



THE Navigator

Spring

Pilot Parents of Southern Arizona

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Providing Information and Resources to Families and Professionals in Southern Arizona

WHAT ARE “SPECIAL NEEDS”? ONE TERM MANY DEFINITIONS

“Special Needs” is an umbrella underneath which a staggering array of diagnoses can be wedged. Children with special needs may have mild learning disabilities or profound cognitive impairment; food allergies or terminal illness; developmental delays that they will be able to overcome or remain entrenched with; occasional panic attacks or serious psychiatric problems. The designation is useful for getting needed services, setting appropriate goals and gaining understanding for a child and stressed family.

“Special Needs” are commonly defined by what a child *can't do*—by milestones unmet, foods banned, activities avoided, experiences denied. These minuses hit families hard, and may make “special needs” seem like a tragic designation. Some parents will always mourn their child’s lost potential, and many conditions become more troubling with time. Other families may find that their child’s challenges make triumphs sweeter, and that weaknesses are often accompanied by amazing strengths.

Pick any two families of children with “special needs”, and they may seem to have little in common. A family dealing with developmental delays will have different concerns than one dealing with chronic illness, which will have different concerns than one dealing with mental illness or learning problems or behavioral challenges. This Parenting Special Needs site devotes sections to the following specific issues: medical, behavioral, developmental, learning, and mental health.

Medical Issues: For children include serious conditions like cancer and heart defects, muscular dystrophy and cystic fibrosis; chronic conditions like asthma and diabetes; congenital conditions like cerebral palsy and dwarfism; and health threats like food allergies and obesity.

Children with medical issues may require numerous tests, long hospital stays, expensive equipment, and accommodations for disabilities. Their families have to deal with frequent crises, uncertainty, and worry.

Behavior Issues: Children with behavior issues don’t respond to traditional discipline. With diagnoses like ADHD, Fetal Alcohol Spectrum Disorder, Dysfunction of Sensory Integration, and Tourette Syndrome, they require specialized strategies that are tailored to their specific abilities and disabilities.

If those strategies are not developed and used, kids with behavior issues throw their families into chaos and are seriously at risk for school problems. Their parents need to be flexible and creative. *(Continued on page 2)*

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Developmental Issues: Are some of the most devastating for a family to deal with, changing visions of the future and providing immediate difficulties in caring for and educating a child. Diagnoses like autism, Down syndrome and intellectual disabilities often cause children to be removed from the mainstream, and parents must be fierce advocates to make sure their children receive the services, therapy, schooling, and inclusion they need and deserve.

Learning Issues: Children with learning disabilities like dyslexia and Central Auditory Processing Disorder struggle with school-work regardless of their intellectual abilities. They require specialized learning strategies to meet their potential and avoid self-esteem problems and behavioral difficulties. Parents of children with learning disabilities need to be persistent both in working with their reluctant learners and with the schools that must provide the help these children need.

Mental Health Issues: A child's problems with anxiety or depression can sneak up on parents; problems with attachment may smack them right in the face. Living with a child with mental health issues can put family members on a roller coaster of mood swings, crises and defiance. Parents have to find the right professionals to help, and make hard decisions about therapy, medications, and hospitalization. The consequences of missed clues and wrong guesses can be significant.

Common Concerns: Although every child with special-needs is different and every family is unique, there are some common concerns that link parents of challenged kids, including getting appropriate care and accommodations; promoting acceptance in the extended family, school and community; planning for an uncertain future; and adjusting routines and expectations.

Parents of children with special needs are often more flexible, compassionate, stubborn and resilient than other parents. They have to be.

This content is provided by national 4-H Council, 4-H experiences help GROW confident, caring and capable kids.
<http://specialchildren.about.com>

ADVOCATE: noun

A person who argues for or supports a cause or policy.

A person who works for a cause or group

A person who argues for the cause of another person

One that supports or promotes the interests of another

“The primary responsibility of an effective advocate is to move the process from an emotionally charged conversation to an evidence-based decision process.” Miriam Webster

ADVOCATING FOR YOUR CHILD WITH SPECIAL NEEDS

Being a parent of a child with special needs brings many new experiences. One of those experiences is learning to advocate for your child. To be effective, you need to have knowledge of the system you are working within in order to effectively communicate with the individuals involved and to enable your child to receive the best services. You need to know what to ask in whatever system you happen to be in. Over the years, you will advocate for your child with health care and education systems and perhaps even recreational facilities, your community and family to help them become included to the maximum degree.

Don't worry if you don't know all the jargon now, in no time at all you will understand the process. And remember at all times, you know your child the best. What works, what doesn't and you innately know what your child needs. You are the expert on your child. Remember that! Having said that, also remember that as your child's advocate, you need to work with the “team” be it medical, educational or some other system. How do you do that? Information, lots and lots of information. Educate yourself, attend workshops, take classes in effective communication and listening skills, check out websites and read about various resources, techniques and procedures. Ask your child's therapist, pre-school teacher, doctor, why certain things are done the way they are, the importance of certain techniques. Become an authority on your child.

Skills take time to develop. Certain skills come easier than others. Experience will teach you a lot.

Remember that your goal is to promote your child becoming the best they can be. The most independent, able to lead as normal a life as possible. Let's look now at helping your child learn to be a good self-advocate.

One of the places to start teaching your child about self-advocacy is in his or her Individualized Education Program (IEP) meetings. They will get to meet the members of the team, and perhaps feel comfortable sharing what their goals are for themselves and develop an ability to speak up for themselves.

What is self-advocacy?

It is never too early to start teaching your child how he or she can advocate for himself or herself. Like many other important life skills, self-advocacy is a critical tool your child needs in order to achieve goals, increase self-sufficiency, and become a successful young adult. It is a life long process that begins with your child learning by watching you, as a parent, be a good advocate.

These skills are necessary to become a self-advocate:

- Speaking up for yourself
- Communicating your strengths, needs and wishes
- Being able to listen to the opinions of others, even when their opinions differ from yours
- Having a sense of self-respect
- Taking responsibility for yourself
- Knowing your rights
- Knowing where to get help or who to go to with a question

Allow your child to practice participating in an IEP meeting by writing down or telling you what he or she wants to learn or work on this year? How do you learn best? What do you need to be successful? What would make learning easier for you?

Teaching your child self-advocacy skills will benefit him or her throughout the school years and far into adulthood. Knowing and exercising your rights as a parent are the first steps in teaching your child to become a strong self-advocate.

Article from PACER CENTER Action information sheets. How you can help your child learn to be a good self-advocate. PACER.org

PILOT PARENTS OF SOUTHERN ARIZONA has a program that may help you become a better advocate/self-advocate. AZ Partners in Leadership is a leadership training program. It helps create partnerships between people who need and use services for disabilities and those who make public policy.

Partners provides the most current information and education about disability policy, the legislative process, and local, state and national issues that affect individuals with disabilities.

Partners learn not only from the presenters who are well trained in their areas, but from each other. You will develop a network of individuals who will help you resolve issues.

The program is open to young adults who have a developmental disability, parents raising young or school age children who have a disability and individuals from rural communities. It requires a commitment from those selected to attend all sessions (one weekend a month for 6 months), review materials and complete homework assignments, participate and complete an Action Group project with fellow participants.

For more information , contact:
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A LITTLE BIT OF THIS AND THAT.....



NATIONAL AWARENESS MONTHS/DAYS

FEBRUARY

[Black History Month](#) (United States and Canada)

[American Heart Month](#) (United States)^{[6][7]}

National Children's Dental Health Month (United States)^[8]

Teen Dating Violence Awareness Month (United States)^{[9][10]}

MARCH

National Kidney Month

Multiple Sclerosis Education Month

[Endometriosis Awareness Month](#)^[13]

[National Reading Awareness Month](#)^[14]

APRIL

National Autism Awareness Month

National Child Abuse Prevention Month

National Donate Life Month

National Facial Protection Month

Irritable Bowel Syndrome (IBS) Month

Occupational Therapy Month

National Sarcoidosis Awareness Month

CAN-EAT© Approach: First obtain GI Comfort and good Nutrition, then Establish Acceptance of easy textures, then Treatment.

This course focuses on how to approach pediatric feeding and swallowing disorders using a medical, nutritional, motor (oral and gross), and behavioral approach. Highlights include: extensive information on medical and nutritional management, prioritizing, intervention strategies and specific therapy techniques for common feeding problems.

CAN-EAT Approach© (Using Medical, Motor, and Behavior Strategies in Pediatric Feeding Intervention) Presented by Krisi Brackett, MS, CCC-SLP

For additional information, contact Lorna Motz:
lorna@mealttimeconnections.com or call (520)829-9635

About the Speaker

Krisi Brackett, MS, CCC-SLP is a Pediatric Feeding and Dysphagia Specialist with over 20 years of experience. She is currently Co-director of the UNC Pediatric Feeding Team at the NC Children's Hospital, UNC Healthcare, Chapel Hill, NC. The team consisting of pediatric GI, speech and nutrition provides multidisciplinary feeding approach. She is also an adjunct faculty member at the Division of Speech and Hearing Sciences, UNC-Chapel Hill. Krisi publishes the popular feeding blog, pediatricfeedingnews.com. Krisi is currently assisting with several pediatric feeding research projects as part of the feeding team and with the UNC research group The Feeding Flock, feedingflock.web.unc.edu. She performs MBSS and FEES in the pediatric population. She is certified in pediatric neuro-developmental training and is a member of ASHA. Krisi lectures nationally, sharing information on medical management and therapeutic strategies for handling this special population.

Dads 4 Special Kids (D4SK)

D4SK Tucson Chapter head, Dennis Cole,
dennis@d4sk.org

Contact him for meeting times and dates.

Event Info

Dates: Friday, February 19th and
Saturday, February 20th,
2016

Workshop location:
Easter Seals Blake Foundation
7750 E Broadway Blvd, Tucson AZ



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What's in a word? Down syndrome and Disability

January 24, 2016 <http://www.newsanchortohomemaker.com/down-syndrome-anddisability>

News Anchor to Homemaker– Down Syndrome Blog

News Anchor to Homemaker is a Down syndrome blog that focuses on real-life inspiring special needs stories and parenting articles from a Christian faith perspective, written by Jillian Benfield.

It started with an analogy.

Less than a century ago, most astronomers assumed the Milky Way was the only galaxy in the universe. As telescopes became more sophisticated, astronomers began to grasp the truth: the heavens are actually filled with countless galaxies, each containing billions of stars. It didn't change the fact that those galaxies were always there, but it changed the way we viewed the universe forever.

This was the introduction to a class I never pictured myself as a student in—a disability course. I'm in Pilot Parents of Southern Arizona's *Partners in Leadership* class of 2016. It's a two day a month course that spans over six months. Even though Anderson (her son) is only one, I thought I would learn about his rights and get a head start on how to work with schools.

What I didn't expect to learn: a hard truth about myself.

After speaking about the (mostly horrifying) history of the treatment of people with developmental disabilities, the instructor said something to this effect:

Around 90% of people who get a prenatal diagnosis of Down syndrome abort. This is because we still view people with Down syndrome by the things they can't do.

This was me.

Although termination was not a consideration for us, the major source of my grieving was based on the fact that my child would live his life with a disability. I equated disability with inability.

I still have a hard time saying it: my son has a disability. I felt guilty about this. Because maybe if I have a problem saying my son is disabled—that means I am still prejudice against people with disabilities.

Here's the Webster's Dictionary definition of disability: a condition (such as an illness or an injury) that damages or limits a person's physical or mental abilities.

This word, disability, only focuses on limits. On what he **can't** do.

When I look at Anderson, I see an infectious smile accompanied by an ever-present chuckle. I see my blue eyes and his father's overly expressive brow. And I see Down syndrome. But with his extra chromosome—I see opportunity amongst the challenges.

Anderson has the opportunity to change the current paradigm surrounding Down syndrome and yes, the disability community, not by the things he can't do—but what he can.

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(Down syndrome blog page 5)

I feared having a child with Down syndrome because of my outdated perceptions. My perceptions have been shaped by history, teachings and my own ignorance.

It's time to re-train my brain and my heart. I'll let advocates, parents who have gone before me and Anderson be my guide.

I feel as if I just got the most expensive telescope on the market. Instead of looking at Down syndrome as something to overcome, I see it as a star among Anderson's own personal galaxy. The star can't be glazed over. Instead we must appreciate its complexity powerful, sometimes unpredictable all together a bright light instead of vast darkness.

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A note to readers: I thoroughly enjoyed the first session of The Partners in Leadership course. I know it will make a huge difference in our family's life.

In this first session:

- * We talked about the history of how people have treated those with developmental disabilities.
- * We discussed how right now, people with developmental disabilities are largely treated as 'clients' with a focus on community based services. Now we need to move from 'clienthood' to citizenship— inclusion, focusing on people's talents, treating people with developmental disabilities as fellow humans.
- * We also discussed Person Centered Planning.

10th ANNUAL SPRING My Health and Wellness Expo

It's free on Saturday April 16, 2016

Held at the DoubleTree
445 South Alvernon Way

Free seminars, gluten free, Yoga, Alternative
Medicine, Fitness books, Financial, Healthy
Eating, Vision, skin care, Reiki, Acupuncture,
Dentists, Health Screenings, Spiritual Healing,
Nutrition.

It's all free. From 10:00 am to 5:00 pm

Myhealthandwellnessexpo.com

Door prizes Free samples



Feds Boost Spending On Special Ed, Disability Programs

by Michelle Diament | January 19, 2016

With funding gains for special education, housing and other disability programs, advocates say the federal government's latest budget is a step in the right direction.

The \$1.1 trillion plan lawmakers approved last month boosts spending – at least a little bit – for most federal government programs that touch the lives of people with disabilities.

Most of the gains are modest especially when spread across 50 states, advocates say, but after years of cutbacks, any rise is a good sign.

“Certainly we're happy to have any increase at all, but it's not what you would call dramatic,” said Annie Acosta, director of fiscal and family support policy at The Arc.

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(continued from page 6) money.

Meanwhile, funding to states under the Individuals with Disabilities Education Act for school-age children is up \$415 million.

Lindsay Jones, vice president and chief policy and advocacy officer at the National Center for Learning Disabilities, said that the uptick is relatively small compared to total spending on special education programs and will likely have a limited effect.

“A cut would have been incredibly felt,” Jones said. “We definitely needed the increase, but it’s definitely nowhere near fully funding IDEA.

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Leadership Education Advocacy Partnership
a program of Pilot Parents of Southern Arizona

Pilot Parents of Southern Arizona is pleased to announce that the Arizona Developmental Disabilities Planning Council has approved funding for Year 5 of the LEAP program. This year we will be focusing on providing scholarship awards for individuals that have not previously received LEAP scholarship funds. To learn more and download an application visit www.pilotparents.org

There is still plenty of opportunity for you to receive a scholarship. Please check our website for some available workshops/conferences

coming up or contact us regarding a conference or workshop you know of that you would like to apply for funding. There is certain criteria that the workshop or conference must have.

Remember that these funds are intended to supplement and not to pay for all expenses.

We look forward to working with you.

