



PATH in Print – Online

*PATH's quarterly newsletter for families
Winter 2008 edition*

TRANSITION & KIDS AS SELF ADVOCATES

By Nanfi Lubogo

My daughter Stephanie is 9 years old and lately I have been hearing *a lot* about transition. Transition from pediatric medical to adult medical, transition into higher education, beyond high school and into the adult world. Some friends who have older children with special needs have been talking about how their children go to doctors visits alone and/or direct their own health and education plans. Huh? What?!! IS someone saying that at some point I will have to stay in the waiting room while Stephe goes into the doc's office, or that at some point SHE will be responsible for directing all her appointments, and care that she receives from all the agencies that she is involved in. She will direct her IEP???? Whoa... I am not ready to hear that!

But...like it or not at some point, I will have to face this. According to the CT State Department of Education, until the age of 18, you have access to all educational records maintained by the school. After your child reaches the majority age (18) or is declared an emancipated minor all rights under special education law will transfer to your child unless a court has appointed a legal guardian for your child. (Which could be you, the parents). You will only have access if with your child's written consent. The same is true in the medical arena; at age 18 a child can choice whether or not to let you have access to their medical records and care. In Connecticut, a statute allows for that to happen as young as 16 or 17 if requested by a minor. This happens only in special circumstances and is granted only by a Probate Court.

Note: There are 3 types of guardianship, full, limited and temporary. Every child is an individual and the court would determine what is in the best interest of the minor. For more info on this visit this link from the Office of Protection and Advocacy for Person's with Disabilities website:

<http://www.ct.gov/opapd/cwp/view.asp?a=1756&q=277250>

Regarding health care coverage: If you go through the Disability Determination Unit at the Department of Social Services (DSS) and your child is identified as an adult with a disability (age 18) then that child will be eligible for Medicaid as an adult with a disability. You can also apply for Social Security for your child with a disability at the age of 18. Again, it is important to do the Probate Court determination so that you can process the checks for your child. If you have private insurance, talk to your provider regarding policies on continuation of coverage as the age may vary.

Whatever the scenario, it is very scary to even think of such loss of control over your beloved child. We have been our children's caregiver and advocate since the day they were born and yes, we know that at some point we will have to let them out into the world to begin their own adventures into adulthood. With our child with special needs, that reality seems daunting and quite frankly scares the heck out of us! How will she deal with all the things that give us a headache and stress us out every day, can she advocate for herself? Why would we even subject her to that? She is only 9. The thing about that though is that she will not be 9 forever. She will grow up and one day become a young lady, an adult. That is what we pray for everyday, that all our children will grow up, become capable adults able to fend for themselves and pave their own way in life. As her parents it then falls upon us to arm her with everything that she needs to be able to achieve all that and yes, take control of her own destiny.

If I have learned anything from this soul searching it is that now, at age 9, now is the time to begin to get her more involved. Start teaching her the skills now so that she will be an "old pro" by age 18. Have confidence in her, believe that all the lessons and skills that we have worked hard to instill in her will shine through. Believe in her.

Years ago when Stephe was about 3, I learned about this wonderful organization called KASA- Kids as Self Advocates, that was created by youth with disabilities who believed that they had the right make their own choices and advocate for themselves. It is a national organization that has chapters in almost every state including CT. In my work, I have referred many parents to this organization, in my own mind; I'd filed it away as something I would deal with when the time came. Since the topic has come up a lot lately, I had no choice but to confront my worries and take a closer look. I have researched in depth the KASA website and found it to be a wonderful resource for families and youths who have questions about self advocacy. It offers useful info on so many topics and inspirational stories all written and directed by the youth themselves which is the best part.

If you have a youth with special needs, I urge you to educate yourself and get your child involved on the path to self advocacy, no matter how hard it is to let go. You can start this process by involving them in the IEP process whenever you deem it is appropriate. There is a wealth of resources available online and one of the best is the KASA website. You will be impressed to learn what these young people have been able to achieve no matter what their limitations have been. We may be a few years away from that transition but we have a lot to gain by being prepared and after all, knowledge is power!

KASA is Family Voices project funded by the U.S Maternal Child & Health Bureau and the Administration on Developmental Disabilities.

Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

www.familyvoices.org

From the CT KASA Website: ABOUT CT KASA

CT-KASA got its start in 2002 when some of the members of the national KASA project came to Connecticut to help us form our own statewide “chapter.” They worked with us to identify what our main issues were and what support we needed to accomplish our goals. Through the years, we have received support from the CT Council on Developmental Disabilities, the CT Youth Leadership Project and the CT Office of Protection and Advocacy for Persons with Disabilities, as well as many others. Currently we have our office at the University of Connecticut Center for Excellence in Disabilities. We also use meeting space at two of the Independent Living Centers in the state and we’re forming new partnerships every day. We maintain our connection with the national KASA group through board membership, email and teleconference calls. Our membership has grown to include more than 30 members, from over 25 different towns in Connecticut. Anyone between the ages of 13 and 24 is welcome to join us! We are always looking for new members who want to socialize, have new ideas, want to learn how to help themselves and want to educate others.

Contact Information

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Writers note:

It is important to note that every child is an individual and that not all children will have the ability to advocate for themselves. There are steps that you can take to protect the rights of your child. One of them is by filing a petition for guardianship. By law, your provider (medical or educational) must inform you of the transfer of rights, at least one year before your child turns 18. The above story is the opinion of one parent and is not meant to alarm but rather to inform and empower.

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You've Come a Long Way **Baby!**

Dreaming About Driving By Jennifer Thomas

I have always imagined myself riding through Montgomery, Alabama on I-65 in my very own Alero Oldsmobile. Luther Vandross's Superstar is playing on the radio. All of the windows are down, and my hair is blowing in the wind under the summer night's sky. Fortunately, I do not have to dream any longer; I am an official licensed driver!

Just like any other 16-year-old, I wanted to drive more than anything. While in high school and before turning 16, I took Driver Education as an elective and learned the rules of the road. My teacher was the first person who had enough faith to let me drive. She accommodated me by placing a cushion behind my back since the seats didn't go up far enough. She also operated the emergency brake and cranked the car. The fact that I took and passed this class and got my permit was enough to convince a few other people to help me practice driving.

My aunt Diane was one of those people. She rode shotgun as I drove her blue Corsica on several occasions. I also practiced with my father from time-to-time. Once when he came to visit, he rented an Alero Oldsmobile and let me practice driving in it. We learned that I could operate everything in this car on my own. I was able to start the engine, change gears, and apply the emergency brake. "Alero, here I come," I thought. This was the car I wanted.

Shortly after I turned 16 and had become a better driver, my father rented an Alero and came to town to take me to get my driver license. While waiting at the DMV, I was so excited. When it was my turn, my dad drove the car around, and I went out to meet him. We waited for a while. Finally two state troopers, one male and one female, came out, and both of them got into the car with me. My excitement turned into nervousness. The female trooper, seated in the front passenger seat said, "At the end of the drive, make a left." I proceeded with caution. I did my very best to follow all of her commands. When we returned, the female trooper asked me to come inside and have a seat, and she went to another part of the building. This was odd; everyone else found out whether or not they passed while still in the car. The trooper came back with another gentleman, and they asked my father and me to come outside. I knew then that there was definitely a problem. The female trooper told me

that my three-point turns and other driving skills were great. She further explained that they could not give me my license because my vehicle had to “have equipment on it and be modified.” I was outraged but I managed to contain myself as I asked her what modifications I would need. She was unable to answer my question. She was also unable to tell me whom to contact about getting these modifications.

After being highly upset, wanting to sue somebody, and crying many tears, I contacted my Vocational Rehabilitation (VR) Counselor. She connected me to the Adaptive Driving Program and arranged a driving evaluation. My mother, father, and I drove a little over an hour north to Birmingham for the evaluation. The results were that I needed a minivan that was no more than four years old. This is what the equipment had to be installed in. I had two problems with this. First I was not a soccer mom and did not want to drive around in a van. Secondly, there was no way I could afford a car this new. I asked if there were any other options. The other options that I was offered were that I could either get a Lincoln Towncar or a Grand Marquis. “I am four feet, 10 inches tall. Are you serious?” I thought. I was upset all over again.

Eventually I calmed down and partially accepted the news. During my 12th grade year of school, I took part in co-op; I was in school for half of the school day and at work the other half. I was having a really hard time. I had to dish out gas money to whomever I could get to take me to work. Before long I was working just to be able to afford to get there. One of the teachers heard about it. She made some contacts and asked the other teachers to donate money to United Way on my behalf. Even with their support, I was still unable to make payments on such a new vehicle.

I went on to college and had no choice but to rely on the para transit system and friends for four years. I was thankful, but relying on the bus was definitely not the easiest thing I have ever had to do. It was late quite often and sometimes didn't show up at all. I practically had to call everyday to schedule appointments for the next week. I had to ride the bus from home to school, from school to work, and from work to home. About a year and a half to two years after graduating college, I had a full-time teaching job and felt stable enough to take on car payments. I called my VR Counselor and let her know that I was ready to get the process started. I also contacted the United Way to see if the money that the teachers from my high school had donated was still available. Fortunately it was, and I was able to use it as a down payment on a new car.

The process that it took to get my car modified was quite lengthy, but it was so worth it. I had to be re-evaluated and found out that the equipment that was suggested for me could now be placed on an SUV. Yes! When my counselor received approval to cover my modifications, I contacted the United Way again. The United Way cut the check for my down

payment, and I went to get my car. On June 26, 2006, my uncle and my mother accompanied me to the dealership to give me advice as I asked for it. I asked questions and completed all of the paperwork. Since I did not have a license, my mother drove my Hyundai Santa Fe off the lot, but I rode shotgun.

In November of 2006, I received a call from a gentleman in Wetumpka, Alabama saying he would be the person handling the modification process of my vehicle. He explained that I would need to bring my vehicle to his shop in Wetumpka, and he was going to personally take it to Texas. He said that it would be there for about six weeks. At that point, he would pick up my vehicle and return it to his shop in Wetumpka. His company would then finish the modifications. When that was all done, he said he would call me in for a fitting, and we would take it from there. My dream was becoming more real as the weeks went by. I was finally getting there!

At the very start of January, I got a call from Wetumpka. The lady on the other line was calling to inform me that my car was back, and that it was time for me to come in for a fitting. I went for the fitting, and all of the adjustments were made. In mid January, my family and I made the 30-minute, or less, drive to Wetumpka. We were given a crash course on how everything worked and were told to call if there were any problems. I was also advised to get in it and practice with the controls as much as possible.

I did just what the people in Wetumpka told me to do. I played with the controls and eventually got brave enough to drive around the neighborhood. Time went on, and I was beginning to wonder if I was ever going to have any official training and how I need to go about getting my driver license. I contacted my VR Counselor to express my concerns, and she contacted the Adaptive Driving Program. The trainer/evaluator came to my area a few times during the month of June. I had the opportunity to get more practice in, and he gave me several driving tips. On June 21, 2007, I was awarded my driver license.

Yes! I don't have to dream about driving anymore! I can come and go when I'm ready, just as long as I have gas that is. I don't have to worry as much about being late, and I don't have to give three to four people gas money during the course of a week. So maybe it all worked out a little differently from how I dreamed. I have a Santa Fe instead of an Alero, and I am not fully comfortable driving on I-65 just yet; however I am driving, comfortably on I-85, and Luther Vandross's Superstar does play on my radio. Most important of all, I don't have to dream anymore: I just drive.

Used with permission from the KASA website: www.fvkasa.org

PATH on the Move



PATH Parent to Parent of CT Parents Available to Help Inc., held its 2nd Annual Walk-Stroll-Wheel-A-Thon October 5, 2008. It was held at Brooksvale Park in Hamden. Although it was a rainy day, everyone still had a wonderful time. There were crafts for the kids to do, prizes for the whole family, and plenty of food.

Thanks....

PATH would like to thank everyone that participated and especially for those companies that were so kind in donating to make the day a success. We would like to thank Dunkin Donuts of North Haven for coffee and munchkins, FASTSIGNS of North Haven for the donation of a banner, Pepperidge Farm for crackers and cookies, Lyman Orchards for providing us with apples and apple cider, Phil Vissicchio for the rolls, State Line Meats for the food, Frito Lays for the donation of chips and the Pepsi company for sodas, and face painting. We also can't forget our Sponsors: St. Therese Religion and Parish for their support, Viglione Heating and Cooling, Mr. & Mrs. William Ortman, and Washington Memorial Funeral Home. We also thank Peabody Museum for coming out to do an educational presentation which was enjoyed by all.

Please note: pictures from the walk are available at our website: www.pathct.org



PATH will be holding their Annual Gala/Silent Auction on March 7, 2009 at Fantasia Wedding and banquet Facilities in North Haven. Enjoy the fun of an Irish Italian wedding with the wackiest bridal party and craziest 2 families that you will ever meet. This hilarious show is run with all the trimmings of a real wedding and the audience plays the role of wedding guests as the characters mingle through out the tables and treat everyone as part of the family.

You can dance the tarantella, Irish jig or electric slide, listen to our vocalist's rendition of Danny Boy, sing along to Italian favorites, catch the bouquet, waltz with the bride or groom (or your loved one), or just relax and watch the fun as the grooms ex-girlfriend crashes the wedding and Don Ziti "the God Father" finds out that his gift has been stolen by one of the guests and much, much more! Grab your friends and join PATH for a fun-filled night out!

If anyone would like more information about the event or to learn more about PATH, please call 203-234-9554/1-800-399-7284 or visit our website at www.pathct.org.

**PATH IS LOOKING FOR SPANISH SPEAKING
VOLUNTEERS**

PATH is looking for Spanish Speaking volunteers who are parents/caregivers of children with special health care needs/disabilities and are able to support other Spanish Speaking families who share similar experiences.

PATH will provide training. All contact is conducted by telephone/email. Phone card provided upon request.

**For more information, please call
1-800-399-7284**

PATH



KIDS

**** Writers note: Since this is a problem for many of our children with special needs, I thought I would include the following great article. If your child is younger, please read this with them and help them understand it. It can be a great tool for coping with bullying and a first example of self advocacy.***

Reprinted with permission from the Pacer Center Website.

Bullying

Bullying can be lots of things. It is hitting, pushing, name calling, teasing, threatening, sending mean e-mails, taking or ruining another person's things, leaving someone out--and lots of other nasty stuff.

**How can you tell if something is bullying? Just remember this:
Its bullying if...**

Someone is hurting another person on purpose **and** the kid who is doing it has more power.

What Bullying Isn't

Bullying isn't okay, fair, kind, or acceptable. No one deserves to be bullied.

Who Does It--and Why?

Kids who bully come in all shapes and sizes. They can be big or small, older or younger, rich or poor, boy or girl. They can be any color and come from any kind of family. They can live in any kind of house. They can be popular or unpopular. You just can't tell who bullies by how they look or where they live.

So how can you spot a kid who bullies? Look for these clues:

They want to have power and control over other kids. They do this by making kids feel bad in one way or another.

They might feel bad about themselves. Some kids who bully think the only way they can feel better about themselves is to make someone else feel worse than they do.

They might think highly of themselves. Some kids who bully think they are better than others and that it's okay to be mean.

Remember, bullies think they have all the power--but they don't.

Who Is Bullied and Why?

Lots of kids are bullied--and NONE of them deserves it. Why does it happen to some kids and not others? Let's peek inside a bully's head and find out!

Kids who bully want to feel powerful and in control, right? So what do you think would make them feel that way? Let's take a look:

What a Bully Looks for Differences

Why? Kids who bully need something to pick on, so they start by looking for someone who is different in some way. Maybe it's a kid's hair color, or disability, or accent, or clothes, or--anything!

Helplessness

Why? Kids who bully need more than a difference to pick on. They also need a target who will feel scared or upset, maybe even cry. They love it when you feel helpless. It makes them feel powerful and in control. Bullies feel good when you feel bad.

Isolation

Why? Kids who bully love it when their target is alone. All the easier to bully! And all the more likely that no one will know. Bullies love secrecy.

In short, kids who bully want someone who is different, will become upset, and is alone. So that's what's going on in a bully's head!

What You Can Do

Now that you know how a bully thinks, you are in control. There's a lot you can do to protect yourself from bullying.

What a Bully Looks for Differences

How You Can Protect Yourself

Respect differences.

Example

Everyone has differences. Just look around you. When you value and respect differences, you let the bully know that being different doesn't bother you a bit. In fact, you like it! If a bully makes fun of your red hair or wheelchair or how you talk, just smile and agree.

"Yes, I do have red hair."

"Yes, I do use a wheelchair."

"Yes, I do stutter."

Then walk away!

What a Bully Looks for

Helplessness

How You Can Protect Yourself

Don't react.

Example

Kids who bully want you to be upset. They're counting on it.

So DON'T give them what they want. Even if you feel scared or upset, try not to show it.

Crying, showing fear, or acting mad encourages the bully to pick on you again.

At recess, a kid starts calling you names.

You probably feel upset and hurt. You might even feel like crying. That's just what the bully wants.

Instead of acting as upset as you feel, do something unexpected. Laugh. Walk away.

What a Bully Looks for

Isolation

How You Can Protect Yourself

Be with others.

Example

Kids who bully love to target kids who are alone. They love it when no one knows what they're up to.

You can do two things to change the situation.

First, try to hang out with other kids or be within sight of a grownup. Most bullying happens when adults are not around.

Second, tell your mom, dad, teacher, or other grownup you trust. Adults can help you stop the bullying.

A kid waits until you're alone in the hall, then shoves you against a locker and threatens to beat you up after school.

What can you do? Plenty.

First, remember that bullies want you to feel scared and to cry. Instead of acting as upset as you feel, keep your voice calm and steady. Hold your head high. Look the bully straight in the eye, and say, "No! Leave me alone."

Second, bullies want you to be alone so make sure other people are around. When you say "No! Leave me alone," say it strong and say it as loud as you can, over and over to attract attention.

Third, tell a grownup that you are being bullied and ask for help.

Other Tips

Trying to get even with someone who bullies is never a good idea. When you fight back, there is a good chance that the bullying will continue and even become worse. Also, the adults at school may see you as a part of the problem.

If you see bullying happen, you can help stop it. How? Speak up! When someone is willing to speak up about what they think is wrong, they can make a difference. If you tell other kids that bullying is not cool, they will be more willing to speak up, too.

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Visit www.PacerKidsAgainstBullying.org

Hope you enjoyed this newsletter. For suggestions on topics please email nanfi@aol.com.

This newsletter is available on our website at www.pathct.org