

Texas Parent to Parent

Providing support and information for families of children with disabilities, chronic illness and other special needs

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School Begins! Which was it for you? "It came too

soon!" or "Finally!"

Compiled by Laura J. Warren, Texas Parent to Parent

have to admit, I was really looking forward to the first day of school this year! July and August were really rough months for me trying to work, take care of my ailing 88 year old mother and a dying dog, not to mention leaving my 17-year-old son home alone -it all took it's toll on me. School would at least take one worry off my list - until Jason looked at me in a panic that first morning and, with tears in his eyes, said, "I don't want to take bowling!" Well, we all know bowling should be a goof-off sport for a teenager but not for one with anxiety, Sensory Integration Dysfunction, and mild Cerebral Palsy. I

took several big breaths and reassured him it would be fine - they would not bowl the first day. They'd probably just meet in the gym and talk about how to get across the street to the bowling alley. His Occupational

Therapist
had said
she would
go with
him the
first couple of

days. By the time we got to school, he was still nervous but was able to get out of the car and into the high school. He's taking all regular classes this year and he works very hard. Well, I was right about the first day - they did

not go to bowling. However, my smugness didn't last long - he very angrily informed me on the second day of school that you have to have SOCKS to bowl AND know what size shoe you wear AND tie shoe laces! How could I forget all of that!?!

I knew then I wanted to hear other people's first day stories and get some ideas that may help parents with some of the transitions we and our children face at school. Here is what I received: *Let's start the last day of summer. Jordan woke up screaming, "My life is over" when he realized this was the last day of summer. It also turned out to be the day he picked up his first pair

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Fall 2003

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Tips for Ensuring that IEPs Accurately Reflect ARD

Discussions

By Ronnie Schleiss, Austin, Tx

you will be heading into an ARD meeting with the objective of altering and hopefully improving your child's educational program. If you want to be as effective as possible, there are a couple of things you should be aware of and a couple of things you can do to increase the likelihood of having your requests honored and accurately recorded and made a part of the official ARD record.

But, before we get to what you need to do in an ARD, you need to be aware that most teachers, principals and other parents have never read the law and that you cannot count on them to know the

letter of the law nor to give you an totally accurate interpretation of the law. Most people know what they know about the law through memos, workshops, and what someone told them. The chances are very high that you will, at some time, be told grossly inaccurate information that may or may not have been intended to circumvent the requirements of the law, but none the less, might severely alter the appropriateness of your child's program. It is for this reason that you need to be well informed about the law, have access to all IEP data, and always ask to see written support of any district claims that limit access to

services. The following can help insure your requests for services are not ignored or unjustly denied:

1. Do your best to stay informed about the law by becoming very familiar with www.wrightslaw.com or obtain (and read) a copy of From Emotions to Advocacy by Pete and Pam Wright. This book can be ordered from their website or any book store.

2. Come to the ARD prepared: Have a list of the things you expect to discuss and services you are seeking. Review IEP data prior to the ARD so you can measure progress.

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of glasses. Although we did do something fun that day, he wasn't thrilled about wearing the glasses to school. He said people would call him "four eyes." After reassuring him that many people wear glasses like one of his best friends and both of his teachers (not to mention mom & dad), he reluctantly wore them. Jordan is ten years old entering fifth grade. On the first day of school, we pulled up to the curb for the drop-off. Jordan had his backpack stuffed with school supplies, with another huge bag to carry in. As he stepped out of the car, he bumped his head, something he had never done before, and then almost missed the step up the curb. He said, "I just can't wear these glasses!" Well I didn't blame him and wanted to say, "Just let me park the car and help you." Instead, I took a breath and said, "Just wear them. You'll get used to them." To my amazement, he turned and walked into the school. Three weeks later, he's still wearing the glasses, and still going to school!

Charee Vogel *I'm sure that this is not unique to us, but this is probably one of the most valuable things we've done for Jake over the past several years. We did this when he transitioned from one campus to another for second grade, again when the attendance zones changed and his home campus was changed, and then this year when he was about to go from his elementary campus to his "new" middle school campus: we arrange a meeting and tour of the "new" campus with the principal, usually after school when things are quiet and pretty empty. We have also arranged opportunities during these times to meet his new teachers and explore classrooms and other facili-When he transferred from Buda Elementary to Elm Grove Elementary at the end of 2nd grade, he was horribly anxious about the fire drill bells at the new campus. An email to his new principal resulted not only in a personal tour of the campus, but also a running of the fire drill bells so that Jake could get a feel for how loud they would be and what kind of sound it would make. His new principal allowed him to make an announcement over the PA to all staff on campus at that time that the bells were just a test. The fire drill was initiated by the principal by using a wall

control panel and certain number codes. Thank > goodness we had told her ahead of time about Jake's fascination with numbers and his incredi-

ble memory. She was able to shield her input of the numbers from Jake's view so that he would not be able to initiate a fire drill of his own! At the end of last school year, his new principal, his "old" counselor, Jake, and I toured his new middle school campus. He looked in many classrooms, visited with several people, and even met the campus police officer. His anxiety level diminished immediately, to one that is probably more fitting for any child about to go from elementary

to middle school. After tours and visits like this, he was able to visualize what his "school life" would be like and was ready to get started!

Jeanine Pinner

*When moving from elementary to middle school, I pulled David out of school during the day and went over to the middle school so he could experience the bell for class change and the throng of people in the hallway before he really had to. I did the same thing moving to high school - and a good thing, too. Instead of a nice bell, they have a claxon horn!! Rilla Chaka *When it was time for Kaly to transition from elementary school to middle school, I spent an awful lot of time trying to prevent the whole "moving up" business and keep her where we were comfortable. However, it seems that all the time it takes to finally get comfortable dissipates and it is time to move on again. So, when it was time for high school, I was a mess. In her March ARD, we decided that Kaly could go to the High School (with one of the aids from her class) for 3 afternoons a week until the end of the year. This allowed her (and me) to get use to the idea of her new school with someone she (and I) were comfortable with. Then when school was out that summer, Kaly attended summer school there, which gave her the freedom to learn about the school without most of the students being in the way. By the time the first day of high school came around, Kaly and I Continued on Page 3

The Search for a <u>Diagnosis</u>

can't believe it has been a year since we received the Lowe Syndrome (LS) diagnosis for our son, Kyle, and my husband, Greg, Kyle and I headed off to the 2002 LSA conference in Chicago. It took us almost 12 years to receive the LS diagnosis and, during that time, we always questioned Kyle's medical and behavioral difficulties. was born October 19, 1990, two months premature and spent 4 weeks in the NICU. During those long hours and days, Kyle went through many tests and we were told he had cerebral palsy. The

doctors explained he had damage to his white brain matter (cerebral palsy) and peripheral cataracts due to being on the ventilator for an extended period of time.

When we finally brought Kyle home he was on an apnea monitor for the first 12 months because, at times, he forgot to breathe. As parents of a child that required constant medical attention, we knew our son had a long road ahead of him. The doctors believed Kyle would be delayed, but given time along with extensive therapy, he would catch up. We enrolled him in every form of

By Debbie Jacobs, Dallas, Tx

therapy recommended by his doc-We engaged him in play groups, early childhood schooling and social activities that we believed would enable him to play catch up. Kyle was unable to hold his head up until he was almost 9 months old. He didn't sit unassisted until almost 12 months and he didn't crawl and walk until many years later. We watched as Kyle grew and rejoiced at the milestones that are taken for granted by most parents.

At about 3 years of age, Kyle began Continued on Page 5

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School Begins! Which was it for you? "It came too soon!"

or "Finally!"

were very comfortable with thewhole situation. If I had known how wonderful high school would be I think we would have skipped middle school! Tammy Mann *Christain started Middle School this year and, although she is adjusting, she still asks for her teacher of last year and she points "that way" to where her Elementary school is. She is doing quite well and she walks all by herself from the last 2 periods to the bus or to where I pick her up after school. However, I am not comfortable with Middle School because the teachers expect her to do everything for herself and that means going to the classes by herself. Being Middle School, I'm just afraid the students (some intentionally and some not) will trip her and she may get hurt. So far, she is doing very well and I am so proud of her.

Feliciana Govea

*Chris and my school days are over since he is now 32, hard for me to believe. But every year at this time, I feel a bit melancholy and sad for he has flown from the nest, as has my daughter. All the stress of what the new teacher is like, how he'll adjust, will he be happy, and even if the bus can get him home to the right house is over and whereas it would be insane

to say I miss it, it would be a lie to say I don't miss it a bit. My mornings and evenings are so quiet, too quiet. I miss having him

around too since he's so happy in the group home. So, while it seems so hard for all of you, stop and think how quiet and sad it will be when it is all over. Enjoy your hurried breakfasts, tears of separation, lost lunches, ARD meetings, Continued from Page 2

"he's not my friend" remarks, bus rides, stinky shoes and progress reports for they all do end and far sooner than you realize now.

Ann Hardie

Thanks to all the moms who shared their stories. I hope we have given you some useful ideas to use for your child's upcoming transitions. By the way, Jason has now figured out what a goof-off class is - he can get other kids to bowl for him and the coach doesn't even notice!

One mom told me that the first day of school was great - she just didn't send him to school but chose to home school instead. We have started a listserv for parents that have chosen to home school their children with special needs. If you would like to join this group to share ideas on home schooling, please email me at Laura-txp2p@sbcglobal.net

Legislative Update: "And Here We Go!"

By Colleen Horton, Texas Center for Disability Studies, The University of Texas

any of the changes mandated by House Bill 1 (Appropriations Bill) and House Bill 2292 (Health and Human Services Reorganization Bill) are beginning to be implemented. The benefit changes to the Children's Health Insurance Program became effective September 1st, as did many

changes in programs/services at both the Texas Department of Mental Health/ Mental Retardation and the De-



partment of Human Services. Other changes such as the implementation of cost sharing in the ECI (Early Childhood Intervention) program and the reductions in the In-Home and Family Support programs will become effective this fall or early in 2004.

Concurrently, the transition of the health and human services system in Texas is in full swing and advancing quickly. Earlier this month, the newly appointed Transition Legislative Oversight Committee met for the first time. At this initial meeting, key HHSC staff presented an overview of the legislation that

mandates the reorganization and provided some general information on the new health and human services system and the transition process.

Also this month, the Transition Oversight Committee, along with representatives from HHSC and various state agencies, held a series of six public forums around the state to listen to the concerns of those affected by the systems. They particularly wanted input in the following areas:

- 1. Timing: What needs to happen first as we merge agencies? What needs to happen later?
- 2. Improvements: Where or how can we improve services when merging HHS agencies?
- 3. Priorities: What is important to clients, providers, and taxpayers in the state's delivery of care?
- 4. Risks: What challenges do we face when merging agencies? Where should special care be taken and why?
- 5. Savings: What changes can we make that would improve services and save money?

If you were unable to attend one of the public forums and want to provide the Health and Human Services Commission with your thoughts and comments you can contact them at:

Gregg Phillips

Deputy Commissioner of Program Services, Texas Health & Human Services Commission P.O. Box 13247 Austin, TX 78711

Comments can also be sent by email to http://www.state.tx.us/Consolidation.asp

It is especially important for parents and families to follow the current changes being implemented, learn about the new system and new policies, and become active participants in the development of new systems. Without a doubt, it is the "squeaky wheel" that gets the grease. As changes occur, families and advocates need to start making a lot of noise and letting their voices be heard, or the program and service reductions of this past session will only be the beginning.

For more information, feel free to contact Colleen Horton at colleen.Horton@mail.utexas.edu/

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Tips for Ensuring that IEPs Accurately Reflect ARD

Discussions

speech".

- 3. If you make a request in the ARD, be sure it is reflected in the minutes in the specific terms you stated: "Parent requested that speech be provided as one-on-one direct services instead of consultation because there has been no progress in the use of the communication device "vs "parent asked about
- 4. Make sure the minutes then reflect one of 3 definitive answers: AGREEMENT to provide the service sought including the agreed frequency, duration and start date, REFUSAL and the district's specific reason for refusal, or AGREEMENT TO ASSESS for educational need. (Remember, the IEP should be derived from accurate assessment.)
- 5. If the school refuses and they state the law or district policy as the reason they are refusing your request, ask to see the section of the law or the policy and procedures, or the criteria for their determination. Many schools have matrices they use to determine how

much of a service a child gets - ask to see whatever it is they are basing their position upon. Do not move forward until they provide it to you. 6. If the school tries to avoid

giving a clear yes or no (a common tactic that allows the issue to never get recorded), do not move on until you have a clear position from them. If

they are hemming and hawing over it, then politely state, "well, it sounds like my son will not be getting one on one services and you are refusing my request. I need to make sure you write that in the minutes." Do not move forward until it has been written and read back to you and you agree the statement accurately reflects what was discussed. If they refuse to write it in the minutes, remind them that the minutes are supposed to be an accurate reflection of the discussion. Do not hesitate to end a meeting if they continue to refuse to accurately

Continued from Page 1

record the request and the school's response.

- 7. At the end of the meeting, do not sign anything unless you firmly believe that you child will be getting an appropriate education. Otherwise, take the papers home and re-read them. Attach an addendum to correct ANY statements you disagree with keeping in mind that letting seemingly small inaccuracies remain as written may come back to haunt you later.
- 8. If at the end of the meeting you did not get something that you believe is required for a Fair and Appropriate Public Education (FAPE) to be conveyed to your child, SIGN "DISAGREE". Do not sign "agree" then complain to someone that you could not get a one on one for your child. Be aware that when you sign "AGREE" to the IEP you are saying you agree with EVERYTHING written in the IEP, including the type and level of services that are different from what you requested.

HIDDEN TALENTS: MAKING ART WITH YOUR CHILD

By Emily Cicchini, VSA arts of Texas

VSA arts of Texas is a statewide organization that promotes the creative power in people with disabilities. VSA arts offers people of all ages the *vision* of an inclusive community, the *strength* of shared resources, and physical, cultural, and economic *access* to the arts.

VSA arts of Texas encourages you to try arts as a means of deepening communication with your child. Through the arts, you can uncover new ways for your child to experience self-expression. Currently, VSA arts is accepting artwork by Texas children with disabilities who are up to 18 years of age for our FOLLOW THE DREAM project. This year's theme is "I AM A STAR." The artwork is due by December 15st, 2003 and must be submitted with an entry form, and selected entries will be displayed at

the Texas Capitol Building in the Spring of 2004. Full entry rules are available at www.vsatx.org, or by calling (512) $454-9912 \times 15$, or (512) 454-6298 TTY.

What follows are some suggestions for exploring the theme of "I AM A STAR" with your child. First, you should try to activate your child's prior knowledge through sensory experience: visual, aural, touch, smell, and taste. Talk about stars. Stars can be literal, like stars in the night sky, or stars can be cultural, like movie stars, rock stars, or sports heroes. The shape of the star itself is interesting and can be found in many places, from holiday decorations to nature, such as starfish and starfruit. Stars can have five points, six points, or many points, or, like our Sun, might be represented simply by a brightly

colored circle. Then you can explore and discover new knowledge through an arts activity.

STAR QUILT PATTERNS: A good way to introduce printmaking and patterns.

What You Need:

- Paint or ink stamps. (to make tempera paint thicker and stickier, add a touch of flour or glue)
- Sponges in interesting shapes and the top of a egg carton or Styrofoam tray. (use only a little bit of paint at a time on the sponge)
- Paper
- A covered work area.
- •Star shaped objects of all kinds, such as star stamps, potatoes cut Continued on Page 7

We would like to thank:

Parkland Community Health Plan

6300 Harry Hines, Suite 300, Dallas, TX, 75235

1-888-672-2277, 1-800-735-2989 (TDD)

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and

Parkland KIDS first

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to exhibit many of the classic signs of autism. He loved to repeatedly open and close cabinet doors and run his hands up and down walls while in his walker. Kyle was very sensitive to sounds and the noises around him and that acuity continues today. He loved Barney, Mr. Rogers and music videos, but his greatest joys were toy airplanes, golf and computer games. Those loves and obsessions continue today.

We knew that Kyle wasn't a typical premature child and when he caught a cold it usually turned into a major medical crisis and, a few times, required Kyle being hospitalized. Kyle was hospitalized numerous times during his early childhood for minor illnesses. It was at 8 years of age that we discovered Kyle had kidney problems and our quest for answers began. Every time we had a blood test performed, the results would show some other medical problem and off we would go to consult a new specialist. We continued this specialist hopping for over 3 years until one doctor finally suggested we have genetic testing performed on Kyle. We retained copies of all of Kyle's test results and in the margin of one of the doctor's notes was a scribble

regarding Lowe Syndrome. However, the doctor discounted the possibility Kyle had LS due to some medical technicality.

Based on clinical observation, the geneticist believed that Kyle had Williams Syndrome and declined to test him for Lowe Syndrome until the test results came back on Wil-

liams. During the weeks of waiting for the Williams test results to come back, I started research Lowe Syndrome. looking After over the LS website I had

"We knew that
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no doubt that Kyle had Lowe Syndrome. So many answers to all his quirky medical problems lay within the LS web pages. When the Williams test result came back negative I strongly suggested the geneticist perform the skin biopsy to test Kyle for Lowe Syndrome. With much hesitation, the geneticist performed the procedure and we waited the 7 weeks for the results. What a long wait, but yet I knew in my heart that we had finally found the "why"

to all of Kyle's strange medical and behavioral issues.

I'll always remember the day we received the positive LS test results. To me, it was a day filled with many emotions. On one hand, I was finally glad to have the puzzle solved, but I wished in my heart that they were wrong. No one in my family knew about Lowe Syndrome and finding out that I am a carrier has not been easy emotionally or physically for me. I went through a deep depression that lasted weeks and I lost a good deal of my hair over the course of a few months. It wasn't until I looked inside myself while holding Kyle that I realized nothing had really changed. During the past 12 years we've dealt with the curve balls of the syndrome and we survived, some days better than others, but nonetheless, we survived. We have good days and not so good days dealing with Kyle's behavior. The guilt for passing along the genetic disorder will always be with me, but I am no longer angry with myself. I believe we are placed on this earth for a purpose and, as I watch my son strive forward, I know we are blessed.

Healthy G-Tube Feeding

y sweet daughter, Abby, is now 8 years old. Due to many complications at birth, she had a Gtube placed in her stomach when she was 4 months old. This also included the fundoplication surgery. I am unable to report this without a flood of emotions overcoming my heart and the desire to say I am sorry that we all have experienced this, something no parent ever anticipates in their wildest dreams and no baby or child should ever have to endure. That is my opinion. I must also add that I personally have a strong faith in God and am peaceful in knowing there is a greater reason for all my family has been through, that we are unable to comprehend.

I also believe we are supposed to feel all of this along with our child... we are not to turn our emotions off or become hard to it in order to survive.

Instead, I pray a lot and listen a lot. God is so awesome and is with

us every step of the way if we allow Him to be.

So, back to Abby's nutrition. The G-tube caused her to have much discomfort with each feeding, including symptoms such as gagging, retching, sweating, and back arch-

ing. We spent the next 6 months like this with our hearts breaking, our child miserable, and the doctors telling us they had never seen this before and were



unable to help. I finally realized that if Abby's problems were to be solved, it was up to me, a very scared, desperate, tired mom. We experimented with her position while being fed, rate at which she was fed, volume of formula, formula ingredients, types of feeding apparatuses, time of day, and a mixing and matching of all of the above. My overall feeling was that her tummy was needing the same

By Wendy Jimmerson, Austin, Tx

foods all those other little tummies were getting . . . pureed fruits, vegetables, meats, cereals, and formula. So I figured out a way to fit the daily dietary needs of any other child her age into a daily intake for her. All of this went through her tube.

The result was exactly what I was searching for . . . comfortable feedings and a happier, healthier child. I progressed like this and modified with time depending on her developing dietary needs. I have an extremely powerful, commercial grade, blender that works wonders. She now gets fresh whole foods just like any other 8 year-In fact, her diet is much healthier than the average 8 year old as you might imagine (if you have other children you know what Overall, Abby is so I mean). healthy and happy. I strongly believe this fresh and varied diet vs. the canned formulas has made a world of difference. It has also

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The House That Kerry Built

The House That Kerry Built, The Center for Medically Fragile Children, Inc. (THTKB) is a non-profit organization located in Abilene, Texas that is licensed by the Texas Department of Human Services and the Texas Department of Protective and Regulatory Services. It serves Medically Fragile Children (MFC) and their families through its multiple component program. THTKB's Mission is threefold:

- 1. To provide specialized daycare services from birth through twelve years of age for those children who cannot attend typical daycare because of chronic medical conditions, with emphasis on their educational, social, and emotional development, as well as intense attention to their medical needs.
- 2. To provide Families of Medically Fragile Children opportunities to earn income essential to the family's well being, knowing that their child is safe and professionally cared for, and to afford Families of Medically Fragile Children the opportunity to access the resources and education they need to enhance their home lives.
- 3. To deepen the community's awareness of and involvement with these children and their families. Because technology has advanced so rapidly, the number of children who are living longer lives, but are technology-dependent, is growing at an ever-increasing pace. Unfortunately, the support services needed to keep pace with this growth have not progressed as rapidly. THTKB's seven-component program has been developed to fill this void in services.

THTKB's vision has been to provide "One-Stop Shopping" for these families, and in an effort to meet that goal, has developed the following program components:

1. Medically Supervised Daycare - the first program in the State to provide Medically Supervised "normal" Day Care for technology-dependent children enabling parents to continue employment, job training, or school. Parents pay a financial portion, based on an individual

sliding-scale fee, and volunteer time with one of THTKB's programs.

- 2. Respite two events each month Medically Supervised Care for the Medically Fragile Child and community sponsored care for the healthysiblings; free to the parents.

 3. In-Home Nursing for the Medically Fragile Children who require one on one nursing in the home environment. Continuity of care is an essential element of the program by providing the same nurses for all program components.
- 4. Resource Library a developing program to provide current information for families, professionals, and the community on the multiple needs and services for the Medically Fragile Child.
- 5. Parent Mentoring Program experienced parents provide positive role models, support, and networking for novice parents.
- Support Groups individual and family therapy; client, sibling, and parent support groups
- 7. Specialized Case Management 24-hour availability for families of Medically Fragile Children, meeting their needs for support, information, service assistance and crisis management

When THTKB's Respite Night began only two of the THTKB's six clients attended. Today Respite Night averages between thirty and forty children, the Support Group Program is active and receives positive approval from the families, the Day Care Program is full, the Resource Library continues to be developed, the Parent Mentoring Program grows as the Case Management Program grows - both interacting to support the families in their times of stress and joy, and the In-Home Nursing Program serves clients in all areas who need Skilled Nursing Care (SNC) and Personal Assistant Services (PAS). As a direct result of inclusion in one or all of THTKB's many programs, many of our children's parents have remained married, become employed or continued employment, completed high school, and/or have been able to continue college education. Because of the stress reduction, the successes that lie in the arms of THTKB are numerous and amazing. Families have literally turned their lives around. The **real** success stories of THTKB, however, are the children; little children, who run, play and feel a little more "normal" everyday.

Medically Fragile Children cope each day with pain and fear that



most adults cannot even begin to imagine. Many of these children and their families are isolated from the rest of society due to the fact the Medically Fragile Child represents everyone's biggest fear: sick and dying children. All of these factors combine to produce little boys and girls who grow up very fast - too fast. For example, one of the Medically Fragile Children at THTKB recently had to undergo yet another life threatening procedure, ironically to continue life. The night before surgery, when this thirteen year old boy should have been struggling with which baseball team he would end up on this season, he was confessing to his mother that he really did not think he would survive this time. The Mission of THTKB is to "restore the culture of childhood" to these very special individuals. THTKB achieves its mission by allowing these children to come together in the daycare, at respite, and in various social situations and feel "normal." At long last, these children can bring their machines, tubes, medicines, needles and anything else they depend on for their life in society with them and be told they are "ok." Finally these children come to a place where everyone looks past all of the medical jargon and paraphernalia and sees only the children.

Please visit us at our web page, www.medicallyfragile.org for additional information or email us at thtkb@camalott.com.

THTKB is currently serving clients in Abilene and the Burleson area, and is in the process of developing new sites in Cedar Park, north Dal-

Would you like to write something for the TxP2P Newsletter? Or do you have an idea you think would make a good article? Contact Laura at 512-458-8600, 866-896-6001 or Laura-txp2p@sbcglobal.net

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HIDDEN TALENTS: MAKING ART WITH YOUR CHILD

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into stars, dried starfish, starfruits cut in half, Styrofoam stars, starshaped cookie cutters, holiday stars, buttons, candles...feel free to experiment.

What You Do:

- Dab the objects into the paint filled sponge or ink stamp and stamp them onto paper in random or ordered patterns.
- 2. All items should be prepped and tested to make sure they print well by an adult first.
- 3. An option is to use a white sheet of paper for the initial prints, and then cut pieces of the printed paper

into stars, and affix them to a colored construction paper background, making a pattern on pattern effect.

Be sure to have your child sign their creation!

At VSA arts, one of the ways we suggest to keep the activity inclusive is to let the child make as many decisions as they can during the creative process. For instance, if your child has trouble with manual dexterity, you can help put the stamp to the page: but let your child pick what color, and help guide where on the page the image should

We hope that you will explore making arts with your child often, as we believe every Texas child should have arts in their life, every day! For more information about VSA Arts of Texas, contact

Emily Cicchini, Manager of Arts email Education, via emily@vsatx.org or by phone at (512) 454-9912 x 15. Their website is <u>www.vsatx.org</u> See more about START WITH THE ARTS at http://www.vsarts.org/programs/ swta/index.html

Healthy G-Tube Feeding

increased her weight, mental alertness, and interest in

eating more orally because her tummy feels better. It has also



duced and seemingly eliminated reflux. Abby now has 3 younger sib-

lings...yes, our house is wonderfully crazy . . . and some days I could easily leave off that wonderfully part. I must add that this diet can ONLY be used for children whose G-tube goes directly into the STOMACH, not the intestines. This is also not a cure for disease and may not be helpful for every child.

If you are interested in learning the specifics of what I do, email your

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request t o Lauratxp2p@sbcglobal.net Please do not attempt this until you have read my entire packet detailing the procedure AND discussed the packet with your physician in regard to your child.

Blessings to you and that sweet child of yours.

Toll Free Hotline for Air Travelers with Disabilities

The U.S. Department of Transportation is calling on all disability organizations to promote public education about its Toll Free Hotline for air travelers with disabilities through

their organization newsletters, listserves and sponsored events.



Hotline

disabled air travelers has been in operation since August 2002 and is available for callers from 7 a.m. to 11 p.m. Eastern Time, seven days a week. It is currently not being fully The Hotline serves two main purposes: (1) education and (2) assistance in resolving disabilityrelated air travel problems. Call the Toll Free Hotline 7 a.m. to 11 p.m. EST: 1-800-778-4838 (Voice); 1-800-455-9880 (TTY)

Many disabled air travelers are not aware of their rights and the Hotline, in part, exists as an educational service to inform air travelers with disabilities about their rights under the Air Carrier Access Act and the Department's implementing regulations 14 CFR Part 382 (Part 382). Hotline operators are well versed in the ACAA and Part 382 and can provide callers with on the spot general information about the rights of air travelers with disabilities. The Hotline operators also respond to requests for printed consumer information about air travel rights of the disabled.

The Hotline can also assist air travelers with disabilities in resolving real time or upcoming issues with air carriers. The purpose of "realtime" assistance is to facilitate airline compliance with DOT's rules by suggesting to the passenger and the airline involved alternative customer -service solutions to the problem. The airline remains responsible for deciding what action will be taken to resolve the issue in accordance with the ACAA and Part 382. Generally, if a caller has a real time problem or an upcoming issue with an air carrier, a Hotline Duty Officer will contact that air carrier and attempt to resolve the issue. For example, there have been a number of incidents in which Hotline Duty Officers have contacted air carriers and convinced them to accept service animals and electric wheelchairs on board flights, to stow folding wheelchairs in the cabin. and to provide requested wheelchair assistance.

Air travelers who want information about the rights of persons with disabilities in air travel or who experience disability-related air travel service problems may call the Hotline to obtain assistance.

Air travelers who want DOT to investigate a complaint about a disability-related issue still must submit their complaint in writing via email at airconsumer @ost.dot.gov or postal mail to:

Aviation Consumer Protection Divi-

U.S. Department of Transportation 7 t h Street, Washington, D.C. 20590

To request flyers promoting the Hotline to distribute to your membership, contact (202) 366-1617 (voice) or (202) 366-0511 (TTY).

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Texas Parent to Parent 3710 Cedar Street, Box 12 Austin, TX 78705

Toll Free: 866-896-6001 Local: 512-458-8600 Fax: 512-451-3110

Website: www.main.org/txp2p Email: txp2p@sbcglobal.net



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.

During the 2003-2004 school year, the Texas Education Agency and Education Service Centers will be hosting 20 public input and information meetings to gather input on special education services for students with disabilities. The input from this and other public meetings will help the State identify and address areas for improvement and also build on current strengths related to the provision of special education. These public input meetings are a part of the Texas Special Education Continuous Improvement Process (TCIP) and will be held on an annual basis. The following meetings are left for the 2003 Fall semester: Nov. 12 - Kilgore, Region 7 ESC; contact 903-988-6908; Nov. 19 - Austin, Region 13 ESC; contact 512-919-5432. More to follow in the Spring se-

No. to	Confeners Tials	Lagger	
Date	Conference Title	Location	Registration Information
Friday, Nov. 14, 2003	Autism/Asperger's Super Conference 2003 - featuring Temple Grandin, Mary Wrobel, Diane Murrell, & Jim Yerman	Houston, TX	For more information, call Future Horizons at 800-489-0727
Saturday, Nov. 15, 2003	Eleventh Annual Jo Wingo Confer- ence, Children's Special Needs Network	Bethel Assembly of God 22621 SE H.K. Dodgen Loop 363 Temple, TX	For more information, call Mary Klentzman at 254-778-6412 (Temple) or 800-600-3940 or mklentzman@special- children.org
Saturday, Nov. 22 through Sunday, Nov. 23, 2003	The Center for Autistic Spectrum Disorders Autism Conference, Model for HOPE & Physician's Training	The Westin City Center Dallas, TX	For more information, call 512-565-4828; email kazuko@ grandecom.net; website: www.casdweb.org
Friday, Nov. 21, 2003 through Sunday, Nov. 23, 2003	Federation of Families for Chil- dren's Mental Health 15 th Annual Conference	Renaissance Hotel, Washington, D.C.	For more information, call Sandra Spencer at 252-758-2574 or email her at sspencer@grenvillenc.com or visit their website at www.ffcmh.org
Wednesday, Dec. 10, 2003 through Dec. 13, 2003	The TASH 2003 International Conference Possibilities	Chicago Hilton & Towers, Chicago, IL	For more information, contact TASH at 410-828-8274 or visit their website at www.tash.org/2003conference
Wednesday, Feb. 11 through Saturday,	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