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Texas Parent to Parent

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

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There is still time to get organized for a successful

Summer!

hhhh! Summer veteran parents this is here! Time to sleep in late, watch the flowers grow

playing quietly at our feet while we sip our iced tea. NOT! Let's be honest here, we are all hot, tired, swamped

and enjoy the children

do lists, and the kids are pulling h e house

down

with to-

around our ears all the while singing out, "We're Even my non-Bored!" verbal child with cerebral palsy gets that look on her face like she is bored of vacation already. What is a Mom to do? We asked our

question and here is some of their infinite wisdom, condensed into sound bites for the summer stressed parent.

Hint #1: Summer success seems to depend on a schedule. Almost every parent stressed the fact that establishing a routine was of primary importance.

✓ Build a routine: Monday is library, Tuesday is swimming, Wednesday is a community outing such as the zoo, a visit to the pet store, Thursday is friends come over, Friday is rent a video day, etc., etc. Think about what your child will find interesting and that you can tolerate. Build a schedule or calendar and make it very visible.

This gives everyone something to look forward to and helps parents avoid the guilt trips that their children are not getting enough community exposure, etc. Ronnie Schleiss

✓ A schedule for time at home: I've always had to do this for Jake to save my own sanity and to keep him involved in more than the one thing he is obsessed with at the moment. I try to design the schedule with him, but I have strict parameters of what I'm willing to accept and what I'm not. Jeanine Pinner

I usually use Spring Break as a trial run for how I want to plan the summer (since Michael needs a lot of structure):

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Summer 2003

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Compiled by Patty Geisinger, TxP2P

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How to Advocate For More Services for Your Child

Compiled by Laura J. Warren, TxP2P

get many phone calls from parents who are struggling with their early childhood program, school, or insurance company to get the services they feel their child needs. I decided to ask the experts on these subjects - parent professionals who deal with these questions every day people I go to or send parents to when I don't have the answers. It finally dawned on me that I could get the word out to more parents by putting it in the newsletter. I hope it helps!

When Working with an Early Childhood Intervention Program:

By Susan Prior, Information & Training Support Coordinator, ECI State Office

If your child is receiving services from an Early Childhood Intervention (ECI) Program and you are not happy with the services or feel your child requires more, follow the steps listed below to help resolve your concerns:

When your child enters the program, you and your team members from your program will develop an Individualized Family Service Plan (IFSP) of what the services will look like based on your child and family needs. You are a very important part of that team and you have the right to receive answers to any questions you may have. You need to ask!

- Sometimes parents and ECI staff disagree. It is important for you to talk with the person you disagree with. If that is not possible, talk with your service coordinator and/or program director. If you are not satisfied, you can call the State ECI office at 1-800-250-2246 and ask for help resolving your disagreement.
- You have the right to ask for a change in your IFSP whenever your child has met a goal, isn't progressing or the plan is not appropriate. Your program is required to review your IFSP with you every six months and more often if needed.

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There is still time to get organized for a successful Summer!

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I can see what is realistic or not. Chances are, if I can't do something over Spring Break, I probably won't do it over summer. I also think, as Michael gets older, to arrange as much help as possible so that I am not exhausted when school starts in the fall. Finally, if our children are old enough or can communicate, give them as many choices as possible. Odds are that if they choose the activities, the day will go much smoother. Joanne Weaver

Hint #2: For a fun filled, cool summer, try swimming. Every community has a pool nearby, find out the hours and read on.

✓ Swimming is a regular afterdinner activity. The pool is not crowded so its peaceful, we don't have to use sunscreen, and the water is good for Maverick in so many ways--calming, proprioceptive, socializing, exercise, etc. **Denise Sonleitner**

✓ I try to schedule one play date per week to come swim at our house. Not this year, but in years past, we'd take Tom to Schlitterbahn about three or more times with a season pass.

Val Sutorius

✓ Swimming lessons at Austin city pools (very cheap and very valuable) -- they got us both out of the house, Jake learned a lot, got some exercise, some vitamin D/K (or whatever you get from the sun), and then he and I played together in

the water.
We've usually
managed to
organize a multifamily camping
trip to a local



state park at least once during the summer. Spend a couple of days fishing, reading, eating, playing on jet-skis, etc. **Jeanine Pinner**We go swimming for at least an hour every day. **Rilla Chaka**

Hint #3: Libraries, summer school and reading programs are more ways parents can fill the hours of long hot summer days.

✓ Because Jessica is confined indoors due to her seizures for most of the day, we go to the library once a week for story-time, and rent her books on tape. She loves to listen to them while lying in bed. There are many times that her two

little sisters join her on the bed and they all listen together. Patty Geisinger

✓ Gary (my husband) usually home -schools Tom in one subject that he needs to improve on like Math or Reading. So, Gary takes Tom to the Library about every 2 weeks to get a new book. Or we look up the space station orbit schedule on the NASA.gov website, then go outside, and watch it go overhead for three thrilling minutes every so often. One Mom I know who home-schools year round has theme week at home. One week is Egyptian and they not only study the culture but also prepare an Egyptian meal for dinner one night. They dress in costume and play a game from that country.

Val Sutorius

My kids like to read but don't always want to stop playing to do it. So, we came up with some unusual places to read and wrote them on Popsicle sticks, such as in mom's garden, bathtub with pillows, under the dining room table like a cave, that sort of thing. Then each day at reading time, we draw sticks to see where we go for an hour (including mom)! They like the variety and the unusual nature of it and the surprise. Rilla Chaka

✓ I recommend working with your school district to create appropriate Extended School Year (ESY) programs, including inclusive settings with Extend-A-Care, regular summer school in elementary or middle school, or career exploration/pre-voc community settings in high school. (We have had ESY every summer since Trey was in 1st grade--we don't always go every day for the entire time, but we do at least half of the time.) We used the extra time to focus on one particular area of need, such as private reading and math tutoring--this summer it is Auditory Training for auditory processing. Jill Haas

Local bookstores and libraries have reading programs that can be a lot of fun. In years past, Barnes & Noble offered numerous free books for kids who reached certain reading levels during the summer. Jeanine Pinner

Hint #4: Movies, TV, board games, and inside fun are also

some neat ways to while away the sunny days.

✓ Have "Board Game Days" where friends come over every Wednesday from 1-3 to play Clue, Monopoly, etc. I have gotten six kids and their parents to agree to try to come every week, but anywhere from one to six shows up (average of 2). Most of the kids are latch-key kids who enjoyed a chance to

get out of the house and the parents liked it, too. Or we watch old movies, like The Three Stooges, and Laurel and Hardy. Rilla Chaka

ger movie theatres have their children's summer series one or two days out of the week. The movies are free and start showing around 10 a.m. It's gotten pretty popular the last few years so I recommend you get there early. I use it as a reward system for the boys and a cheap outing too.

M. Helen Esqueda

Hint #5: And finally, we have camps, museums, the lake, and other outside activities

One week of Skin Camp and one week of Vacation Bible School take a big bite out of the 84 days of summer vacation. This summer I want to spend at least one day at U.T. at the refurbished Harry Ransom Museum. At least it will be cool inside so it is probably a good 11 am - 3 pm activity. Val Sutorius Camp C.A.M.P. takes Jessica every year even though she seems to gets sick as soon as she gets there. They have an infirmary and she does just fine in there, but this year I'm sending her on antibiotics so she can have more fun and participate in all the activities. Patty Geisinger

✓ We will have community outings to museums, libraries, services (such as dry cleaners, florist, pharmacy, gas station, etc.) and talk about what you do there and who works there. We are starting a career journal as part of ESY this summer and will continue to add to it. We'll also have family vacations and go to recreation center programs (we did Austin Recreation and we know parents who have had good luck with McBeth Recreation

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Center). And we'll have his big sister haul him around with her friends to the mall, bookstores, restaurants, movies, etc. Jill Haas We have picnics in the yard (or what Halla and Annie really like, picnics and camp-outs in the family room with blanket-tents), go for a drive looking at the pretty houses (a.k.a. mansions) while eating ice cream, or go to Half-Price Books and stock up. Linda Thune

Although we have only listed a few

ideas for summer, many of these

parents had similar many ideas. I hope that you found just one thing to try this summer your community. Although some of these places are in Austin, it does not mean

"Ahhhh!
Summer is here!
Time to sleep in
late, watch the
flowers grow
and enjoy the
children playing
quietly at our
feet while we sip
our iced tea.
NOT! ."

that your community does not have them. Look around in your libraries, museums, and summer school programs. I bet you can find tons of fun things to do to make the summer go smoothly and successfully. And as one mom so eloquently put it

"But mostly, summer is about getting to sleep late and eat lunch when we want to. That has to be my favorite part!!" Val Sutorius

<u>Legislative Update: The Good (not much of that), The Bad</u> (plentiful), and The Ugly (more to come) . . .

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

n the beginning, (January 2003) things were very, very, very bad. In the end (May, 2003) things are not as bad as initially proposed, but much damage has been done, and it is probably not over yet. As the agencies scramble to implement measures passed during the session, all efforts may come to a screeching halt, as the Texas Comptroller did

not certify the budget (H.B. 1). What this means is that the budget passed by the Legislature exceeds the



amount of money the state will have to spend over the next two years. The Texas Constitution does not allow this. Therefore, the following information is based on what happened during the regular session and what we know today (6/19/03). If the Legislature is required to develop a new budget, some things will obviously change.

* * * * * * * *

What happened during the session you ask? That is a very good question. Many of us are still trying to wade through the mountains of paper. While you might expect that we would know everything that was passed, it is difficult because of the crazy way things are done in the final days of the legislature. During that time, many bills that died in committee or never got a hearing on the House or Senate floor are amended onto bills that are moving quickly through the

process. The result of this mayhem is that bills passed in the final days of the session often look very different than they did when presented in committee. Sometimes this works for us, sometimes this works against us. One thing is for certain, however, even though we lost some very important things and basically gained nothing, the damage would have been much worse without the efforts of parents, families, and consumers.

So, our congratulations to those of you who participated by making phone calls, sending emails, and visiting legislators. It was more important this session than ever before, and it will be even more important in the years to come. A trend has been established to reduce government and consequently reduce services to people who

need them. Please do not think it will stop here. In the minds of many policymakers, this is just the beginning. Keep in mind, not a single new waiver slot was appropriated. In some waiver programs, attrition slots (those made available when someone leaves the waiver program) may not be made available and the total number served may actually be reduced. This is not the direction we want to go.

So it is time to sharpen your advocacy skills, stay informed, and be prepared when the call for help comes. It is only the voices of the masses that will make a difference in this environment. In the words of Barbara Jordon, "Government was never meant to be a spectator sport."

Major Implications of House Bill 1 (Appropriations Bill) and House Bill 2292 (Health and Human Services Reorganization):

House Bill 1 is the Appropriations Bill that tells state agencies how much they can spend over the next two years and what they can spend those dollars on. House Bill 2292 is the legislation that will reorganize the state's health and human services system. two bills are closely tied as many of the projected cost savings in HB 2292 are assumed in HB 1. No part of the system was left untouched. While transition planning is underway, the process is expected to take 4-6 years. The Health and Human Services Commission (HHSC) will become a very large service provider under the direction of the Executive Commissioner. The current 11 separate health and human services agencies will be consolidated into four agencies and will be directed by four Commissioners. All rule making authority will rest with the Executive Commissioner of HHSC and will no longer rest with individual agency boards. The boards of each agency are eliminated and replaced with advisory councils that will have significantly less authority.

In addition to changing the structure of the health and human services system, H.B. 2292 contained many program changes to CHIP, Medicaid, Temporary Assistance

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to Needy Families (TANF), and various agency programs. Some of the major changes are outlined below.

Children's Health Insurance Plan (CHIP)

- □ Eligibility remains at 200% of the federal poverty level.
- □ Assets test will be applied to those at 150-200% of federal poverty level.
- □ Continuous eligibility is now 6 months instead of 12 months.
- □ New provisions will require a 3month waiting period for coverage to take effect
- Benefits will be reduced speech therapy, occupational therapy, physical therapy, dental care, eyeglasses, home health, and mental health services are eliminated.
- ☐ Increased cost sharing will be required.
- ☐ Income disregards will be eliminated making fewer children eligible for coverage.
- □ Number of insured children will be reduced by approximately 122,000 clients in FY04 and 161,000 clients in FY05 due to the above policy changes

Medicaid

- □ Pregnant women over the age of 19 with income above 158% of the federal poverty level will not be eligible for Medicaid services, eliminating services for approximately 7,831 women per month in FY04 and 8,144 clients in FY05.
- □ Medically needy adults with income from 17-24% of the federal poverty level will no longer receive Medicaid services, eliminating services for approximately 8,472 individuals per month in FY04 and 9,959 clients per month in FY05.
- □ Medicaid provider rates will be reduced by 2.3-5% (depending on the type of provider) which will likely cause a reduction in the number of providers willing to accept Medicaid consumers.

Department of Human Services

 Personal attendant hours for long-term care services will be reduced by 15% for many community care recipients.

 Funding reductions in the In-Home and Family Support Program at DHS will cause elimination of services or reduction in services for

more than 2,345 consumers.

The rider allowing the funding to follow the individual out of nursing facilities re-

"Keep in mind, not a single new waiver slot was appropriated."

mains intact providing opportunities for individuals to choose community services over nursing home care.

<u>Texas Department of Mental</u> <u>Health/Mental Retardation</u>

- ☐ Mental Retardation Community Services are reduced by 11% resulting in a reduction of the number of clients served by approximately 2,570 individuals.
- □ Mental Retardation In-Home and Family Support is reduced by 61% resulting in 2,587 fewer clients being served. Approximately 1,654 individuals will continue to receive services.
- □ Mental Health In-Home and Family Support program is totally eliminated resulting in approximately 2,946 individuals losing services
- □ HHSC is required to perform a study on the feasibility of closure and consolidation of state hospitals and state schools.
- □ MHMR is required to study the conversion of 3-4 bed HCS group homes to 6-bed group homes.

Early Childhood Intervention (ECI)

- □ Although ECI funding avoided major reductions, the program will still undergo significant changes.
- □ Rules relating to cost sharing for ECI services have been proposed and some form of cost sharing will likely be initiated.
- □ Eligibility for ECI services is being tightened. A workgroup is currently working on recommendations.

Special Education Legislation

The environment in the Education Committees was also tough. More time was spent to ensure that bad things did not happen instead of working to pass new legislation.

- □ H.B. 1314 included language that was originally in H.B. 2707. This bill initially attempted to weaken the protections for kids around restraint and seclusion in public schools. Due to the efforts of parents who provided moving testimony, the author of the legislation willingly amended the legislation and current restraint and seclusion protections remain intact.
- □ H.B. 1339 affects the timeline that schools must follow to conduct a full individual evaluation of a student for special education services. The 60-day limit now begins on the date that the parent provides written consent for evaluation. Previously, verbal requests for evaluation began the time clock.
- □ H.B. 320 prohibits school employees from threatening to report parents for abuse in order to coerce them into giving their children psychotropic drugs or consenting to psychiatric or psychological testing or treatment of their child. In addition, when a district obtains consent to evaluate a child for special education services, upon the parents request they must provide the name and type of examination the district plans to use. must also tell the parents how the results will be used to develop their child's individual education plan.

This is probably enough to digest for now. As the budget redevelopment begins and the health and human services reorganization proceeds, and as opportunities for family/consumer input develop, I will pass that information on to you. If you, or someone you know, would like to be added to the email alert list, please let me know. If you have a parent group that is interested in learning more about legislative/policy advocacy, I would be happy to help with that too. It is important that more parent/family voices be heard. You can contact a t $C \circ I$ leen.Horton@mail.utexas.edu.

We would like to thank:

Parkland Community Health Plan

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

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for sponsoring this edition of the TxP2P Newsletter!

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How to Advocate For More Services for Your Child

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- Most <u>importantly</u>, keep communication going with your program.
- Know your rights! Refer to your ECI Handbook or call the ECI State Office at 1-800-250-2246 if you have any questions.

When Working with your Child's Special Education Program in Your Local ISD:

By Rosemary Alexander, PhD, Parent and School Support Team, Austin ISD

Having your child covered by IDEA, the federal law that mandates special education services, is a great opportunity. Your child has the chance to receive the supports and individualized education he or she needs while you, the parent, have a chance to be involved in the decision making process regarding your child's educational services. IDEA provides you with a way to be a part of the educational team and voice

your concerns, what might work best to help your child succeed, and your vision for your child's future.

vision
child's
going with your
program."

"Most

importantly,

However, to take advantage of

these opportunities, parents must know about IDEA, understand the decision-making process, and learn how to be successful advocates for their children. Here are a few pointers for being an effective part of the school team:

1. Stay in communication all year. Get to know your child's teacher through chance encounters, phone conversations, and informal meetings.

Set up a regular communication system, such as a notebook, a checklist, regular phone calls, etc, that keep both school staff and family informed about routine concerns and events.

Volunteer at the school or ask how you can help from home.

Acknowledge through small gifts or treats that you appreciate the efforts of school staff.

2. Get ready for IEP meetings (called ARDs in Texas).

Keep a copy of your child's IEP (Individual Education Program) and latest evaluation handy. Know what

it says.

Before the annual ARD or IEP meeting, meet with the teacher and other key service providers to look at the current IEP and discuss how to change it for the next year.

Get to know IDEA and the IEP process. Check out the following websites: www.advocacyinc.org, www.thearcoftexas.org, www.nichcy.org, and www.wrightslaw.com.

Go into the IEP meeting with a clear idea of the issues and what outcomes you want from the meeting.

Take a picture of your child or have your child attend the meeting. Provide a written statement from your child of what he or she would like to say to teachers, or have him or her say it directly.

3. Act carefully and thoughtfully when disagreements arise.

If you and school staff run into disagreements or hard feelings, take a deep breath and step back from the situation. Do not explode, but rather find someone outside of school to hear your story and sympathize with your emotions.

Write down what you are mad about, but also what you would like to see happen.

Find out what your school-system hierarchy is—who is the key person at each management level. Find out who allocates resources and can make a difference.

Now take action. Write letters and talk to the right people: start with the person closest to the problem, and then if you do not get help there, talk to the person next up the line.

Approach each meeting or phone conversation as a business meeting, with a business-like attitude.

First meet informally to resolve the problem, then have an ARD to write your new decisions into the IEP.

Ask for more testing to get a more accurate picture of your child's needs and abilities.

Bring in tangible evidence about your child's abilities and needs, such as videos of your child doing things he does not do at school or participating with friends outside of school; make a strong case for what you are asking for your child.

Think before meetings about areas where you are willing to compromise

and where you cannot compromise.

Keep your poise and focus on issues not personalities, facts not feelings. Do not look for revenge but try to solve problems. Keep the school team looking at long-term outcomes for your child: what's really important for him or her to learn before graduating from school? What will make this child successful after graduation?

If all else fails, find out about mediation and due process.

Consult www.feta.com for many more advocacy and conflict resolution suggestions.

4. Teach your child to participate also.

As your child gets older (around middle school), start to involve him or her in the IEP process as much as possible. Guide your child to be a "self-advocate," able to describe his or her disability and the accommodations needed.

Encourage your child to make choices at first about little things, then about more important issues. Give your child opportunities to speak for him or

herself in a vari-

ety of situations.

"As your child gets older (around middle school), start to involve him or her in the IEP process as much as possible."

Work with the school team to coach your child to speak up in the ARD meeting, even to lead it as he or she gets older.

Begin to help your child to think about the future, what work to do, where to live, and how to find friends—the elements of a good transition plan for the future.

Good luck in the process of building a team with school staff and in building a positive, productive relationship with your child's school.

When Working with your Insurance Company:

By Leah Rummel, Executive Director, Texas Association of Health Plans

I receive many calls from parents having problems navigating their insurance to obtain services for their children. I have found over the years that navigating the sys-

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How to Advocate For More Services for Your Child

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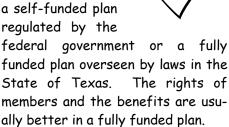
to the unending arrangements physicians and providers have with the insurance company. Most of these are not known by you, the parent, but affect how you can receive services.

My first advice to parents is:

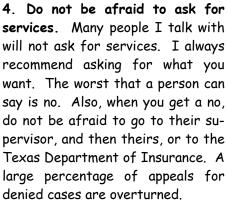
- 1. Ask for case management. If your insurance company has case management ask for it or insist to have those services. You life will be much easier if you only have to deal with one person at the company whose job is to navigate the system for you. Case managers have been known to find alternatives to services that may not be covered by the insurance, get approval for services that may be less expensive but more appropriate to your child, find other resources available in the community for your needs and suggest equipment, specialists or the latest technology available for your child that you may not know about.
- 2. Read your policy. Never be without your policy. Your policy will tell you what is covered and how much your costs will be from the coverage. Most people who call me do not have their policy, do not know if they have a HMO or PPO, and do not know if their policy is a self-funded ERISA plan or a fully

insured regulated plan. Ask your

employer for a copy of the policy and find out if it is an HMO, PPO, Point of Service Plan or EPO. Find out if your plan is a self-funded plan regulated by the



3. Know your rights. You always have the right to appeal a denial; you usually have a right to have an independent review for medical necessity cases and you have the right to sue your insurance company if they have incurred harm. You have the right to information concerning your policy, and the list of physicians and providers on the network. You have the right in most cases to never be charged more than the deductible or co-payment for services with in-network physicians or providers and you have the right for help from the Texas Department of Insurance. Their toll free number for assistance is 800-578-4677 (in Austin, call 463-6169).



5. If you have a choice of insurance companies, pick carefully. If your company has a choice of insurance companies to choose from, pick very carefully. You need to take into consideration which physicians your child uses regularly and if they are on the network, what services your child uses regularly and what level of reimbursement those are paid for by the insurance company, whether network restrictions can work for you and how much out of pocket can you afford. You can also ask other parents about their experiences with the insurance company or look at their complaint record at the Texas Department of Insurance.

Remember to ask for help when you do not understand your policy.

How to Advocate for Parent Liaisons at Your ISD

By Joan Givens, Education Specialist, Region XIII Education Service Center

s educators improve partnership practices with parents, more schools and districts are adding the position of parent liaison. Although many have been funded with Title I monies, an increasing amount are hired for the specific purpose of working in the area of special education. So, how

do you convince your child's campus and/or district to bring a parent liaison on board? First, get involved. Check



with your child's principal or with the district's special education director to find out about the membership and activities of parent advisory committees (PAC). These might exist at district or campus levels to address issues pertinent to all education; and there may well be additional PACs that have been organized just to help guide special education services at the district or campus levels.

By becoming familiar with (and maybe serving on) these committees, you will be better able to identify the needs that a parent liaison could fill for students, schools and families, and will have the information to advocate for the funding of a paid position. Depending on the focus of the job, monies may be found in general education (including federal title programs) or special education budgets.

Many of the paid parent liaisons who are working in special education started out as active parent volunteers. They helped organize and

maintain parent information and support groups. As more and more services were made available to and accessed by families, special education directors realized the value of creating a staff position to coordinate the development of proactive partnerships with parents.

Present yourself as a partner and problem solver. Work in collaboration with educators towards mutual solutions rather than as adversaries. Educators and parents alike have a common goal—to help kids be successful.



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Meeting Mobility Needs

When you have a child who uses a wheelchair, getting them where they need to go is not always easy! However, finding the right type of van, a lift to fit your van and your needs, and a system to secure the wheelchair into the vehicle are easy when compared to locating assistance with funding for the purchase.

If you are one of the fortunate few who have a Medicaid wavier program such as CLASS, MDCP, or HCS/MRLA, you can obtain assistance with the expenses. If not, you may have already called the local civic groups in your area (Elks, Jaycees, Lions Club, etc.) or every church in the phone book for help.

The June issue of Exceptional Parent magazine focuses on mobility. (If you do not get the magazine, you can go to their website for the article: http://www.eparent.com) The article that really caught my eye was "Financing Your Mobility Needs." The American Association of People with Disabilities (AAPD) and Digital Federal Credit Union have collaborated to provide "a wide range of easily accessible financing opportu-

nities" to assist with purchasing modified vehicles. You can become a member of AAPD for \$8.00 and then become a member of the credit union by opening a checking/savings account with a minimum of \$5.00. For more information, check out their website at www.aapd-dc.org or call (866) 241-3200.

To learn more about modified vehicles, both new and used, you can look under "Mobility Products" in the yellow pages or on the web or see the advertisements in Exceptional Parent. Alamo Mobility, Liberty Motor Company, and Ride-Away are a few companies that make these modifications in Texas.

Other important items:

- Vehicle Manufacturers provide various rebates for modifications to their automobiles
- When purchasing a vehicle that will have accessible tags, you are not required to pay taxes on the purchase
- Start with the type of modifications you want and find the vehicle that will accommodate those modifications

By Tammy Mann, TxP2P

- Talk to others that have vehicles like the one you are interested in if possible (TxP2P can help with that)
- Some places have modified vehicles for rent which provide you with the opportunity to try out various styles

I have had 3 vans for my daughter a full size, a full size-extended roof, and a minivan. I love my minivan and am amazed that it actually has more head clearance for my daughter when getting her in than the other two. However, I hate the feeling of "bottoming-out" every time I hit a speed bump because the van has been lowered! As much as I love my van, everyday I see options that I wish were available when I purchased mine in 2000 like rear entry lifts! Regardless, having a vehicle that allows you to travel with your family, even if it is to therapy, is awesome!

You are welcome to email me at Tammy-txp2p@sbcglobal.net or call me at (512) 458-8600 or (866) 896 -6001 if you would like more information.

"<u>Don't stop. Don't ever give up</u>!"

Laura ran her 4th Junior Dillo mile on Saturday, March 30, 2003. She coaxed her cousins into running with her this year. She also called her Grandma Mable to come watch her at the finish line. Laura doesn't worry if she'll get tired. She knows

she will. She knows all the kids will pass her in the first several seconds. With half the race to go, I watch her and think of the long distance runner. Most of the kids have already



finished, and Laura has the track all to herself, no one to pace her. Later, I asked her what she thinks about during the race. She answered, "Just a little bit more." She's instructed her parents to stay on the sidelines. We try not to coach her during the race. She knows her body, and what she can do. She knows that a policeman will be trailing her on a motorcycle. It scared her that first year. I see her slow down, but she never stops.

She hears a cheer from an onlooker, and her pace quickens; her smile widens. She knows she has people waiting for her. She knows she is not forgotten. As Laura approaches the finish line, the crowd cheers and chants her name. Her time is 22 minutes, 5 seconds—a minute, 36 seconds faster than last year's. Grandma Mable is confused about why the crowd is cheering and that they know Laura's name. She asks Laura if she won. Laura explains, "Everyone is a winner!"

Note: Laura, born prematurely at 27 weeks, has spastic dyplegia cerebral palsy. She is now 8 1/2 and enjoys running, swimming, and yoga.

NANCY CAN RUN, TOO!

I thought I would surprise Laura, and myself by running in the Capitol 10K this year. It's been 17 years,

and a little more than 17 pounds since the last time I had participated in the 6.2 mile run. I started training a couple of months ago, working my way up to running 5 miles a few times a week. I asked Laura for some running

By Nancy Joe, Austin

tips. She told me, "Don't stop. Don't ever give up." I thought about her words more than a few times during my early morning runs. They kept me going. I wondered if I had said those words to her.

It's not easy running with 14,000 other people. My starting place was

in the back with the fun runners and the walkers. I told my mother, Mable, to walk outside her a part ment today to see



me run. She was on Enfield, just before the 3 mile mark. I called to her. She yelled back, "Nancy, (I) wait long time!" Jess and Laura were waiting for me at the 5 mile mark. Both Laura and I enjoyed that moment of role reversal. She was there for me, and I felt very special.

I was pleased with my 77 minute finish. I beat the guy dressed up like a cow, walking with the hula dancer.

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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.

Date	Conference Title	Location	Registration Information
July 15	2003 TX Association Of Mental	Adam's Mark Hotel	TAMR
to	Retardation (TAMR)	Dallas, TX	P.O. Box 29149
July 18, 2003	Annual Convention:	Ballas, 170	Austin, TX 78755-6149
	Stars Across Texas		Phone: 512-502-1883
	Creating a Culture of Success		www.tamr-web.com
July 15	Advancing Our Profession,	Dallas, TX	Association on Higher Educa-
to	Refining Our Vision Conference,		tion and Disabilities
July 19, 2003	Association on Higher Education		Phone: 847-925-6266
	and Disabilities		Email: tthompso@harper.cc.il.us
July 13 - 18	Developmental Disabilities	Camp C.A.M.P.	Children's Association for
&	Review Course XVI:	Center Point, TX	Maximum Potential (C.A.M.P.)
August 3 - 8,	Multiple Disabilities		Phone: 210-292-3566 or 3574
2003	CME/CEU/Graduate Credits		Email: campmail@sprynet.com
Thursday,	"That All May Worship"	El Paso Community College	Gloria Lopez
July 24, 2003	Conference	9050 Viscount Blvd.	El Paso Rehabilitation Center
		El Paso, TX	Phone: 915-544-8484
July 26	American Society for Deaf	Texas School for the Deaf	Phone: 512-462-5329
to	Children's 18th Conference:	Austin, TX	Email: ERCOD@tsd.state.tx.us
July 30, 2003	Family Reunion: Nuturing		
	a Lineage of Support		
August 23	21st Annual TX	Omni Southpark Hotel	BIATx
to	Brain Injury Conference:	Austin, TX	1339 Lamar Sq. Dr., Ste. C
Aug. 24, 2003	Working Together for a Better		Austin, TX 78704
	Future		Phone: 512-326-1212
			Toll Free: 800-392-0040
			www.biatx.org
August 29	Texas Fiesta Educativa 2003	Sheraton Gunter Hotel	Texas Fiesta Educativa
То		San Antonio, TX	1017 N. Main Ave., Ste. 207
August 30,			San Antonio, TX 78212
2003			Phone: 210-222-2637
			Toll Free: 800-682-9747
			Website: www.tfepoder.org