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***Circuit** is a quarterly publication of South Dakota Parent Connection providing stories around a central theme for each issue. **Circuit** is intended to be a reference publication packed with information and is provided electronically and in printed format.*

South Dakota Parent Connection also produces an electronic semi-monthly newsletter (weConnect) with current events and time-sensitive information.

Circuit

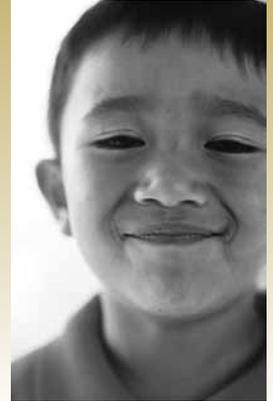
Offering information and assistance to parents and families caring for children with a disability or special need.

In this Issue:

What Parents Should Know About Shame, Blame and Resiliency

“Resilience is about believing in yourself, and trusting your own wisdom rather than being swayed by the opinions of others.”

- Jonathan Lockwood Huie



The Road to Resiliency

By Marcia Maltaverne, SDPC Project Coordinator

The miracle of a having a child stirs something basic in a parent’s sense of being. There is a sort of spirituality in knowing that a life has grown from our very existence. We hold visions of hope, dreams, and expectations for them even before they are born. Our children are seen by us and the outside world as reflections and extensions of ourselves. We imagine the kind of person our child will become, the relationships we will have with them, and the pride and joy we will experience as a parent. These visions and dreams help us prepare to make the commitment for the long journey of raising our children that includes sacrifice and emotional and financial investment. However, high hopes and expectations may be crushed when those heartfelt dreams are shattered by disability or a medical condition. How does a parent survive the blow and go on to help their child, their family, and themselves? How do they bring up the child they have and let go of the child they dreamed of?

Although most parents are eventually able to focus on and celebrate their child’s strengths and contributions, when they first learn their child has a disability, they often react to it as a death - of certain hopes, dreams, and expectations. Reactions include a sense of loss of “normalcy” for their children and lifestyle, shame and humiliation among family, friends, and colleagues, a profound disappointment that the dreams that reflect the meaning of their very existence have been shattered. It is often referred to as a grieving process in which parents experience the stages of denial, anxiety, fear, guilt, depression, and anger before acknowledgement. Some parents blame themselves or others, become bitter, turn into a crusader or a deserter; an alcoholic or a workaholic. They may feel responsible for their child’s disability because they did not take steps to prevent a birth defect, or believe it is punishment for a past thought, feeling, or action or regretting the pregnancy sometime during gestation. Parents

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The Road to Resiliency

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may also believe they must be bad people because their child was born with a disability. Parents must face a complicated and frightening task – they must go on with their lives, let go, cope, and eventually create new dreams. They must experience, accept, and express the feelings that accompany the news that their child has a disability. They must practice resiliency.

Resilience is most commonly understood as a process, and not a personal trait. In the search for a definition of resiliency we found such phrases as “the capacity of a strained body to recover after a period of stress;” “the ability to recover from or adjust to misfortune;” or “the process of persisting in the face of adversity.” In regard to disability, it is usually thought of as the end product of an effective coping strategy, of rebuilding and replacing those hopes, dreams, and expectations they had prior to their child’s birth with the realities of their child’s actual prognosis. It is not itself a protective factor, but a system or process that allows people to ‘bounce back’ during or after a major stressor.

Seeing Beyond the Disability

The 2000 U.S. Census shows us that 49.7 million people in the U. S. age five and over have a disability -- nearly one in five U.S. residents, or 19 percent. More recently, the US Department of Education reported in 2009 – 2010 almost seven million children aged three to 21 were served in special education programs.

Culturally, we have different ways of understanding disability. In the US, definitions of disability hinge on words such as ‘condition,’ ‘disadvantage,’ ‘restriction,’ ‘impairment,’ and ‘limits.’ In northern Mexico and Botswana it is reported that the birth of a child with a disability is evidence of God’s trust in a parent’s ability to care for that child.

The deaf culture celebrates when a child is born deaf because it is seen as the preservation of the culture.

For the Lakota, there is no such thing as impairment because they recognize personhood and the full range of intellectual and physical abilities as simply part of the normal range of human possibilities. This does not have a bearing on their ability to be spiritual, kind, happy, helpful, or a contributing member of their community.

Research has uncovered certain factors shown to strengthen resilience in people struggling with the effects of difficult life situations. Factors include a strong self-esteem and sense of purpose, relationships that provide care and support, good communication and problem solving skills, the ability to manage strong feelings and impulses, and community support. Parents and others can strengthen their own resilience by trying the following suggestions:

Strengthen Connections: Spend time with family and friends talking about your feelings and gain their support and encouragement. By taking care of yourself and each other, you are offering your children a stable and loving home. Connect with colleagues and other parents who have lived through the experience. Ask for individual assistance from SD Parent Connection. Relationships that provide care and support, trust and encouragement, both within and outside the family help you provide your children with a loving and stable home. Know that asking for help is a sign of strength, not weakness.

Act: Make realistic plans and carry through with them. Make and attend the appointments that will give you the information you need, call the school to request that meeting, share the plan with someone you trust and who will help keep you accountable. By taking action you give yourself a sense of purpose and continued hope for the future.

Believe in Yourself: Have confidence in your own strengths and abilities. Remember the obstacles you have overcome to this point and use that knowledge to forge ahead. Your confidence will prevent you from feeling like you have no control over things that happen to you and your child without your permission. Maintain a hopeful outlook. An optimistic outlook enables you to expect that good things will happen in your life. Try visualizing what you want, rather than worrying about what you fear. Know that you will be your child’s strongest cheerleader and advocate.

Communicate Effectively: Share your feelings with others. The holding in of thoughts, feelings and emotions can develop into internal anxiety, fear and depression which prevent you from reaching out to your child, family, and available assistance. Take time to think through and write down your questions prior to meetings and appointments.

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State your questions and desires to doctors, teachers, and other providers clearly. It may be helpful to share information such as the diagnosis, disability, and doctor's reports with family members. Educate siblings to help them understand and accept their brother or sister and prevent them from feeling left out. This will allow your family to be on the same page to best meet the needs of your child.

Practice Personal Control: The capacity to manage strong feelings and impulses is seen as a factor in strengthening resilience. Even when facing very painful events, try to consider the stressful situation in a broader context and keep a long-term perspective. Avoid blowing the event out of proportion.

Reach Out: Today more than ever there are many services and supports that can be beneficial in strengthening resilience. Develop a support network of medical and helping professionals including trained caregivers to provide respite. Counseling, education, and support groups can help you and family members to redirect emotions into something positive for the family and the best interest of your child with a disability. Talking with others can help parents find balance and perspective.

When parents become resilient in the face of their child's disability, the goal is not to deny the reality of their lost hopes but rather to gain insight into their child's talents and inner strengths so that they can experience pleasures, rewards, joys, and connection with their child. It is not the child's disability that handicaps and disintegrates families; it is the way they react to it and to each other. Acknowledging and answering tough questions, connecting with helpful people and resources, and dealing with loss and frustration with creativity are all ways parents practice resiliency and embark on the road to hope.

Two join SD Parent Connection Team

Teresa Nold has joined SD Parent Connection as an Outreach Specialist working in the Sioux Falls office for the Rural Health Outreach Project. Nykki Sutton is SDPC's new Office Coordinator.

Teresa is a former SDPC Board member. She was raised in a family where American Sign Language was primarily used. She is married and has two sons. Her husband is deaf as well as her oldest son, who is deaf and has additional disabilities. Her other son has been diagnosed with ADHD. Her previous places of employment include Communication Service for the Deaf and the USD Sanford School of Medicine Center for Disabilities.

Nykki is experienced in computer usage and has worked in Omaha and Fremont, NE. She enjoys doing crafts with her mom, sister, and daughter.



Next Sibshops Will Be in Feb. and April in Sioux Falls

The Sibshops program is designed specifically for brothers and sisters, ages 6-12, of children with special needs or disabilities to enjoy friendship, activities and learning together.

The February Sibshop on **Saturday, February 9** at Children's Care Hospital and School will feature a swimming event. Bring your own swimsuit (changing rooms available) and towel. Flotation devices are provided, but participants may also bring their own. Children will be grouped according to swimming skills and all groups will be supervised.

Activities begin at 10:00 a.m. (lunch included) and conclude at 1:00 p.m. Children can be picked up at the front entrance. Pre-registration required.

The April Sibshop will be held in conjunction with Partners in Policymaking and will be **April 27, 2013**.

To register for either Sibshops call 1-800-640-4553 or email sdpc@sdparent.org or visit www.sdparent.org and click on the family life/ sibling page and click the registration link (<http://www.surveymonkey.com/s/J8MWV9S>.)

Sibshops is co-sponsored by South Dakota Parent Connection, Children's Care Hospital and School and Here4Youth.

If you would like to help endow the Sibshops program in South Dakota, please contact Elaine Roberts or Cheryl Crase at 605-361-3171.



Beyond Tunnel Vision

by Kathie Snow

Kathie Snow is a public speaker, trainer, consultant, book author and creator of products that promote positive ways of thinking about disability; and host of the website www.disabilityisnatural.com. She is a parent of a son with cerebral palsy. This article is reprinted with permission of Kathie Snow and cannot be reprinted in part or whole without the permission of Kathie Snow and Disability is Natural.

Tunnel vision: we all have it—to one degree or another and in one area or another. And when we recognize we have it, we can then work to eliminate it! I discovered it in myself recently, and it was an eye-opening revelation.

While spending time with my 81-year-old mother, I went shopping for some things she needed. (She was recovering from a broken hip.) On the shopping list was a lampshade for a “near-antique” lamp. The base of the lamp was a horse (probably made of bronze with that greenish tint common to aged metal). It was in my mom’s study, which included a large Oriental carpet of red and white, with a little gold and green. The lampshade was in good shape, but it was solid black, which didn’t allow much light. Thus, in my mind, a white or beige shade would be better. Off I went to the store, where I was able to quickly find the right-sized lampshade from all the light-colored shades on display. Wow—that was easy!

My joy was short-lived, for when I returned to my mom’s with the lampshade, I found it wouldn’t work. The “harp” (the thing that holds the shade on the bulb) was made for a different type of lamp. So back to the store I went. This time, I realized I needed to be more thoughtful. As I stood back from the display to take it all in, imagine my shock when I saw *more* than the light-colored shades I had seen before. I saw the *perfect* lampshade: a red, green, gold striped fabric that matched the colors in her room. I took it down from the shelf to take a closer look and thought, “Why didn’t I see this the first time around?” Because I had tunnel vision. I was focused on finding a light-colored lampshade, and *that’s all I saw!* My mind was not open to any other possibility the first time around, so I literally did not see anything else! Only when my *mind* was open to other possibilities did my eyes see other possibilities! This experience led to my thinking about how many times we’ve had tunnel vision about individuals who happen to have disabilities.

How many of us—parents, teachers, service providers, and others—see a person primarily through the lens of the disability? In doing so, we may literally be unable to see anything beyond the diagnosis, like the person’s strengths, abilities, talents, etc., as well as options, possibilities, and/or strategies to ensure a person can live the life of his or her dreams.

How many physicians continue to spew dream-crushing prognoses to parents about their children, because they can’t see that people with disabilities can lead happy, productive, successful lives? How many parents are fearful about their child’s future, because they see only what “experts” tell them? How many are hopeless, because they can’t see a real life for their child beyond the service system?

How many parents and therapists (physical, occupational, speech, etc.) are focused on remediating a child’s “deficits” through therapy, instead of recognizing the value of power wheelchairs, communication devices, and other supports that would render many therapies unnecessary? How many parents allow their children’s (and families’) lives to be taken over by therapies and interventions, because they can’t see more natural ways of assisting their children?

How many educators believe a student with a disability cannot learn and be successful in general ed classrooms, because they can’t see the many ways a child can learn? How many service providers believe an adult with a disability can’t have a real job, live on his/her own, etc., because they just can’t see how any of that would ever be possible, for whatever reasons?

How many children and adults with disabilities do not believe in themselves and their potential, because they’ve never seen anyone else believe in them? And in the process, how much potential is ignored and how many hopes and dreams are crushed?

And now here is my secret, a very simple secret; it is only with the heart that one can see rightly; what is essential is invisible to the eye.

Antoine de Saint

When doing a particular presentation and/or when talking one-on-one to a family member, I often ask others to tell me the strengths of a person with a disability (their child, the person they provide services to, etc.). I wait for a response, and when none is forthcoming, I repeat the question in different ways, such as, “What does he/she love to do? What does he/she do well? What is he/she interested in learning?” All of these things, and many more, are strengths. But in response to my questions, many people respond with blank looks and are speechless; they’re unable to see any strengths in the person—and how incredibly sad this is, for all of us have strengths!

Too many times—like my lampshade experience—we see only what we plan to see, want to see, or expect to see. Our minds are closed to other ideas, unless and until we widen our perspectives *and* eliminate the diagnosis as the defining characteristic of the person. On the one hand, it seems progress is being made as more and more people replace antiquated, pejorative descriptors with the more respectful People First Language, and put the person before the disability. On the other hand, how much progress has really been made if we choose to *speak* respectfully, but are still unable to see or think beyond the diagnosis? We may talk the talk, but don’t walk the walk. And our actions always speak louder than our words.

One mother of a 14-year-old girl who has a diagnosis of autism had a life-changing epiphany right before my eyes. She admitted that from the time her daughter was diagnosed at the age of four, every time she looked at her daughter, she saw the word “autism” tattooed on her forehead. That’s all she saw! She then burst into tears, recognizing that this narrow vision of her daughter had resulted in many negative outcomes, and she resolved to change her ways on the spot—and she did. Her tunnel vision was gone, and her daughter’s life changed for the better. The same can be true for anyone.

What will it take for each of us to eliminate our tunnel vision and the harm that it engenders? First, recognize that *you* may be “afflicted with tunnel vision!” Acknowledging the problem is the first step in resolving it. Second, step back to get a wider view (like I finally did in the lamp shade aisle). Instead of allowing your perception of the person’s disability to overshadow everything else, recognize that a disability is just a medical diagnosis, and it’s just one of many characteristics of the person (and certainly not the most important one). And learn to see with your eyes and your heart. The person you’re looking at is a multi-dimensional human with feelings, dreams, experiences, hopes, and more—just like you. So, third, consider what you haven’t yet seen that’s been there all the time. What *are* the person’s strengths, abilities, interests, and dreams? And how do these make the person more *similar* to you (and/or others without disabilities) than different? Fourth, what possibilities, options, choices, and/or opportunities can now be explored?

Finally, try to walk in the shoes of the person with a disability you care about. What would it feel like if those who cared about you had tunnel vision and saw you only through the lens of one characteristic, like *your* medical diagnosis, your “inappropriate behavior” (we’ve all been “inappropriate” at one time or another), your difficulties/problems, and so forth.

When we widen our perspectives, imagine the changes that can occur, in ourselves and in the lives of people with disabilities. And won’t it be a wondrous joy to get to know the “new person”—*the real person*—your newly-opened mind has discovered?

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Resources For Families

- ***The Journey: A Parent Comes to Terms with Her Daughter’s Disability*** by Virginia Richardson. www.pacer.org/parent/php/PHP-c26.pdf *
- ***The Challenges of Emotional and Behavioral Disorders.*** www.pacer.org/parent/php/php-c86.pdf. *
Parents are often blamed—by other families, teachers, and the professionals who work with their children—for not providing the structure, limits, discipline, or supports that seem to work well for most children. Worse, they often blame themselves for not being able to control their child.
- Sometimes we get hit with challenges that really test our ability to handle life. ***Handling Challenging Times*** from the Montana State University Extension discusses how stress impacts the entire family and provides ideas on how to better handle challenging times. <http://msuextension.org/publications/HomeHealthandFamily/MT200210HR.pdf> *
- ***50 Stress Busting Ideas for Your Well-being.*** by Stephen F. Duncan. <http://msuextension.org/publications/HomeHealthandFamily/MT200016HR.pdf> *

* If link doesn’t work, paste it into your browser. If you can’t access these on the computer, contact SDPC at 1-800-640-4553.

Tools to Listen, Learn, Plan and Problem-Solve

Mary wanted people to know her son, Tommy, (7) who has challenges communicating, in a meaningful way. She created a Communication Chart to help people understand and see what Tommy could do.

“A Communication Chart is a **Person Centered Thinking** tool that helps others better understand how best to communicate with the person by actions and words,” said Brenda Smith, an advocate, person-centered thinking trainer and SDPC consultant for the Families Planning Together program.

Person Centered Thinking is a set of values, skills and tools that gives us ways to listen, learn, problem solve and plan with people who need support, explains Brenda. “It helps people and their families think about their lives; about what is important to them, what support they need, and what they want for their future. **Person Centered Thinking** builds on the strengths, gifts, talents and contributions of the person,” said Brenda.

Over the past six years **Person Centered Thinking** has spread across South Dakota. It began in 2007 with three community support providers making a commitment to become Person Centered organizations. With support from the South Dakota Division of Developmental Disabilities, South Dakota Council on Developmental Disabilities, South Dakota Department of Education Office of Special Education and South Dakota Parent Connection it has grown to include not only many of South Dakota’s community support providers, but also self-advocates, families and schools.

Finding Balance Is At Core of Person Centered Thinking

One of the core concepts within **Person Centered Thinking** is that of understanding the balance between what is “*Important To*” and “*Important For*” the person/family. For example, Megan is moving back to her home community from a specialized education facility. Megan and her family are using a One Page Introduction to let others know what is important to Megan and how to support Megan. The One Page is helping others get to know Megan in a meaningful way. It will help Megan have a balance of things *Important To* her to be happy and things that are *Important For* her to be safe as she transitions to adulthood. “What is *Important To* someone includes those things that really matter to them from their perspective,” says Brenda. “It’s the things that make them happy, content and feel fulfilled. What is *Important For* someone includes issues of health and safety and how the person can be a valued member of their community.” **Person-Centered Thinking** is having a balance of what really matters most to people and what they need to be healthy and safe. “Each situation is different, because everyone is unique. The focus of **Person Centered Thinking** is listening to people and providing support in a way that makes sense to them,” explains Brenda.

Person Centered Thinking also helps identify the supports a person needs in their day-to-day life. “It is important to acknowledge that ALL of us need support of one kind or another in our lives,” notes Brenda. “No one is so independent that they don’t need anyone. We all need support, some people just need support in a little different way.”

For every young person entering high school for the first time, it is a step into the unknown and as a result, creates a little anxiety. Angela and her mom created a One Page Introduction to introduce Angela to her new teachers. The One Page helped her new teachers know how best to support Angela and helped Angela to let teachers know what is *Important To* and *Important For* her to be successful. “It helps Angela to have more good days, and we all want to have good days,” concludes Brenda.

Person Centered Thinking is also empowering. Susan’s daughter had been in the Early Childhood Program, and now was about to enter kindergarten. Susan created a One Page Introduction for her daughter to help lead the discussion about her child’s special education needs. Creating the One Page Introduction gave Susan confidence to start the conversation about her daughter with less apprehension. “It made me feel strong,” said Susan. From that first step Susan became more involved and a stronger voice for her daughter.

“We love our children, and we all want people to see the great things about them,” notes Brenda. “**Person Centered Thinking** tools help us showcase our kids to the world. Then, everyone can see beyond what they can’t do, to know what they CAN do, and envision greater expectations.”

“Everybody in this world today needs support of one kind or another.... There is no person so independent in the world that they don’t need anybody.”

Michael J. Kennedy

Bring Families Planning Together To Your Community

South Dakota Parent Connection is partnering with the South Dakota Council on Developmental Disabilities to offer **FREE "Families Planning Together"** workshops.

Families Planning Together offers family members an opportunity to learn Person Centered Thinking tools in a one-day workshop. They learn practical strategies that help them gather meaningful information to problem solve and plan with and for their loved one.

The tools also provide effective ways to communicate with providers, school personnel and others. Throughout the workshop families use the tools to create a One Page Introduction for their family member. The One Page Introduction is one way families can help others get to know their loved one in a meaningful way.

The Families Planning Together Program is facilitated by Brenda Smith for SDPC. Brenda is a parent, advocate, Person Centered Thinking trainer, and Families Planning Together facilitator. If you are interested in scheduling a Families Planning Together workshop in your community, contact Brenda Smith at mbsmit@msn.com or SDPC at sdpc@sdparent.org, 361-3171 or 1-800-640-4553.



Attend Parent Education Sessions Online or at DDN Sites

The **FREE** Parent Education and Support sessions are held each month through Dakota Digital Network (DDN) video conferencing at 7 p.m. CDT (6 p.m. MT). Sessions will also be available **LIVE via the Internet** with the ability to ask questions of the presenter through a chat feature.

Videos of the presentations are archived at www.sdparent.org (**Family Life, Parent Education Series**) for viewing at any time. The sessions are appropriate for parents and those working with or supporting children with cognitive, developmental, emotional/behavioral or physical special needs. Monthly sessions are held throughout the school year on the second Thursday of the month at 7 p.m. (CT) or 6 p.m. (MT).

Upcoming Sessions

December 13 - Cutting Through the Static: Bridging the Communication Gap with Your Teen with a Mental Health Challenge. Communication is vital in all aspects of our lives. Living in a family where someone, especially a teen, has a mental health challenge can put extra obstacles in the way of having a message "understood." This session will contain practical information you can incorporate into your daily life that will help you effectively communicate with this special person in your life. Presented by Phyllis Arends, Executive Director, NAMI of South Dakota. **December DDN Sites** are **Sioux Falls** at USD Wegner Library, 1400 W. 22nd Street; **Rapid City** at School of Mines, 501 E. St. Joseph Street Classroom Building; and **Salem**, McCook Central School, 200 East Essex Avenue.

DDN Sites for January - May: **Spearfish** at Black Hills State University, **Sioux Falls** at University Center, 4801 N. Career Avenue; **Rapid City** at School of Mines, 501 E. St. Joseph Street Classroom Building; and **Salem**, McCook Central School, 200 East Essex Avenue. Contact SDPC at 1-800-640-4553 with questions.

January 10 - Keeping It Together: Skills to Maintain Your Composure When Your Teen Has Lost Theirs. The human brain is not well developed until the early to mid-20s. Adolescence typically brings challenges for caregivers; adding mental health problems to the equation creates even greater difficulties. Helping our children get through these trying years can test our patience. This session will contain information to help you learn positive coping skills. When caregivers use positive coping skills we model behavior that, hopefully, our children will learn and use. Presented by Phyllis Arends, Executive Director, NAMI of South Dakota.

February 14 - Understanding Behavior Issues. If you are the parent of a child with behavioral difficulties, you may often feel at a loss before, during, and/or after these frustrating outbursts. When these occur, parents want tools they can use on the spot. In this session, Vicki Isler, Ed.D, BCBA-D, Clinical Director and Principal and Darcie Knight, Ed.S, School Psychologist, both of Children's Care Hospital and School will discuss not only what to do in the midst of an outburst but, more importantly, how these behaviors can be prevented. They will also talk about the importance of teaching and reinforcing appropriate behavior-- and how to make it all work within the family structure.

Also save the dates of **March 14 - SSI: Common Questions and Concerns; April 11 - Guardianship: One Size Does Not Fit All; May 9 - Connection Before Correction** for the remaining 2012-2013 sessions. More information on these sessions will be included in the Spring *Circuit*.



SOUTH DAKOTA
ParentConnection
Resources for families of children with disabilities.

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Friends of SDPC will match every dollar you contribute through December 31, 2012 to SDPC*.

It's easy to contribute. Visit www.sdparent.org, click on the **Donate Now** button and you can donate with a **secure electronic bank draft or credit card**. You can make a recurring gift as well. Or, **simply send your donation in the envelope included with this issue of the Circuit.**



YOU CAN MAKE A DIFFERENCE.....

Support SDPC in its mission to connect families to resources and help other parents be champions for their children!

*"We first came in contact with SDPC many years ago when our son was diagnosed with ADHD. He was 3 years old. We knew he had problems, but we didn't know where to turn or where to find help. **The staff at SD Parent Connection was awesome!** They listened to us and provided us with **LOADS of information and resources** to help us navigate the special education system and get him the help he needed. Over the years our son has had many more diagnoses added and had many more difficulties in life. **SDPC is still there for us**, 17 years later, guiding us through and helping us find services and resources to best fit out son's needs."*

Sarah

**Cumulative gifts up to \$5,000 by December 31, 2012 will be matched.*

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