



*Special Mother's Day Edition*

*In honor of mothers caring for special needs children.*

**Tips of the Month**

 **Application tips for Child's SSI:**

To apply for SSI benefits for your child, you will need to complete an SSI application and a Child Disability Report.

The Child Disability Report can be completed online at the SSA.gov website, but you will have to call or visit your local Social Security office to complete the SSI application.

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*Dear Mom of a Special,*

*You know only too well that being mom to a special needs child can be emotionally challenging, physically draining, and sometimes terribly lonely.*

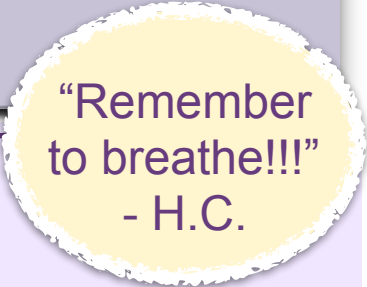
*Our staff includes several moms of special needs kids and we understand the unique challenges that arise in these situations. We also see the precious and treasured moments that can only be truly appreciated by uniquely situated moms like yourself.*

*In honor of YOU, special Mom, we share this collection of advice, suggestions, encouragement, and stories from other moms of specials.*

*Please know that you are not alone in this journey. Hang in there, take life one moment at a time, and keep doing what only you can do.*

*God Bless,*

*Deborah L. Hardin, Managing Attorney*



**Scared. Frustrated. Overwhelmed.  
.....ALONE.....**

From the day of my son's birth, we knew something was different. He cried nonstop for his first six weeks. As he grew up, he clashed with or ignored people. We were a family living with autism, a social-communication disorder. Not only did our child struggle to interact with others, but I had found renewed energy in a fruitless determination to try every strategy and work with him incessantly to "fix" him. My single-minded pursuits and my son's therapy sessions left little time for anyone or anything else. The feelings of isolation were deep, cold, and unrelenting.

"When my kid acts like that, a good spanking cures it." Insensitive, misguided comments like this pervaded my conversations with other moms. I took my son to the park daily so I could work with him to build his physical strength, improve his agility, as well as teach him how to interact with other

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## Scared. Frustrated. Overwhelmed. .....ALONE.....

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children and use a playground. Fellow moms talked and encouraged one another under a pavilion while their kids played. In contrast, I was rushing after my son to incessantly redirect him from running off the playground and into the street.

I wasn't able to add anything to other moms' conversations about how their child was absorbing life like a sponge, naturally learning new things. My child was wasn't able to process the stimuli around him. We had to manually move his limbs, one by one, to teach him to crawl. Though our victories were minuscule in any other parent's mind, they were huge for us. When I tried sharing our proud moments with friends and family, it felt like my words of joy fell on deaf, uninterested ears. Others couldn't intimately know the details of my child's diagnosis or unique abilities. It was a lonely place.

We weren't invited to many birthday parties. The few we attended, my son usually offended other kids, so I was busy diffusing conflict instead of building bridges with other moms. Social situations left me drained and deflated.

Fortunately, I found comfort in a local and online support group. As a special needs parent, isolation is real. But I eventually realized that I was no different than anyone else; My sense of aloneness was precisely what united me with other special needs parents. For that, I am so grateful!

- Patricia Morin, Legal Assistant 

"There is so much in life that truly does not matter. Focus on love and relationship above all." - S.J.

## Tips of the Month


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### Appeals tips for SSI:

A letter or evaluation from your child's teacher is vital evidence in your child's claim for benefits. **Do NOT rely on SSA to gather this evidence.**

### Hearing tips for SSI:

The judge or your attorney will ask you and your child about your child's activities at home and school, interaction with others, ability to complete tasks, and to describe any difficulties.

These hearings are usually quick, so have your answers ready. 

"Don't sweat the small stuff, learn to pick your battles and you will be inspired" - S.P

## Something was different...

When did I start to realize something was *different*?

***I always had this feeling something was different.***

We struggled through 3 months of breast feeding. STRUGGLED.

She was not only being seen at the pediatric clinic but also the Early Developmental Intervention Service (EDIS) offered on base. She was not meeting the usual milestones. She could smile, she would laugh, she would rarely babble. She started crawling at 4 months, walking at 12 months, was a great eater, and loved being on the move....

At 15 months she had 1 word: Mama. So the EDIS clinic suggested that we start using sign language. I purchased several books and a video so that [the family] could start learning along with her. We would sign while saying the word so that she could

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## New Dream Come True

When K first came to us, he was a year and a half old. He was not talking yet, but otherwise - he was a perfect and healthy little blue-eyed, blond haired, happy, smiling little boy. He did not know a stranger and had no reservations about letting me hold him. We were delighted, of course!

Right away, we noticed behaviors that we did not understand and were quite troubling. This perfect little boy would bang his head against our hard wood floors and scratch at his own face, but did not seem to feel a thing. He was terrified of the walls, and would scream and fight if we tried to comfort him. He hated being snuggled or rocked to sleep at night.

Around his 2nd birthday, we started taking him to a therapist. She was certain that he had Reactive Attachment Disorder, which is common in adopted children. We attended these therapy sessions together about twice a week for two years. Our therapist practically became one of our family. We learned holding therapy, which was supposed to result in K giving up the fight and learning to trust us. We practiced holding K daily, for HOURS, for two years. Never once did he give up. He fought hard, and glared at us like we were demons from Hell, until he finally fell asleep from exhaustion. But, he never gave in. NEVER. That connecting moment where child and parent look into each other's eyes and build the trust ...simply did not happen.

His behaviors only became more worrisome. He saw danger everywhere. He was convinced other kids were "bad guys" and he had to save the world from them. He was obsessed with violence, despite our ban on violent shows or toy weapons. He was kicked out of one daycare or preschool after another for acting out and hurting other kids. He had no empathy for others, and no understanding of consequences. He could go for days without sleep. Although he was "behind" in his learning, his behaviors were our primary focus.

Our therapist was just as frustrated and worn out as we were. She decided that she could no longer treat children. She found a new job with hospice, and referred us to her mentor. We all cried (except K) as we said goodbye at that last session.

During our very first session with her mentor, we were told that this is not Reactive Attachment Disorder. K seemed to be having hallucinations and should be evaluated immediately. We took him for testing, and found out the mentor was right.

"Be empathetic.  
Be careful with your  
words. Don't be ashamed  
to take a self-timeout."  
- M.T.

K was schizoaffective-bipolar and intellectually disabled. The prognosis was not good – **this was not something that could be "fixed" no matter how much we loved him.**

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### Something was *different...*

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learn both at the same time per recommendations from the EDIS clinic.

We had successful communication. The screaming in frustration at not being understood had (mostly) ceased. We didn't have a complete vocabulary, but enough to meet her needs.

At her 18 month well-check, the pediatrician said to stop the signing, she needs to talk. OK? Now what? We still continued to accept the limited signing from her, but we lost effective communication.

Somewhere [along the way], she discovered Dora the Explorer. We watched HOURS of Dora and she picked up words like "Map", "Boots", "coqui". Our life became Dora everything. If it gave her joy to watch and help her to learn words, she was going to watch it.

She started really talking at age 6. Up to now she had words, but she didn't have the skills. Although there was the one time when she was 5, I had to send her to her room for being naughty, she glared at me from the top of the stairs and yelled, "YOU.....YOU.....EYEBALL HEAD!" I told her to get in her room before I came up the stairs. So she stomped into her room and slammed the door.

***THEN, I laughed.***

- S.H., Contributor 

## New Dream Come True

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K would never learn to read or write, and he would never live independently. All we could do is learn how to “manage” the psychosis.

I was shocked. I knew nothing about schizophrenia, bipolar, or mental retardation (as it was called at the time). I learned. I grieved. All the hopes and dreams that I had for my little boy were gone – just like that.

Grief is normal for parents in this situation. The dreams and expectations for your child’s future are suddenly gone in a puff of smoke. This is a real loss that must be acknowledged before you can move forward with a new plan for the future.

*Fast forward many years ... we have all come a long way.*

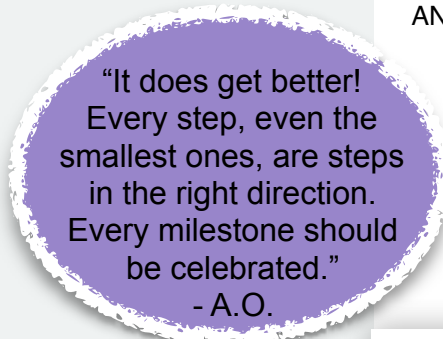
K has just turned 18 and is graduating from his special needs high school. He cannot read and write nor live independently. Mentally, he is closer to age 5 than 18, but he is a delightful young man to be around. He still does not know a stranger and almost always has a smile on his face. He is the most generous person that you will ever meet, and would gladly give you his last French fry. The psychosis is well managed by medication, so the paranoia (and violence) is kept at bay.

He is transitioning into a supervised living situation where he will learn to be a “grown up.” He will be learning to cook, clean, and care for himself (with supervision). He will get to be part of a baseball team, go to dances, plant a garden, and be very involved in the community. He might even get a job. He will have friends with similar limitations to share these experiences with. K is excited about moving into “his new place.”

As time moves on, our plans change and our dreams change. This may not be the dream that we had for K as a toddler, but his life is going to be good, full, and satisfying.

For us, this is ***a new dream come true.***

- Deborah Hardin, Managing Attorney 




### What do YOU wish someone had told you about raising special needs kids??

“You will go to ANY length to help your child. There is nothing will not learn, no sacrifice you will not make, no action you will not take.

I once offered our neurologist part of my brain for a transplant to help our daughter. It seemed the only reasonable option (sadly, it couldn't be done).

Feeding tubes, therapies, hundreds of thousands of dollars, going bankrupt, ANYTHING. And these amazing little people NOTICE that our love cannot be exhausted (even though our bodies and emotions can).

Our love IS their quality of life. Never give up. Even those who cannot speak know when they are cherished.” - B.Y. 



### Community Resource:

Looking for recreational opportunities for your special needs child?

#### Community Connections

in Conway offers: sports, music classes, respite, sibling workshops, Super Science Saturdays, and more!

These activities are all geared towards special needs children, young adults with disabilities, and special needs families.

#### For more information:

call: [\(501\)733-1627](tel:5017331627) or visit: <http://www.communityconnectionsar.org/>

\*Please note: we have not investigated this resource, are not affiliated with them, and do not necessarily endorse this resource..\*

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