



Family Connections

A Family Newsletter from OASIS
Oklahoma Areawide Services Information System



ON THE ROAD
FAMILY PERSPECTIVE
CONFERENCES

The next On The Road Family Perspective Conference will be held during the Fall of 2007.

If your community would like to host a one day conference and want more information—

Call Sally Selvidge at OASIS at 1-800-426-2747 or email her at Sally-Selvidge@ouhsc.edu

Volume 17

Spring 2007



What is a Positive Ritual?

By Sally Selvidge
Edited by Pam Lindsey

Merriam-Webster defines “rituals” as:

an established and prescribed pattern of observance; the performance of actions or procedures in a set, ordered, and ceremonial way. A formalized pattern of actions or words followed regularly and precisely.

We all have rituals that we perform each day. Bleary-eyed and sleepy, we stumble to the kitchen to make that much needed first cup of coffee... We flip on the TV to see what happened around the world as we slept... We jump into a refreshing shower before we are decent to hold a conversation with anyone...

These are all rituals we expect others to honor; however, for people who have a disability, performing their rituals comes at a price. Because the rituals of people with disabilities are not respected, they are often labeled as behaviors in need of extinguishing.

Rituals help give us the coping skills to face life’s many challenges. In addition to daily rituals, we have rituals of comfort and relationships. Comfort rituals make us feel good. It could be a particular type of music, activity, or season of the year. Relationship rituals come not only from the people who have touched our lives, but also memories we have built around these relationships.

Being denied the opportunity to express our rituals by others is rejecting our right to be an individual. Each of us has developed patterns or rituals that help define the boundary between ourselves and the outside world. When people without disabilities perform their daily routines they aren’t looked upon as being non-compliant, aggressive, or stubborn. No one tells them they cannot do something or go somewhere that makes them feel better. They are able to use their own judgment and common sense to make decisions for their lives.

Unfortunately, the rituals of people with disabilities aren’t often viewed in such a positive light. I became aware of Michael Smull’s concept of positive rituals when changing service providers for my son, who has autism and an intellectual disability. Smull wanted the concept of positive rituals to act as a paradigm shift in the service delivery system for people with disabilities.

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On Going Events



Arthritis Community Education and Self Help Courses: Contact Marisa New, Oklahoma Arthritis Network for schedule - (405) 271-9444, ext. 56410 or by e-mail: marisan@health.state.ok.us

Statewide Training and Regional Supports (STARS) The mission of STARS is to support the provision of individualized, comprehensive, multidisciplinary, family-centered, community-based programs and services for people with disabilities through a coordinated training system. Staff and contractors of the SoonerStart program, local public schools, and DDS, as well as families accessing services from these agencies may attend STARS trainings at no charge. Others are welcome to register and attend STARS trainings on a “space available” basis for a charge of \$50.00 per person per workshop. A list of workshops and more information can be found at: http://www.ah.ouhsc.edu/tolbert/courses_workshops/

The Olmstead Strategic Planning Meetings. These meetings are held the first Thursday of each month at the Oklahoma State Capitol in Room 419C from 1:30 - 3:00 p.m. They are open to the public and anyone interested in having input on how to implement the Olmstead Strategic Plan for people who have a disability to live in the community is welcome to attend. Please call Rose Ann Percival at (405) 522-0600 for more information.



Upcoming Events, Conferences and Workshops



April 9 – 10, 2007: Governor’s Conference on Developmental Disabilities: *Possibilities For Every Ability.* Tulsa Renaissance Hotel. Featured Speakers include Patrick Schwarz, Ph.D. and Stephen Nowicki Jr., Ph.D. More information to come.

April 20, 2007: Family Matters Conference - *Helping Children Face the Future* Moore/Norman Technology Center, South Penn Road Campus, 13301 S. Pennsylvania Avenue, Oklahoma City, OK. Planned session topics include Smart Start--Oklahoma’s Support for Families; Mi Casa es Su Casa--helping parent educators reach across the cultural barriers; and Literacy--More than Reading. Registration deadline is April 5, 2007. For more information call Donna Jones at (918) 696-7292.

April 20 & 23, 2007: The Oklahoma State Department of Education Special Education Services Division will hold **IDEA 2004 Public Comment Meetings** in Oklahoma City and Tulsa. Dates, times and locations are listed below.

Tulsa

Friday, April 20, 2007
6:30 p.m. – 9:30 p.m.

Tulsa Technology Center, Riverside Campus
801 E. 91st Street
Tulsa, OK 74132

Oklahoma City

Monday, April 23, 2007
6:30 p.m. – 9:30 p.m.

Metro Technology Center; Main Building – Big Dipper Room
1600 Springlake Drive
Oklahoma City, OK 73111

April 28, 2007: Prader-Willi Syndrome Association of Oklahoma 11th Annual State Conference. Central Christian Camp & Conference Center, One Twin Cedar Lane, Guthrie, Oklahoma. 10:00 am to 3:00 pm. For more information contact Daphne Mosley at rdmosley@swbell.net

May 8 – 10, 2007: Oklahoma Conference on Aging. Reed Center, Oklahoma City. Mark you calendar! Postcard available online at <http://oasis.ouhsc.edu/Mark%20Your%20Calendar%20Postcard.pdf>

June 7-10, 2007. 8th Annual UCO Endeavor Games for Athletes with Physical Disabilities. Hosted by UCO Disabled Sports and Events. Held at Univ. of Central Oklahoma and Edmond North High School. Entry fee \$25 for one sport, \$30 for two and \$35 for three or more. Fee includes T-shirt, athlete goodie bag, participation in opening ceremony, a lunch and the athlete banquet. For more information contact Shelly Ramsey at (405) 974-3151 or sramsey2@ucok.edu



Special Education Resources



- United States Department of Education
<http://www.ed.gov> or <http://idea.ed.gov>
- Oklahoma State Department of Education
<http://www.sde.state.ok.us/home/defaultie.htm>
- National Dissemination Center for Children with Disabilities
<http://www.nichcy.org>
- Office of Special Education Programs Technical Assistance Center on Positive Behavior Interventions and Support
<http://www.pbis.org>
- National Early Childhood Technical Assistance Center
<http://www.nectac.org>
- IDEA2004 Resources
<http://www.nectac.org/idea/idea2004.asp>
- Wrightslaw
<http://www.wrightslaw.com>
- From Emotions to Advocacy
<http://www.fetaweb.com>
- Parent Advocacy Coalition for Educational Rights
<http://www.pacer.org>
- Online Tool for Discipline Issues and parents handbook
<http://www.advocacyinc.org/guides>
<http://www.advocacyinc.org/handoutEducation.htm>
- Parent Training and Information Centers and Community Parent Resource Centers
<http://www.taalliance.org/centers/index.htm>
- National Association of School Psychologists
<http://nasponline.org/advocacy/IDEAinformation.aspx>
- The American Occupational Therapy Association, Inc
<http://www.aota.org/nonmembers/area21/index.asp>
- The Beach Center on Disability
<http://www.beachcenter.org>

These are just a few sites - just type in 'IDEA' in an online search engine and many more sites are available for your information and review.

Meets Every 2nd Wednesday at the Oklahoma Dental Association
317 NE 13th St.
Oklahoma City, OK
(405) 848-8873

Everyone is Welcome who has an interest in Improving the Quality and Access to Oral Health Care for Children with & without a disability in Oklahoma.

For more information or questions , call Sally Selvidge at (800) 426-2747 or email her at Sally-Selvidge@ouhsc.edu



For Dads this Month..

Uncommon Fathers: Reflections Raising a Child with a Disability. Paperback. Edited by Donald J Meyer.

Married with Special Needs Children: A Couples Guide to Keeping Connected. Paperback. By Laura E Marshak and Fran P. Prezant.

Bethy and the Mouse: A Father Remembers His Children with Disabilities. Paperback. By Donald C Bradley.

OASIS/OUHSC does not endorse the information from these Publications. It is provided as a convenience to our readers and is for informational purposes only.

What is a Positive Ritual?

Continued from page 1

Smull hoped through this process that our obsession with writing and implementing a program plan, where change is dictated by the support staff and not by the individual who has the disability, would give way to plans with more time spent on supporting people in their positive rituals and less on programming their every waking moment.

I found that writing a short positive Ritual story about my son, Thomas Selvidge, helped give the staff that would be working with him a quick snapshot of who he was as a “person.” He is not an object or a behavior that needs eliminating...A non-compliant person with peccadilloes to be ignored or cast aside. He is a fun, loving, creative person who deserves to be treated with the same dignity and respect that everyone else expects.

According to Smull, rituals ease us through our day and add much to our quality of life. Our differences are what make the world a wonderful place. It would be very dull place if we were all alike.

For more information on “how to write your own positive ritual call or email Sally Selvidge at 800-426-2747 Sally-Selvidge@ouhsc.edu and Vyonda Martin at Vyonda-Martin@ouhsc.edu.

Information for Michael Smull:
Michael Smull
Support Development Associates
3245 Harness Creek Road
Annapolis Maryland 21403
(410) 626-2707
FAX (410) 626-2708
Email mwsmull@compuserve.com
www.allenshea.com

A happy, smiling
Thomas Selvidge



Thomas' Positive Rituals By Sally Selvidge

Hi. My name is Thomas. I am 25 years old and live in the community with a nice lady named Judy and her husband Sam. I go to work everyday at Dale Rogers Training Center in Oklahoma City, OK. I have autism and an intellectual disability/mental retardation. I am mobile, but unable to communicate verbally very well, but I would like for you to know how I do communicate and the things that I enjoy doing that make me who I am.

Daily Rituals

I like to maintain a schedule throughout the week that doesn't vary. People think because I can't communicate in words very well, that I don't understand. I get agitated and anxious when people don't take the time to tell me when there is a change in my routine. I like it when people take the time to tell me exactly what we are doing and why we are doing it. They do, however, need to get a verbal okay from me so they know I understand.

I hate to get my head wet and particularly dislike showers. The water often rushes out of the showerhead to fast onto my skin, which is very sensitive not only to the hot and cold, but also the beating of the water makes my skin hurt. I often resist and will run into the other room if anyone even mentions washing my hair. In order for me to cooperate you must explain what you are doing and how you are going to do it or I will stiff-arm and push you away and say no. I do

Continued next page

love to take nice hot soaking baths. It feels good on my skin and helps me relax. I do take showers, but prefer baths. I like to take my bath every night after dinner and don't like this routine to vary, because I look forward to this relaxation at the end of the day.

I love to ride in pick-up trucks, buses, and cars that shift gears manually. I like the sound of the gears shifting in the motor and often imitate those sounds as I ride along.

I also like the swishing sound of the washing machine, the hum of the dishwasher and the roar of a lawn mower. I often go out outside while Sam or Dad are mowing the grass or jump high on the trampoline when the neighbors are mowing so I can see over the fence and watch them mow their grass.

Comfort Rituals

I like to listen to most kinds of slow and easy music. I especially like Neil Diamond. Since I process sounds very slowly in my brain Neil's music is easy for me to understand. I also interact with people through music. Singing is fun and easy for me because I can repeat the same words over and over again and don't have to worry about finding words I can't retrieve to make conversation. I often get very involved and act out a scene or sing at the top of my lungs at certain points of my movies or when a familiar tune comes on the radio.

I love the outdoors and in nice weather I like to go outside and sit on my porch swing and eat my popcorn, drink a coke, and flap a good belt up and down in the air. I can sit for hours enjoying the sunshine and warm breeze on my skin and listen to the repeating sounds of nature. This relaxes me and releases the built up tension in my body. I also like to sunbath on the trampoline.

I like to sit in my room in the dark and watch TV and listen to music at the same time because the overhead light or lamplight is often too bright for my eyes. I can sometimes synchronize the Neil music on the VCR and the CD player to play the same tune at the same time. I love to sit and listen to the same song and maybe the same segment of a movie over and over again for hours.

Relationship Rituals

Since I have trouble expressing my feelings verbally I often show my displeasure when someone invades my space by physically pushing them away, holding out my arm, or if someone invades my space too fast I used to throw something at them to stop them in their tracks, but now I have learned to just keep moving away. I have to approach people in my own time and in my own way to feel comfortable. I often hover, jump up and down, chew on my thumb or run into another room if I feel scared. To allow me to approach you gives me time to adjust without causing me tension or anxiety. I get very Anxious if I see someone at work, at home, or in the community that is not in his/her regular space.

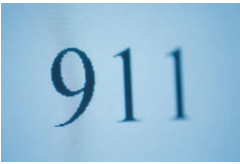
I love Judy and Sam, the people I live with a lot. They always let me approach them and respect my space. Judy has taken me to camp for many years to have fun and see Robert and Lonetta. They all took me snow skiing one winter with the camp. That was one of the highlights of my life in addition to being able to see Neil Diamond Live in concert several years ago. I also like to call my sister, whom I call Bessie on Sunday afternoons. I don't talk on the phone very well, but mom and dad put her on speakerphone and I sit and listen and tell her I love her.

Most of the time I am an affable and pliable young man. I do, however, express myself when I get upset by biting the tops of my hand and jumping up and down in place and telling you if we are out somewhere in the community "Go get in the Car!" In crowded places it is hard for me to tune out all the sounds at once, but I have learned how ever, over the years to adjust to displeasing sites and sounds. I like to go places now in the community and see new things and experience new adventures. If I do get too agitated, I can be calmed down by having my back rubbed, being read to or holding my Cascade Detergent box up to the side of my face. The rubbing releases built up tension, the words of my books bring me peace and the box acts like a security blanket. The box also blocks out sounds and keeps people at bay until I can adjust to new situations.

Please know that I appreciate any effort that is made on my behalf to understand who I am and how I react to the world around me.

Thank You. Thomas

***If reproduced please give credit to Sally Selvidge, Family Outreach Coordinator/OASIS-Information and Referral for Children/Adults with Disabilities/University of Oklahoma Health Sciences Center, PO Box 26901, OKC OK 73190; 1-800-426-2747 or Sally-Selvidge@ouhsc.edu.**



Disaster and Emergency Preparedness: Who's Responsible for Whom?



Rick Barcus, Oklahoma Developmental Disabilities Council

Disaster can and does take many forms, from terrorist attacks, hurricanes, fire in the home, tornadoes, ice storms, to wild fires and chemical accidents. In Oklahoma, we have seen all but hurricanes.

There are a multitude of federal, state and local agencies with disaster plans written and ready to be put into action. Working with people with disabilities is mostly unfamiliar territory to these agencies. So how do we help them, help us? Become involved with your local emergency management office. Offer input into their plans on evacuation, sheltering and the needs of individuals with disabilities. Volunteer for training and emergency drills.

To answer our question, we are ultimately responsible for our own safety and well being in the event of an emergency. Each of us should have a personal or family evacuation plan written for home and work. We should practice that plan. We should have an emergency supplies kit ready. We should plan for our service animal or pets. We should make family, friends, and providers aware that we have our plans together, and that they need to be practiced, checked and updated at least annually. Then and only then, can we be sure that we will be safe.

All of this may sound a bit daunting but it isn't. Involve your family, friends, and providers. Use the following links for assistance in putting your plan together.

- www.nod.org
- www.dhs.gov/disabilitypreparednessicc
- www.dol.gov/odep
- www.fema.gov
- www.redcross.org
- www.srh.weather.gov
- www.salvationarmyusa.org
- www.cdc.gov

General Contacts

Telephone Numbers:

Main Number: 1 (940) 898-5399

Congressional Inquiries: 1 (940) 898-5104

Media Inquiries: 1 (940) 898-5104

Mailing Address:

Federal Emergency Management Agency / www.fema.gov
FRC 800 North Loop 288
Denton, TX 76209-3698

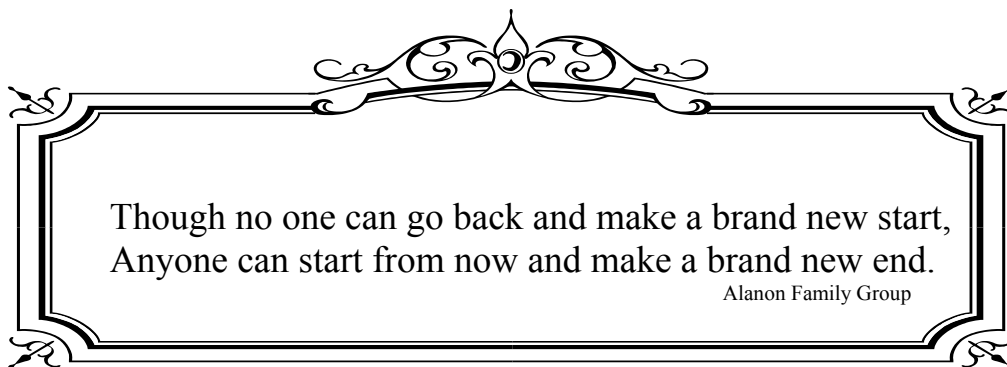
Serving:

- Oklahoma
- Arkansas
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Benefits of Group Support

Group support?

- Learning from one another
- How to take responsibility for their own lives
- Reminding one another that life is not fair
- People are not always reasonable
- Each person is responsible for his/her own feelings
- Hear others stories
- Watch their coping styles provides a mirror in which we can reflect on our own situation.
- Group give kindred souls the requirement of the new roles they are being asked to play
- Group give each person a new shot of self esteem
- Listening without judging
- Safe haven
- Trust is formed that allows for the free flow of information
- Good listener leaves their own personal value system out of the equation
- Empathy and sympathy—not been there but understand and are concerned is sympathy
- Feelings are not right or wrong. People need to feel safe sharing their feelings without judgment or retaliation.
- Sadness leads to healing. Exercise and laughter release brain chemicals called endorphins—stimulants that help fight off depression.
- Regardless of an individual’s personal religious beliefs, belonging to a group often creates this kind of spiritual connection.
- Ground rules for most groups stress nonjudgmental acceptance, encouragement, listening, trust, and forgiveness.
- Difference between hope and denial is that hope transcends reality, whereas denial avoids reality.
 - Hope is not static; it changes as situations and circumstances change.
 - Hope gives us peace in the midst of turmoil and continued strength for the day.





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Or mail to OASIS/OUHSC, PO BOX 26901, OKC, OK 73190

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