



TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

TVDSA Newsletter

January 2013

Newsletter Editor: [Celena Auger](#)

In this Issue

With the New Year, we wanted to go back to the start of every family, to the parents. Included in this month's newsletter are articles that hopefully can help you as a parent, or help other family members help "parents" of a child with Down syndrome.

The TVDSA Newsletter staff wants to hear from you!

- What do you want more/less of?
- What topics do you want to read more about?

We realize there is a wide audience this newsletter reaches, but we want to make sure you are getting out of the newsletter what you need and want for your family. In 2013 TVDSA hopes to bring you even more of what you need to advocate and be a healthy family. Please email any comments or suggestions to: newsletter@idahodownsyndrome.org

Monthly and archived TVDSA newsletters are available on our website at: www.idahodownsyndrome.org for viewing and sharing.



Welcome 2013!

The TVDSA Christmas Parties were fun for all that attended – here are some highlights:

There were over 125 people that came together to celebrate the holidays at the TVDSA Potluck dinner in Nampa. Good food, good company and good dancing was shared by all.

At the 3rd Annual Snackin' with Santa there were almost 50 children that sat on Santa's lap, made Christmas cookies and played with friends.



TVDSA hopes everyone had a safe holiday season break from routine and has a wonderful 2013 to come!

Parenting Style Has Big Impact On Kids With Disabilities By Michelle Diamant

The approach that parents take with their children who have developmental disabilities is directly tied to how cooperative and independent they become, new research suggests.

In an analysis of existing studies looking at the influence of parenting on children with special needs, researchers found that when moms and dads employed so-called positive parenting, their kids exhibited greater independence, better language skills, stronger emotional expression and social interaction as well as improved temperament.

"In households where positive parenting is applied, the symptoms and severity of the child's disability are more likely to decrease over time," said Tim Smith of Brigham Young University who worked on the study, which was published in the journal *Research in Developmental Disabilities* this month.

"Research has consistently shown that the earlier and more consistently positive parenting is provided, the greater the child's development," he said.

Smith and his colleagues identified three main approaches to parenting. Permissive moms and dads are accepting and not demanding, while authoritarian parents are more

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January 8th:

TVDSA Family Meeting
7:00pm-9:00pm at A New Leaf. Topic: Children's Medicaid Benefits Redesign
Contact: [Erin Rosenkoetter](#)

January 12th:

Idaho Stampede Night
7:00pm game, \$12.00 Tickets. Please pre-order by January 4th
Contact: [Malu Mulholland](#).

January 18th & 19th:

i.s.e conference
Portland, OR

January 19th:

AIM & Cool Club go bowling at Big Al's in Meridian from 3:00pm-5:00pm.
Contact: [Freddie Gallas](#)

January 22nd:

D.A.D.S. Meeting at Fuddrucker's in Meridian from 6:30pm 8:30pm
Contact: [Gus Olmos](#)

January 26th:

2nd Annual Family Caregiver Conference
8:00am-2:00pm at BSU, Student Union Building. \$15 per person, includes conference, expo, lunch and parking. To register: www.fiaboise.org or call 333-1363 Register by January 24th

January 28th:

Lil' Buddies Playgroup at 10:00am-11:45am at Charlotte's house in Boise.
Contact: [Kristie Yerger](#)

February 7th:

Infant Motor Development Milestones from 7:00pm-8:30pm at St. Luke's Meridian, lower level conference rooms. Free, but must pre-register at 489-5099

February 7-8th:

PEAK Parent Center Conference on Inclusive Education
Denver, Colorado

February 8-9th:

ID Miss Amazing Pageant
Boise, ID



Are You Recharging Yourself? By Roberta R. Omin, CSW-R

Special needs children are likely to be high maintenance children. Whether a disability is developmentally, neurologically or medically based, these children require significant time, attention, planning and support. They are sensitive on many fronts. Their emotions, behaviors, likes and dislikes are often intensified. Their health, learning and/or social needs are vast. These sensitivities necessitate that parents adjust their usual style in order to suit their child's unique needs and ways of responding.

Parents often have a range of experiences and feelings: worry, burden, inadequacy, frustration, and exhaustion (emotional and physical). Over time, this may bring about depression, isolation, resentment and guilt. While there is no fixed rule, women and men have different styles and beliefs regarding self care. Women have been socialized as caregivers and may find it difficult to claim time for themselves due to an inner notion that it is "selfish." Men, on the other hand, are socialized to be providers and often overwork. For both, self care can seem elusive or inconceivable and for some, even unacceptable.

While there is no magic cure to relieve some of the realities of having a high maintenance child, taking time for yourself helps. A good place to start is for couples to talk with each other about their self care needs and then co-create nourishing and re-energizing opportunities for them as individuals and as a couple.

Below are ideas that make caring for yourself a manageable reality:

- * Remind yourself that you and that your couple relationship require attending. Find your "us."
- * Let go of the notion you have to do it all by yourself.
- * Identify what is extraneous and depletes your energy.
- * Practice saying "no" on occasion.
- * Learn to share responsibility with your spouse.
- * Ask for help from family/friends.
- * Overcome being intimidated by others who seem to do this effortlessly.
- * Find professionals who work respectfully with you.
- * Broaden your parenting skills to better handle taxing behaviors or circumstances.
- * Find environments that fit your child and yourself (e.g. don't go to supermarkets with your child if it creates tension).
- * Network with parents whose children are older and have similar profiles to learn what lies

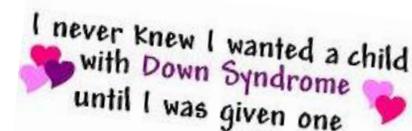
ahead. Ask about their coping strategies and techniques.

Meeting your own needs can come in a variety of forms, depending on what would be fulfilling at a given time. Perhaps your internal batteries can be recharged with quiet reflection and other times rejuvenated by having contact with people whom you feel close and understood. Ideas to consider for revitalization are:

- * Develop a relationship with a sitter whom you can trust; who can be trained to work with your child.
- * Block out non-negotiable time for you and your spouse on your calendar.
- * Go out on dates with your spouse — something interesting, novel and fun.
- * Find a form of exercise you like to do; designate time, even if for short periods — it will be invigorating.
- * Meditate, learn relaxation techniques.
- * Get involved in something you thought you would never do and things you like to do. It builds up your reserves.
- * Start or join a book club, support or discussion group.
- * Attend the theatre, lectures, movies, music and/or sporting events.
- * Get good rest, including power naps.
- * Keep a private journal to pour out your dark thoughts and negative feelings.
- * Create a space for a safe haven in your home; make it your special retreat.
- * Have lunch with a friend or a close family member.

By challenging your attitudes about self care and not abandoning your needs, you will gain new perspectives about renewal and energy. More often, by making yourself do some of these things, you'll discover you cope more effectively, minimizing the risk of burnout. You deserve to claim time and space for yourself and each other. In being creative, your possibilities are endless.

Jenny Frank, CSW, and Roberta Omin, CSW-R, are clinical social workers in Westchester County, N.Y., who have extensive experience working with individuals, families and children with special needs. They co-founded and co-write for their newsletter Special Parenting Matters of Westchester published three times per year. This article is a reprint of the Winter 2004, Vol. 3, No. 1 issue. February 18 2009.



Parenting Style (Continued from Page 1)

controlling of their kids. Positive parents fall in the middle, striking a balance by allowing their child's self-will while also maintaining expectations of discipline.

Despite the clear benefits observed from the balanced approach, researchers said that taking the middle road can be especially challenging when a child has a disability.

"When you think of parenting a child with a developmental disability, it might be more intuitive to be authoritarian and assume that the child can't figure out things alone. On the other hand, with a child who has autism, it may seem easier and less contentious to be more permissive with the child and thereby avoid conflict," said Tina Dyches of Brigham Young University who also worked on the review. "But there needs to be a balance. A child with a disability should not be subject to different rules in a family, nor be the center of a family."

The findings from the analysis are among the first to assess the role of parenting style specifically in kids with developmental disabilities, researchers said. Thousands of studies exist examining parenting of typically developing children, but researchers behind the new review say they found just 14 studies between 1990 and 2008 focusing on those with autism, Down syndrome and other developmental disabilities.

Despite the small body of research, however, the benefits of positive parenting are clear for children with all types of developmental disabilities no matter their age, the study found.

Researchers said their findings highlight the importance of promoting effective parenting skills as part of early intervention services.

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10 Hurtful Comments from Relatives About Your Child with Special Needs

One of the painful parts of parenting a child with special needs is dealing with comments and questions from concerned family members. Most of the time, these remarks arise from love for the child and consideration for the well-being of the whole family.

But the questions and comments don't always come out that way, and the fallout may shatter family relationships.

Tact and gentleness are necessary when discussing disabilities and developmental delays – especially in children, because the long-term prognosis is often unknown. Here I've collected some real-life quotes along with some suggestions to soften the dialogue for more constructive purposes.

1. "It's just a phase. You're over-reacting!"

Instead: "You seem to have a lot of concerns. If you want to talk about it, I'm ready to listen."

2. "She looks normal to me. She just needs a little help with ____."

Instead: "What type of support does your child need?"

3. "Maybe if you didn't ____, then he wouldn't ____."

Instead: "What can I do to alleviate some of the stress?" Or offer to do something specific for the family, such as mowing the lawn, making dinner, taking the child outdoors to play for 15 minutes, tidying up the toys – whatever you are capable of doing at that moment.

4. "Can't you just...?"

Instead: "I guess there are no easy answers in this situation, but you'll always have my love and support."

5. "Haven't you tried ____?"

Instead: "I keep hearing about new therapies. Is there something I can research for you?"

6. "Does he talk yet?"

Instead: "How are you? Tell me about the wonderful things that your child has been doing lately."

7. "I'm glad you're finally doing something about your child."

Instead: "I can see that you're working hard to do what's best for your child. It's been difficult for me to observe everything that's happened, but I'm here for you."

8. "Did you read the Newsweek article/see the story on the news about ____?"

Instead: "I want to learn more about _____. Could you recommend some reliable sources of information?"

9. "Why are you so sensitive about this? I'm only trying to help."

Instead: "I love you and I love your family. What can I do to help?"

10. Silence – no phone calls, e-mails, birthday cards or holiday visits.

Instead: Pick up the phone and say, "How are you? I was just thinking about you today."

Source: [Friendship Circle Blog](#) July 26, 2012 by Karen.



TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

Social Groups Page

Dads Appreciating Down Syndrome (D.A.D.S.) Meeting:

January Meeting will be held
Tuesday, January 22nd
at Fuddruckers
at Ustick Rd and Eagle Rd
in Meridian
from **6:30pm-8:30pm**.

For more information about
D.A.D.S. please contact [Gus Olmos](#)

TVDSA Family Meeting:

Tuesday, January 8th
A New Leaf: 2428 N. Stokesberry
Place in Meridian
from **7:00pm-9:00pm**.

Topic: Children's Medicaid Benefits
Redesign Information

Speaker: Nora Lee Fitch from the
Idaho Department of Health &
Welfare will be discussing the ins
and outs of the new family
directed service program.

TVDSA Calendars and Cards will
also be available for sale.

Or more information, contact: [Erin
Rosenkoetter](#)

Moms' Night Out:

There will be No Outing in January.

For more information or to help
organize, please contact [Kristie
Yerger](#)

Lil' Buddies (age birth-5 years) Update:

January Gathering:

Lil' Buddies will meet on
Monday, January 28th
from 10:00am-11:45am
at Charlotte's house:
12067 Goldenrod Ave in
Boise.

Need more information
on **Lil' Buddies**?
Interested in helping
organize the monthly
gatherings? Please
contact [Kristie Yerger](#).



Best Buds (Elementary) Update:

There will be NO official
January Gathering for
Best Buds.

We hope to see you at
the **Stampede game,**
January 12th at 7:00pm!

Need more
information on **Best
Buds**? Interested in
helping organize the
monthly gatherings?
Please contact [Kristie
Yerger](#).



Adults in Motion (AIM) and Cool Club (Jr./Sr. High)

January Gathering: will
be **Saturday, January
19th from 3:00pm-5:00pm**
at Big Al's at 1900 N.
Eagle Road in Meridian
for bowling and fun.

For more information
about **AIM** contact:
[Freddie Gallas](#).

For more information
about **Cool Club** please
contact: [Melanie Berlini](#)



TVDSA will pay for the
games of bowling and
Nachos to follow.

Recommended Videos to Touch the Heart of a Parent:

- Four Minute Touching Motherhood Video: When Sarah Littman visited StoryCorps with her son, Joshua, he was a seventh-grade honors student having a tough time socially. Joshua, who has Asperger's syndrome, had some unique questions to ask his mother. [Watch here](#).
- Three Minute YouTube Video: You are So Beautiful to Me -- a Sweet Mama Dog interacting with a Beautiful Child with Down syndrome. [Watch here](#).

GoodSearch and TVDSA

You search the internet all the time anyway, why not do it and earn money for TVDSA. Just go to: www.goodsearch.com and select TVDSA as your favorite cause. Simply search Down syndrome, we can be found near the end of the list. Then every time you do an internet search a donation is made to TVDSA. Tell everyone you know about GoodSearch for TVDSA.

Kids with
Special Needs
Need **Special**
Moms...

Conferences, Workshops, Webinars & TVDSA Scholarship Information

Your Voice- Your Story

An Interactive Presentation
Addressing Advocacy and Self-
Advocacy Skills

January 10th 2:00pm
Region 3 – 3402 Franklin Rd
Caldwell
Region 4: 1720 Westgate Dr.
Boise
Region 5 – 823 Harrison, Twin
Falls
FREE – but you must register:
jennifer@ipulidaho.org

[PEAK Parent Center Conference on Inclusive Education](#)

February 7-8, 2013
Denver, Colorado

[Down Syndrome Affiliates in Action Leadership Conference](#)

February 21-24th, 2013
Cincinnati, Ohio

Early Birds save \$100 if register
before December 1st!

TVDSA Scholarships

Did you know that TVDSA
supports members in gathering
information at local and
national conferences and/or
workshops?

The TVDSA Scholarship program
is NOT income based, so
everyone is eligible.

Please see our
[Scholarship application](#)
for the guidelines and how to
apply today.

[Inclusion Works!](#)

February 7-9, 2013
The Renaissance Hotel
Austin, Texas
Registration closes January 27th!

[Trisomy 21 Conference](#)

March 2, 2013
The Renaissance Hotel
Houston, Texas

[r.i.s.e conference](#)

Respect, Inspire, Support and
Educate 23rd Annual Parent
Conference

January 18th & 19th, 2013
Portland, OR

[ID Miss Amazing Pageant](#)

February 8-9th, 2013
Boise, ID

This pageant is for girls ages 5-
35 (different age categories)
with disabilities.

[Wrightslaw Conferences](#)

Special Education Law
and Advocacy

Various dates and locations
across the U.S.

**My grandkid has
more chromosomes
than yours!**

Down Syndrome Awareness

Achieving a Better Life Experience (ABLE) Act (H.R. 3423/S.1872)

- The ABLE Act will give individuals with disabilities and their families the ability to save for their child's future just like every other American family, and help people with disabilities live full, productive lives in their communities without losing benefits provided through private insurances, the Medicaid program, the supplemental security income program, the beneficiary's employment, and other sources.
- The account could fund a variety of essential expenses, including *medical and dental care, education, community based supports, employment training, assistive technology, housing, and transportation.*
- The ABLE Act provides individuals with disabilities the same types of flexible savings tools that all other Americans have through college savings accounts, health savings accounts, and individual retirement accounts.

What's new in the 2011-2012 ABLE Act?

- This is the third Congress in which the ABLE Act has been introduced, and there have been some specific changes that were made to the bill for this Congress. Some of the changes would result in providing more flexibility in the account along with a clear path to bring the accounts to the marketplace. Others have been added to help bring down the costs to the federal budget. Most importantly, all of the changes give the bill a much better chance to pass into law.
- The resulting "ABLE" account would now fall under the 529 program. That means that the tax free, fraud protection, account limits, reporting provisions and rollover provisions that apply to 529's would now apply to the ABLE account.
- A provision was added that suspends the beneficiary's SSI check during any period of time the account has assets over \$100,000. It is important to note that although the payment is suspended the individual does not lose their eligibility to receive the payment, so that when the assets are spent down it can be reinstated.

What can you do? Contact your US Senators and Representative by mail, phone or email and tell them you would like them to co-sponsor the ABLE Act. Don't know who are your senators or representative? Go to www.whoismyrepresentative.com.



TVDSA & the Idaho Stampede Have you Gotten YOUR Tickets Yet?

TVDSA will be teaming up with the Idaho Stampede for a family fun night and spreading awareness. Mark your calendars now for **January 12, 2013**. Game starts at 7:00pm. Tickets start at \$12 each. The ticket order form can be found on our [website](#). Please mail in your order form for your tickets by Friday, January 4th, 2013.



TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

PO Box 1404
Meridian, Idaho 83680

We're on the Web!

See us at:

www.idahodownsyndrome.org

Check us out on
[Facebook](#) and [Twitter](#)!

TVDSA 2013 Calendars Still Available!



It's not too late to get your 2013 TVDSA
Calendar for just \$15.00

You can order your calendars [online](#).

Announcing the TVDSA Greeting and Note Cards!

TVDSA has greeting & note cards available to purchase. The original calendar photo shoot pictures are now greeting & note cards!

You can purchase a set of 11, with one of each of the prints, or a set of 10, of a single print/month. Cost: \$7.00 per set.

To [view and order](#) the greeting/note cards visit our: [website](#) or contact: [Kristie Yerger](#).



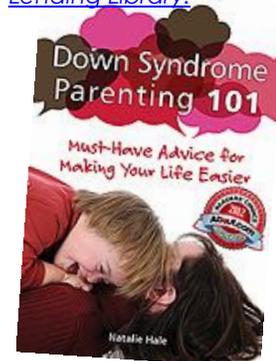
From the TVDSA Lending Library:

Down Syndrome Parenting 101: Must-Have Advice for Making Your Life Easier by Natalie Hale

Do I even need to write a review about this? The title says it all, right? This upbeat book addresses parenting needs which are unique to raising a child with Down syndrome. Short chapters are arranged by topic and categorized by developmental age. Any parent of a child with Down syndrome can scan the table of contents and, within seconds, find a topic he or she is wondering about. But parents will want to read this book straight through to fully appreciate the wealth of information and the author's pleasant writing style.

This book is available from the TVDSA library. Members may reserve it by contacting the librarian at library@idahodownsyndrome.org.

For a complete list of the books/DVDs available through TVDSA, please check out our [Lending Library](#).



The mission of Treasure Valley Down Syndrome Association is to enhance the quality of life for persons with Down syndrome by promoting inclusive environments, providing accurate information to parents, families, and the community, and by advocating respect, dignity, and appropriate supports for people with Down syndrome.

Board of Directors:

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Buddy Walk Chair: [George Taylor](#)
Community Outreach Chair: [Erin Rosenkoetter](#)

For more information, articles, past newsletters and more, please visit our website: <http://idahodownsyndrome.org>
Mailing: PO Box 1404 Meridian, ID 83680; Check us out on [Facebook](#) and [Twitter](#)