

Texas Parent to Parent

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

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TxP2P Parent Conference 2007 June 6-8th Omni Austin Hotel Southpark



We had kids, miniature horses, & Pet Pals



Family Gathering & Laura Freeman singing



Teen Transition Expo and SibGroups



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Volume 6, Issue 2 Summer 2007

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The 80th Texas Legislature - Summary of Legislation Affecting People with Disabilities

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

Following is a summary of legislative activity that will impact children and adults with disabilities. This is not an all inclusive list; it is an attempt to provide information on some of the major "disability related" legislation.

THE GOOD:

HB 1 (Chisum) - Appropriations

- Waiting lists (see summary - page 3)
- Independent Living Centers - funding included for two new independent living centers; locations to be determined.
- 1915(c) riders - allows children re-

siding in institutions access to the Medicaid waiver that will allow them to access the services needed to leave the institution.

- Promoting Independence - funding for relocation contracts, HCS slots for those residing in ICFsMR, HCS slots for children aging out of foster care.
- \$82.3 million for Crisis Mental Health funding rate increases for Medicaid and CHIP providers
- SB 673 (Zaffirini) - Scooter's Bill**
 This bills allows high school students who have finished 4 years of high school, but are returning to school

for additional IEP services, to participate in graduation ceremonies with their peers. These students will receive a certificate of completion in lieu of a diploma. They will receive their diploma when they exit the public school system on completion of their IEP. Prior to this legislation, youth with disabilities were during their senior year of high school.

HB 1230 (Rodriguez/Zaffirini) - Transition and Supported Employment

This legislation addresses three

Our third annual conference was even better than the last - over 300 people attended the three day event. We knew that having the conference at the hotel, the Omni Austin Hotel Southpark, would make things easier for the participants and us but we didn't know how great it would be. The hotel was beautiful and the pool seemed to be the hot spot. Many parents left the Friday night Family Gathering to hit the pool - as one mom said, "It was wonderful to look around and realize that no one was staring at my child because they all had children with disabilities too!" Many similar comments were found on the conference evaluations. We have already set the dates for next year's conferences: our 4th Annual Parent Conference will be June 27 & 28, 2008 at the Omni Austin Hotel Southpark and the Wrightslaw 2-day Boot Camp will be August 1 & 2, 2008 at Region XIII Education Service Center. Hope to see you all there!!

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Family to Family Health Care Information and Education

Center Grant: Year Two

Jeanine Pinner, TxP2P

We're nearing the end of the 2nd year of our Family to Family Health Care Information and Education Center (F2F HIEC) grant, funded by Centers for Medicare & Medicaid Services, and I wanted to let you know how terrific it's been getting to meet so many of you around the great state of Texas! Since our F2F HIEC grant started in October 2005, I've gotten to meet and work with parents, parent groups, and the professionals who work with our kids in many areas of the state: Austin, Corpus Christi, Dallas, Houston, the Rio Grande Valley and San Antonio. We've done trainings on advocacy, health care systems, transition, starting parent groups, Medicaid Waiver programs, self-determination, and much more. Your requests for trainings have kept me hopping and I love it! As we approach the final year of our grant, I am working with an increased emphasis to connect with as many parents, parent groups, and professionals in as many areas in Texas as possible, so don't hesitate to let me

know if your group is interested in one of our trainings! This grant provides the funding that enables us to travel around the state to provide these trainings, so our F2F HIEC trainings are typically free. For more information about the presentations currently in our inventory, please go to www.txp2p.org and click on any of the following: *Services for Parents*, *Services for Parent Group Facilitators* or *Services for Professionals*. Next, click on *Trainings for parents and parent groups are available through the Family to Family Health Care Information and Education Center*. Please also feel free to call or email me for a copy or to discuss a training for your group. As we approach the 3rd and final year of our grant, we will continue to serve and support all areas of the state through trainings and assistance in starting parent groups, with an emphasis on El Paso and the Texas panhandle areas. It is our goal and desire to connect with as many parents, parent groups, pro-

professionals and other organizations as possible to provide trainings and support, but in a state as large as Texas, that's a monumental task! Several wonderful TxP2P volunteers have helped us make connections with groups around the state by providing us with contact information, or by making the initial contact on our behalf, and even arranging a lineup of presentations for us in their areas. **Can you help us make those connections?** If your group is interested in one of our trainings or if you're interested in starting a parent group, please call or email me! **Are you interested in helping me do trainings or presentations?** If so, I would love to have you help me with a few presentations and then can schedule you do them when someone in your area requests a training. I'd love the opportunity to work with you and your group and look forward to hearing from you soon! Contact Jeanine: 512-217-3558 or jeanine@txp2p.org

recommendations in the Children's Policy Council 2006 Report to the Legislature. Its intent is to improve post-secondary school outcomes for students with disabilities. The three primary components of the bill include:

- cross-agency training for vocational transition specialists to ensure they are prepared to refer students to all appropriate community supports and services,
- data collection relating to post secondary outcomes for youth with disabilities, and
- efforts to improve and enhance existing supported employment programs across agencies.

HCR 35 (Rodriguez/Ellis) - Elimination of 24-month Waiting Period for Medicare

Currently under federal law, there is a two-year waiting period from the point when individuals with disabilities begin receiving Social Security Disability Insurance (SSDI) cash benefits to the time that Medicare medical coverage begins. During the two year waiting period the people affected by this policy who are uninsured or underinsured at the onset of their illness or disability will either incur significant medical expenses or be forced to forego necessary medical care, often leading to an unnecessarily rapid deterioration of their condition or even premature death. This House Concurrent Resolution requests the US Congress to eliminate the two-



year waiting period to ensure that these individuals have access to medical care. Individuals receiving

SSDI are citizens who have a work history, have paid taxes, and have paid into the Medicare system. They should not have to wait two years for much needed health care services.

SB 758 (Nelson/Rose) - CPS Reform includes increased adoption subsidy for children with significant disabilities

Child Protective Service reform began in the 79th Legislative Session (2005) and continued in the 80th Session (2007) with SB 758. Included in this reform legislation are provisions directing DFPS to develop rules that would allow the adoption

Agency/Program	Waiting List as of Mar. '07	Number Slots to be Released
DADS:		
CBA	44,593	1,607
CLASS	15,805	586
HCS	32,063	2,676
MDCP	8,130	415
DBMD	18	16
Non-Med.	8,982	2,228
IHFS	14,833	1,374
Total DADS Waiting Lists	124,424	8,902

subsidies for children with significant disabilities who would not typically be adopted, to be increased up to the same level as the foster family payment. It is hoped that this will allow more foster families caring for children with significant support needs to adopt these children into their families and still have access to the resources needed to support their needs.

SB 1766 (Watson/Naishtat) - Consumer Directed Services

Consumer directed services (CDS) provide significant opportunities for individuals and families to have more control over who provides their services, how they are provided, and when they are provided. CDS promotes self-determination. The CDS workgroup has worked for years to improve and expand CDS services in Texas. SB 1766 provides for the continuation of the CDS workgroup past the September 2007 date it was previously scheduled to be eliminated.

HB 1919 (Smith/Van de Putte/Lucio) - Health Benefit Plan Coverage for Person with Acquired Brain Injury and Autism Spectrum Disorder

This bill requires insurance companies to provide services specifically needed by individuals with acquired brain injury. It also prohibits companies from imposing higher cost sharing requirements than what is required for other illnesses and injuries. In addition, SB 419 was added to HB 1919 as an amendment at the end of the session. This bill language states that a health benefit plan must provide generally recognized services to children with autism, older than two and less than six. The generally recognized services may include assessment and evaluation, applied behavior analysis, speech therapy, occupational ther-

apy, physical therapy, medications, and nutritional supplements.

HB 109 (Turner/Averitt) - Partial CHIP Restoration

In previous legislative sessions, CHIP eligibility rules were changed significantly causing a large decrease in the number of children eligible to receive the services. Through the efforts of the very effective CHIP Coalition, some changes will be enacted that will restore this valuable medical coverage to a large number of children. Changes include: 12-month enrollment period for most clients, changes to assets tests, elimination of 90-day waiting period for most children, and changes on how income eligibility is determined.

HB 75 (Naishtat/Wentworth) - Judicial Review

This legislation requires the state to develop a system of judicial review of decisions made regarding access to certain public assistance programs. This will provide for an appeal outside of the Health and Human Services system in hopes of balancing the conflict of interest that exists in the current administrative review.

THE BAD . . . (Mostly things that did not pass):

- Died* -- Most special education legislation
- Died* -- Numerous bills on autism
- Died* -- Children's Bill of Rights for Children in Foster Care
- Died* -- Lifespan Respite Act
- Died* -- Advanced Directives eliminating the 10-day futile care provisions
- Died* -- Medicaid Buy-In for Children with significant disabilities

YET TO BE DETERMINED:

SB 10 (Nelson/Delisi) - Medicaid Reform

tailored benefit plan for certain

- populations including children with special health care needs
- medical transportation
- Medicaid health savings account pilot program
- physician centered nursing facility model demonstration project
- regional or local health care pro-

grams for employees of small employers
HB 3575 (Legislative Oversight Committee for Integrated Eligibility (Rose/Herrero/Hughes/Parker/Davis))
•sets goals for improving customer service, reducing processing time,

and meeting federal standards.
Prepared by the Texas Center for Disability Studies at The University of Texas at Austin. For more information contact Colleen Horton, Public Policy Director, 512/232-0740.

That's What Friends are For: Enriching the Lives of our Children

Keynote Address for the TXP2P Conference, June 8, 2007
Rosemary Alexander, Ph.D., TxP2P

Howdy, friends. I love having this opportunity to share my favorite subject with you - building a good life for people with disabilities. I bring a message of hope. From my experience, hope is rare in our world, the world of families of children with special needs. Mostly we end up with dashed dreams, frustration with education systems, lack of funding sources, long waiting lists, closed doors. We learn to expect less, hope for less, lower our expectations, and wait. Less hope is a way to defend ourselves against disappointment and loss. But I would like to inspire you to hope, based on friendship, raised expectations, and collaboration. I want to talk today about how to enrich the lives of people with disabilities, particularly through friendship, through relationships, what keeps us all going.

And I want to mention why I trust you will be interested in the words of a person with a 25-year old son who has disabilities. Perhaps your child is 3 or 5 or 10, and you wonder why my experience is relevant. Why should you care now about quality of life for adults with disabilities? Your child may be 15 years away from adulthood. I know how you feel. I remember thinking, when my son was 5, I'm dealing with all I can deal with right now, I refuse to think about the future. Here is my answer from my current perspective:

1. Preparing your child for the future takes years; for example, the current 10-year waiting lists for our best services.

2. Having a vision of the future influences current decisions, for example, having a vision of connectedness in the future will help you focus now on your child's capacity to build relationships so that he or she will have friends as an adult.

3. Changing the system takes years. Look at what adults are doing now and if you don't like it, remember that your child will be doing the same thing unless we all start now to make changes. What we want is that when your child arrives at adulthood, high quality of life will be accepted, expected, and embedded in the service system.

So please stay with me. I hope by the end, you'll see the point.

First, I'll tell you my own story and why I have become passionate about building a good life for people with disabilities. I'm not a missionary ordinarily but I have become one on this topic. I guess most missions begin with a person in your life, an experience that becomes a motivator for your life, work and beliefs.

My life-changing experience is, of course, Will Alexander. Will is now 25 years old. When he was born I was completely ignorant about disabilities, as most of you were when your child was born or was later diagnosed. I was a college English teacher and a technical writer, and my husband was a computer scientist. We lived in Los Alamos, New Mexico and were on track to become a nice ordinary family. But Will had a brain injury during birth and another stroke at age 3, so I was in-

duced to the world of ECI and early childhood education, IEPs and ARDs, seizures and CP and MR and medications, PTs and OTs and - well you know how it goes. My life was dominated by anxiety, fear, worry. We had another child, we moved to Austin and I lived that overwhelmed life you know too well, taking care of everyone plus all the extra effort of having a child with special needs. It seemed to me that Will's needs were a bottomless pit, a black hole. We couldn't do enough for him, we had to fix him. We took Will to professionals and had them in our home to work on toilet training, eating and dressing skills, walking, talking, swimming, communication, behavior. An increasingly big challenge was his behavior—as he grew bigger he became ferocious, very angry when told what to do. We all bear scars of his bites and scratches, and I became very clever at tricking Will into getting ready for the school bus each morning, against his will. I kept charts, went to behavior classes, learned about antecedents, behaviors and consequences! He was a fanatic - if he saw a wagon, he had to pull it around and could not be parted from it without a huge battle. I leaned to look ahead and avoid those things that triggered unrelenting activity. I developed the philosophy that nothing always works, but sometimes something works. Another of the biggest challenges was Will's seizures, which didn't stop until we

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took him to the ER for an intravenous drug, and the medications he had to take for the seizures, which made him dizzy, groggy & irritable. After all our efforts, Will grew up to be a person without language but very determined to communicate and pretty good at finding the means. He walks but falls easily and has had many injuries, breaks, stitches. He needs help with everything and isn't toilet trained, but he can partly do most self-help skills—he meets you half way when you help him.

But the good news is, Will grew into a happy person. When he was 18, we finally found a drug combination that worked to control his seizures, using drugs that didn't make him irritated and groggy. (Thank you to our neurologist who never gave up!) He became much more alert, responsive, quick to show you he understands, eager to participate and cooperate, full of laughter and glee, smiles and hugs. I guess he always had these traits but there were only occasional flickers through his unhappiness. Now it's reversed - he is usually happy with occasional moments of anger, like we all have! His behavior is modulated, not a fanatic about anything, but right there with you. He doesn't demand but goes with the flow. He has become a pleasure to know - he has become himself.

As Will graduated and embarked on life after school, our focus has changed. Before I worked to "fix" Will but now I work for his quality of life. My goal is for him to be safe and have opportunities each day to be with people who care about him, to have opportunities to learn, to work and have fun, to have choices. Doesn't sound too unusual or demanding, does it? But it is! Nothing is harder than to help an adult with disabilities live a quality life - safe and enriched - a good life. That means having enough money, health care, a pleasant clean cheerful place to live, work, play and friends, some people in your life who are not paid to be there but are there because they want to be. It means having your teeth brushed everyday and Chinese food when you want it. It means having a dog if you're a dog person and a cat if you're a cat person, choices and

Changing the system takes years.

control. If this is a challenge, picture providing that life without you in the picture! Your child's life AFTER YOU ARE GONE! Picture that life after we, his parents, can no longer be his advocates and friends, as we age and die. That's the hardest thing for us all as parents of children with disabilities to face - the fact that our children may outlive us and never again have the care we can provide.

One of the best things that happened to assist with Will's quality of life is that his name came up on the CLASS list. CLASS is a Medicaid Waiver Program that assists people of all ages with disabilities to live in the community instead of an institution. The waiting list is long and Will was on it for about 7 years, but now he gets supports that really make a big difference in his life, 84 hours of attendant care per week. With the assistance of his buddy, he goes to a rec center, music therapy, art and movement classes, swimming, and several hours a week delivers sandwiches at a school and mail at a seminary, mostly through the help of the CLASS program.

Will is one of the lucky few in Texas getting these supports. There are about 90,000 - 128,000 Texans with disabilities waiting for this kind of support, combining all the waiting lists for Medicaid supports and depending on how you count. An analysis of how well each state makes use of Medicaid funds for community supports ranks Texas 50th out of 51 contenders (counts D.C.). (We can always thank Mississippi for keeping us from last place!) View this report at www.ucp.org/Medicaid/ CLASS and other Medicaid waiver programs make use of Medicaid dollars to help a person live in the community rather in an institutional setting (includes group homes). According to this report, our state ranks 50th in the use of Medicaid funds to assist people to live a life integrated into the community. So here is problem # 1: We need more financial supports in this state to provide people with disabilities the means to live in the community, just to provide the safety net, the basics of a quality life.

And here's problem # 2: Government funds provide much needed

supports and services, but they still do not provide an enriched life. Government funds can be used to provide a roof over your head, people to assist in daily care, job coaching, transportation, and access to appropriate health care, all of which are vital to a safe and enriched life - and obviously that's our first order of business as advocates in Texas.

But that's only half the battle. An enriched life means choice, people who care, friendship, meaningful activities and work, fun. How can we provide for those qualities of life, now and when we are gone? I've given a lot of thought to this question, both for Will and through my work.

Now I'm going to tell you about the work I've been doing for the last 20 years: support and information for families of children with disabilities. I've been working in this arena since Will was little, first at our local ECI program, then our local hospital. After my kids had both started public school, I worked at the Arc of the Capital Area for 10 years in a parent-to-parent program, where I found kindred spirits like Laura and Sue and the rest of the TxP2P crew. For the last 5 years, I've been doing similar work for our school district, Austin ISD. As Will has grown up, I've moved into the arena of transition to adulthood and planning for quality of life after graduation. This work has given me the opportunity to assist Will on the personal level and to learn about what's going on locally, around Texas, and beyond to further the goal of high quality of life for adults with disabilities.

The best source of inspiration for me has been a book I discovered while ordering books for the Arc's parent library, *A Good Life* by Al Etmanski. He and his wife Vickie helped to start a parent organization called PLAN (Planned Lifetime Advocacy Network, website is www.plan.ca) in 1989 in Vancouver, founded to answer this question, how do I work for a safe and secure life for my family member with a disability after I'm gone? Reading this book just lit up the landscape for me - because it gave me hope for Will, just as my fears

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were multiplying as he approached graduation. I had always wanted to do a person centered plan for Will but I was afraid to ask other people to come over, sit down and help us plan for Will's future. This book gave me the courage to start planning with the simple advice of "ask - the worst that can happen is, someone will say no!" So that's what we did when Will was 20 - a person-centered plan. Our planning group met 3-4 times and then morphed into a personal network, the fundamental idea presented in *A Good Life*. More about networks in a minute.

In March of 2005 I attended a PLAN institute in Vancouver for a week, learning with 20 other parents about the PLAN organization, its ideals and how it helps families build safe and enriched lives for their family members with a disability. It was a moving experience that further empowered me to carry out PLAN for Will and I hope, for others in Texas.

A Good Life says: *This is not your typical book about people with disabilities. Rather it is a gentle nudge into a new way of thinking. A Good Life offers a very different perspective about what is truly important when contemplating the future of people with disabilities. A Good Life catapults over the traditional supports and services available to most people with disabilities and suggests another approach. (p. 1) Instead of "What variety of services and programs will my relative need?" the question becomes, "What is a good life?" (p. 2)*

I could talk all day about the ideas in this book, but today I really want to just give you the **highlights of a variety of ideas that have come my way in the last 5 years, both through PLAN and other sources.** They are all avenues that someone or some group somewhere has developed to create community for people with disabilities, all based on redefining disability and raising our expectations for quality of life for our friends with disabilities and helping them connect to community. They are all trying to answer that question, how do I help to build friendships for my son or daughter with disabilities?

Here are some of the key concepts from PLAN and the book *A Good Life*:

1. Sharing your Vision

In order to work for a safe and en-

riched life for my child, I need to envision that life and then share that vision with others. This really takes some soul-searching and some difficult conversations. Talk to your family and imagine:

- the best possible day in the life of your family member with a disability on his 20th birthday.
- the worst possible day in the life of your family member with a disability on her 20th birthday.

Now what can you do today to build toward that best picture? Think about it, talk about it, write it down, and tell others in your child's life about your plans.

2. Building relationships: Networks
After step one, *Sharing your Vision*, most people realize that one important goal is having good, caring, involved people in your child's life on that 20th birthday. Friends. How do we work toward that goal?

The idea here is that we create a group of people around a person at risk of isolation, people who volunteer to be a part of the network. Networks can be 2-3 people or 50 people. A whole church in one example from Canada. I'll tell you about Will's network. After our planning process, I invited a group of around 10 people to start meeting every 3 months with us to support Will. We meet at my house, we eat and drink some wine, talk and include Will in the circle. Mostly it's a party, although we also talk about what Will needs. Different people might volunteer to meet sometime with Will for fun, do some research, provide something needed. As the group develops and as our role lessens, the group might take on other functions. It's a support system for social opportunities and it also multiplies the number of contacts, ideas, resources available to Will. And our network came through in a perfect storm of disaster!

Networks expand, enhance, and nurture relationships for people who are isolated and lonely, for people who may need a little push, nudge, or welcome back into the heart of community life. (p. 51) The best guarantee of a safe and secure future for a person with a disability is the number of caring, committed friends, family members, acquaintances and supporters actively involved in his or her life. (p. 52)

This concept can be used with children, with people with all kinds of

issues, with our parents in a nursing home, with a neighbor who has cancer. It's building an informal yet intentional support around a person who needs one. For example, a personal network for a 5th grader with Autism would probably focus on social connections. Could you find some children to form a network, perhaps some the same age, some a bit older, who would learn about your child, how he communicates, what he needs to feel safe, what is fun for him, then do some activities with him on a regular basis?

You may already have a personal network for your child and you just don't call it that. Some people live in big families and your child already lives among aunts and uncles, grandparents, cousins, brothers and sisters. Maybe these people take an active part in your life and your child's life. Maybe you are part of a church or neighborhood where people help one another when needed and offer friendship regularly. We call these natural supports, and you don't need to create "intentional community" - you already have one. But for others, less lucky to be "naturally supported," it's a great way to invite people into your child's life and your family's life.

3. Creating a home

In *A Good Life*, there is the basic concept: my child will only live in a place that I would enjoy living in! Sounds obvious, but historically it is not - people with disabilities have usually lived in places where most of us wouldn't want to reside. What we want is control over our environment and a place to live with family, friends, people we choose to share our lives with.

What's the difference between a home and a house?

*Client → resident → tenant/
renter → owner*

Continuum from least amount of control over your environment to the most control.

4. Making a contribution: work

Everyone needs the opportunity to make a contribution. Work gives us that opportunity, gives meaning to our lives, and gives us connections with people - another avenue to friendship, relationships. We must find a way for our children to be involved in the world as contributors. We must start by seeing their gifts and then finding a place where

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they can use those gifts.

5. Ensuring choices

A Good Life discusses the "balancing act" between keeping our child safe and respecting their choices and preferences. This chapter is a gentle reminder that we can never be an authority on someone else's life. (p. 181) How do we respect the choices and preferences of our relatives while at the same time keeping them safe? This balancing act is a tough challenge. (p. 179) Step five is about resolving that contradiction.

For our sons and daughters to become authors of their own decisions they need to:

- Be respected for their inherent decision-making ability
- Develop an authentic decision-making voice
- Receive support where necessary
- Make genuine choices and options
- Make decisions based on choices
- Have alternatives to legal guardianship
- Be able to make mistakes (p. 181)

This one a very challenging chapter for us parents!

Citizenship

PLAN in Vancouver has gone beyond working for the benefit of individual families to look also at how people with disabilities fit into society as a whole. The result of this inquiry is the PLAN Institute, which explores the concept of Caring Citizenship.

People with disabilities can and want to contribute to the betterment of our society - to fulfill their duties as citizens. By welcoming the participation of people with disabilities - and others who have been marginalized or isolated - everyone benefits. Individuals benefit from being valued as full and contributing citizens, and society benefits from their knowledge and gifts. Indeed, we believe that the health, well-being and strength of our society depends on the presence and participation of all citizens.

What can you do NOW—at whatever age is your child or friend with a disability?

1. Start with yourself - think about your own attitudes and beliefs:

- Quit thinking you have to do it all yourself

- Quit thinking you are the teacher . . . become the learner!

- Start to let go of being the total parent!

- Make time to develop a friendship for yourself.

2. Open your life to others:

- Build networks and collaborations, circles of support for yourself and your son or daughter.

- Don't be afraid to ask. Be creative about whom you ask. Ask for something specific.

- Look for groups to join.

- Start a group.

- Build intentional community.

3. For your child, begin to think long term:

- Learn about person-centered planning or some planning process

- Promote any interest your child might have - interests opens doors to groups.

- Start talking to your child about work, responsibility, the future and the goals that might begin to inspire your thinking.

- Encourage school staff to teach self-determination skills and involve your child in the ARD process.

- Think about what will be most important for your child as an adult—what skills, what connections, what self-attitude? And start to focus on those now.

4. Work to change your neighbor, town, state:

- Tell our stories.

- Collaborate—see what resource you have then look for others with different resources.

- Collaborate with professionals as peers.

- Collaborate with other parents as friends.

- Join advocacy groups.

Friendship is what makes our lives worthwhile, the relationships that keep us going, but people with disabilities often have no friends. Let's start now to build opportunities for friendship, for enriched lives for our children. My message of hope is that we are not alone in this attempt - many groups in our world are striving to build community. So, let's start a movement here in TX, in your town, through TXP2P or some other group.

Be a part of the movement! Our goal is a life for our children with the enrichment provided by higher expectations, friendship, and collaboration.

Finally think about the gifts of our children. Recognize that it's a privilege for others to participate with your family in building friendship, circles of support, for everyone benefits, perhaps most of all the others who join us.

I'm going to end with a speech I gave at Will's graduation May 2004:

As a parent I thought I would be the one to teach. As it turns out, I've been the student and my children the teachers. One thing we've learned from Will is:

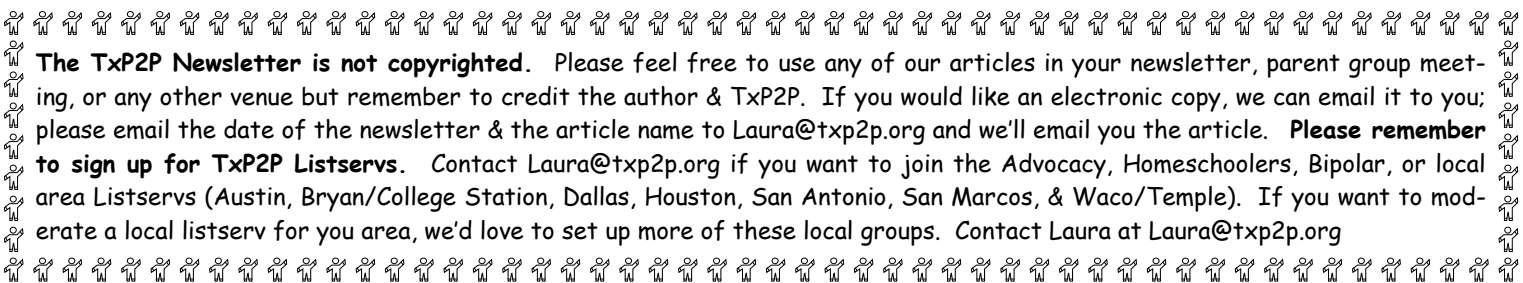
- the advantage of eating salad with your hands - quick and easy and not too messy if you skip the dressing! The same is true for pancakes without syrup.

But that's Will—he grabs life with both hands and enjoys it. He has no use for the formalities of society. Here's what else we've learned from Will:

- you can express a lot without words
- it's more fun to color outside the lines
- it's okay to walk a little slower
- why listen to the news when you could listen to music that makes you move
- when you fall down, laugh
- when you drop something, laugh even harder
- when you get mad, throw something but never stay mad
- greet everyone with a hug
- live in the present moment
- keep trying no matter what horrible things happen to you
- slow down, never rush.

He demands that we learn to:

- give dignity in undignified circumstances
 - value the eccentric and not care what others think
 - advocate for those who need a voice
 - be patient when it takes longer to learn
 - be flexible and open to a new approach
 - be ready for a crisis and ask for help when you need it.
- Thank you to all who have helped.

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Serving children with disabilities, chronic illness and other special health care 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, Sept. 6 th to Saturday, Sept. 8 th , 2007	Texas State Conference on Autism	Omni Hotel Corpus Christi, TX	For more information, contact: ESC Region 2 209 North Water St Corpus Christi, TX 78401 Phone: (361) 561-8400 http://autism.esc2.net/conference.asp
Thursday, Sept. 27 th to Saturday, Sept. 29 th , 2007	Fifth Annual Conference on Brain Injury North American Brain Injury Society	Westin Riverwalk Hotel, San Antonio, TX	For more information, contact: NABIS Conference PO Box 1804 Alexandria, VA 22313 Phone: (703) 960-6500 E-mail: conference@nabis.org http://www.nabis.org/articles/conference.shtml
Saturday, Oct. 6 th , 2007	The Annual Disability Conference & Resource Fair for the Northwest Houston Community	Graceview Baptist Church 25510 Tomball Parkway, Tomball, TX	For more information, contact: Michelle Guppy at MichelleMGuppy@yahoo.com or 281-686-0103
Thursday, Oct. 11 th to Saturday, Oct. 13 th , 2007	The Arc's 56th National Convention	Hyatt Regency, Dallas, TX	For more information, contact: The Arc of the United States 1010 Wayne Avenue, Suite 650 Silver Spring MD 20910 Phone: (301) 565-3842 Toll Free: 1-800-433-5255 www.thearc.org