receive about the IEP process from schools, or about how intimidating school officials can be to parents AND advocates.

The family fight to save the Individuals with Disabilities Education Act [IDEA] is real. The threats to IDEA are real. The intimidation at the school level is real. The schools control the process, and few par-

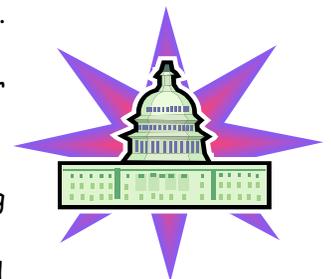
ents truly have access to competent legal advice or the services of trained advocates. The proposed attorney fee cap now being considered by Congress seems designed to make competent help even less available to parents and families. And now the advocates are being intimidated in individual schools.

We would like to think that we parents have control over our children's educational programming. But we're consistently stalked by our own fears and our own experiences sitting in the "mom" chair at the long table. If we don't let our legislators know about that experience, and about the current balance of power in favor of the schools, we have nobody to blame but ourselves if Congress takes away the already limited legal resources we now have.

With this new trend of threatening volunteer advocates with the unauthorized practice of law if they help you at IEP Team Meetings, school administrators have only highlighted the threats to our children and us. We cannot let them get away with this. Write your Members of Congress and your Senators. Tell them about your experiences in the "mom" chair. Invite them or their staff members to attend an IEP Team Meeting with you; to sit on your side of the long table in their own "mom" chair.

Our silence as parents in the face of school attacks on advocates only strengthens the schools and weakens the families. Don't remain silent.

Call your senator today. We're running out of days - and



out of advocates. And only you know how lonely that little chair and long table truly are.

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Music Therapy for Children with Special Needs:

An Overview

From Coast Music Therapy

Defining Music Therapy

Music therapy is a professional health discipline that uses music as a therapeutic stimulus to achieve non-musical treatment goals. Research supports parallels between speech/ singing, rhythm/ motor behavior, musical mnemonics/ rote memorization, and overall ability of preferred music to enhance mood, attention, and behavior to optimize the individual's ability to learn and interact. Music therapists receive specialized training to utilize music in these domains by completing a baccalaureate or advanced degree program in music therapy, in addition to national board certification.

Research documents that many children with special needs exhibit a high level of preference for music and show processing capabilities for musical stimuli that can support deficits in related non-music areas. In this way, music can be used as a motivator and alternate learning avenue for select skills that may be more difficult for the individual to achieve using typical non-music instructional approaches.

Goal Areas

A music therapy session consists of *interactive* music strategies such as songs, rhythm activities, and use of instruments, during which the child must complete tasks relating to *individualized* goals. Sample goal areas could include rote memory for math and literacy skills, learning of basic vocabulary and language concepts, motor imitation, sequencing skills, taking turns, making eye contact, and utilizing communication skills to request, label, or describe an object. The purpose of music in this context is to provide an initial assist and motivation to the individual's learning through music cueing, followed by fading of the music to



aid in generalization.

Models of Service Delivery

Music therapists provide services for individuals and groups in the home or clinic environment after an initial assessment is conducted to determine appropriate goal areas music can assist with*. In some cases, music therapy may be funded by the regional center or the public school system through the Individualized Education Program if it is determined that music therapy is required for a particular individual.

**While singing and the use of musical instruments are important components of music therapy sessions, primary emphasis is placed on achievement of developmental or educational goals rather than music performance. Parents who are seeking music lessons for their child to learn an instrument can locate these services through music therapy interns or music educators with a creative approach.*

How Can Music Therapy Benefit Children with Special Needs?

Cognitive/ Academic

Songs act as a "mnemonic" device to aid in memory of new or difficult cognitive/academic concepts by organizing information into smaller chunks, making it easier to encode and retain. Musical presentation also provides an optimal learning environment for those individuals who are highly attentive to music activities, but are often distractible with other modalities. Educational research supports that our ability to learn and later use new concepts and information is best when we are motivated and the material presented is meaningful to us.

Communication/ Social Interaction

Because singing and speech share many similarities, yet are accessed differently by the brain, music strategies can be used as a means

to functional communication. Vocal imitation, initiation of verbal language, increasing length of verbal utterance, and learning of new vocabulary can be approached by embedding desired language responses into song lyrics, followed by fading of the music to spoken language.

Rhythmic structure also provides necessary timing cues to aid in speech intelligibility for certain individuals. In addition, preferred songs and instruments can be used as motivational tools to elicit eye contact, cause/effect skills, choice-making, and following basic directions. In small groups, interactive music strategies are designed to structure social interaction.

Motor Abilities

Research is highly conclusive in supporting rhythm as an external time-keeper for movement. Basic goal areas such as bilateral integration, crossing midline, visual-motor integration, or imitating movement can be functionally translated into music-based interventions. For these skills, rhythmic timing cues, task-specific song lyrics, and musical instruments are used to increase the individual's motivation to participate, improve coordination, and increase duration of motor participation.

Behavior

Music involvement can be used as a proactive strategy for individuals who display interfering behaviors in the educational or home environment, yet are highly motivated by music. Consultation to staff and parents is another avenue to demonstrate the use of music as an effective reward, contingency, transition aid, or calming agent.

Thank you to Coast Music Therapy for allowing us to reprint this article. For more information, contact Coast Music Therapy at (858) 453-5211 or info@coastmusictherapy.com

God Lives Under the Bed

My brother Kevin thinks God lives under his bed. At least that's what I heard him say one night. He was praying out loud in his dark bedroom, and I stopped outside his closed door to listen. "Are you there, God?" he said. "Where are you? Oh, I see. Under the bed."

I giggled softly and tiptoed off to my own room. Kevin's unique perspectives are often a source of amusement. That night something else lingered long after the humor. I realized for the first time the very different world Kevin lives in. He was born 30 years ago, mentally

disabled as a result of difficulties during labor. Apart from his size (he's 6-foot-2), there are few ways in which he is an adult. He reasons and communicates with the capabilities of a 7-year-old, and he always will. He will probably always

Continued on Page 5

believe that God lives under his bed, that Santa Claus is the one who fills the space under our tree every Christmas, and that airplanes stay up in the sky because angels carry them.

I remember wondering if Kevin realizes he is different. Is he ever dissatisfied with his monotonous life? Up before dawn each day, off to work at a workshop for the disabled, home to walk our cocker spaniel, return to eat his favorite macaroni-and-cheese for dinner, and later to bed. The only variation in the entire scheme is laundry, when he hovers excitedly over the washing machine like a mother with her newborn child. He does not seem dissatisfied. He lopes out to the bus every morning at 7:05, eager for a day of simple work. He wrings his hands excitedly while the water boils on the stove before dinner, and he stays up late twice a week to gather our dirty laundry for his next day's laundry chores. And Saturdays - oh, the bliss of Saturdays! That's the day my Dad takes Kevin to the airport to have a soft drink, watch the planes land, and speculate loudly on the destination of each passenger inside. "That one's goin' to Chi-car-go!"

Kevin shouts as he claps his hands. His anticipation is so great he can hardly sleep on Friday nights. And so goes his world of daily rituals and weekend field trips. He doesn't know what it means to be discontented. His life is simple. He will never know the entanglements of wealth or power, and he does not care what brand of clothing he wears or what kind of food he eats. His needs have always been met, and he never worries that one day they may not be. His hands are diligent. Kevin is never so happy as when he is working. When he unloads the dishwasher or vacuums the carpet, his heart is completely in it. He does not shrink from a job when it is begun, and he does not leave a job until it is finished. But when his tasks are done, Kevin knows how to relax. He is not obsessed with his work or the work of others. His heart is pure. He still believes everyone tells the truth, promises must be kept, and when you are wrong, you apologize instead of argue. Free from pride and unconcerned with appearances, Kevin is not afraid to cry when he is hurt, angry or sorry. He is always transparent, always sincere. And he

trusts God. Not confined by intellectual reasoning, when he comes to Christ, he comes as a child. Kevin seems to know God - to really be friends with Him in a way that is difficult for an "educated" person to grasp. God seems like his closest companion. In my moments of doubt and frustrations with my Christianity, I envy the security Kevin has in his simple faith. It is then that I am most willing to admit that he has some divine knowledge that rises above my mortal questions. It is then I realize that perhaps he is not the one with the handicap-I am.

My obligations, my fear, my pride, my circumstances - they all become disabilities when I do not trust them to God's care. Who knows if Kevin comprehends things I can never learn? After all, he has spent his whole life in that kind of innocence, praying after dark and soaking up the goodness and love of God. And one day, when the mysteries of heaven are opened, and we are all amazed at how close God really is to our hearts, I'll realize that God heard the simple prayers of a boy who believed that God lived under his bed. Kevin won't be surprised at all!

HIDDEN TALENTS: VSA arts' MAKING ART WITH YOUR CHILD CORNER

By Emily Cicchini, VSA arts of Texas

With the holidays fast approaching, here's an easy art activity to try with your child that makes a great gift idea!

SNOW GLOBES

Books to Read:

Bedford, Anne North. Frosty the Snowman. Western Publishing, 1992.
Briggs, Raymond. The Snowman. Random House, 1987.
Burton, Virginia Lee. Katy and the Big Snow. Houghton Mifflin, 1974.

Songs to Listen to:

"The Waltz of the Flowers" by Tchaikovsky from The Nutcracker Suite.

What You Need:

- Small glass or plastic jar, (jam, baby food, coffee, etc.) with label cleaned off and with a good lid
- Silver, white, blue, or multicolored glitter
- Plastic toys or old game pieces from board games (optional)
- Seashells, rocks, or plastic flowers (optional)

- Water, baby oil, or corn syrup

What You Do:

1. Take the jar and pour some glitter into the bottom of the jar
2. Add any small plastic toys or seashells into the jar.
3. Fill with water, baby oil, or corn syrup to the top and place the lid over the top, very tightly. (with water, the glitter will fall faster than with oil or syrup)
4. Then shake the jar and turn it upside down on a hard surface
5. The objects and glitter will fall to the bottom, like snow.

Adaptive Tips:

If your child has never seen a snow globe before, you might want to show them a commercially made one. If your child has difficulty with manual dexterity or is tactilely defensive, focus the activity on the selection of materials to include in the globe, as you proceed through the steps with them. If your child has cognitive disorders, keep the

steps and choices very simple, such as, "Pick between this jar and that jar," "between "white glitter and silver glitter," and once that decision is made, "between this game piece or that game piece." But always try to allow the child to make as many decisions during the creative process as possible.

More Ideas:

Experiment with food coloring to make the water different colors, or mix oil and water for a different effect.

For permanence, glue toy or seashell to the lid with hot glue or super glue and put the lid on the jar (seal with glue). (ADULT assistance required!)

For more arts ideas, visit www.vsatx.org. VSA arts of Texas is the accredited state constituent of VSA arts, which is an educational affiliate of the John F. Kennedy Center for the Performing Arts in Washington, D.C.

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Serving children with disabilities,
 chronic illness and other special needs
 by providing support and information to
 their families through peer support,
 resource referral and public awareness.

Conference Schedule

Date	Conference Title	Location	Registration Information
Thursday, Jan. 22 Through Sunday, Jan. 25, 2004	Weekend Program by TSBVI Short-Term & Outreach Program: Students with Usher Syndrome and Their Families	Texas School for the Blind and Visually Impaired Austin, TX	Students must be referred by their local school district. For more information, go to http://www.tsbvi.edu/school/ special/short-classes.htm
Wednesday, Feb. 11 through Saturday, Feb. 14, 2004	The Arc of Texas' 11 th Annual Inclusion Works! Conference	Renaissance Austin Hotel Austin, TX	For more information, call The Arc of Texas at 800-252-9729 or locally at (512) 454-6694 or visit their website at www.thearcoftexas.org
Thursday, Feb. 19 through Saturday, Feb. 21, 2004	12 th Annual Conference on Parent Education	Renaissance North Dallas Hotel Dallas, TX	Contact Rebecca Edwards for more information: Phone: 940-369-7426 Email: parenting@unt.edu www.unt.edu/cpe
Friday, Feb. 27 through Saturday, Feb. 28, 2004	ADDA-SR 16 th Annual Conference	Dallas, TX	Contact ADD-SR for more information: Phone: 281-897-0982 www.adda-sr.org
Thursday, April 15 through Saturday, April 17, 2004	TSHA 2004 Conference	San Antonio Convention Center San Antonio, TX	For more information, contact the Texas Speech-Language- Hearing Association: Toll Free: 888-SAY-TSHA Phone: 512-452-4636 www.txsha.org/convention/ convention.html