



# Family Driven Family Support Services

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## Sound of Her Voice

*See how nature – trees, flowers, grass—*

*Grows in silence.*

*See the stars, the moon and the sun,*

*They move in silence.*

*We need silence to be able to touch souls.*

*-Mother Teresa.*

Words are powerful things. Words influence the way we think. Words make impressions that last a lifetime. Words are a force for laughter, sadness, delight, chastisements, fear, information, shock, comfort, happiness. Words can bind us for a lifetime together ‘til death do us part’ or bring spontaneous smiles as passersby greet ‘good morning’.

Simply put, communication is the sending and receiving of messages. It is a two-way exchange of information involving someone sending a message and someone receiving the message. While the sender is the source of the information, it is the job of the receiver to interpret the message. Often, there can be tension, unease, between sender and receiver. Other times, the exchange is a dance of synchronization, a union of meaning between sender and receiver.

We cannot not communicate. It is impossible to not communicate. We bond to one another with words. Communication begins with a thought. As the thought grows it sometimes becomes words that we speak. But we also communicate very effectively without using spoken words. We use or withhold touch; we move close or keep our distance. We sign, we sing, we write, we use a communication board, we point, we smile in agreement, we frown our displeasure.

My life’s journey with my daughter Sheila is a steady rhythm of nonverbal communication that beats predictable, constant, regular. Primarily nonverbal, Sheila understands all that is said but is hindered by an expressive language disability. Sheila, her dad and I are a triad, comfortable with each other, moving through life in a dance of accommodation that blends us so thoroughly I think our hearts must beat as one.

And, then suddenly, like a flash of gold lightning, my heart skips a beat. Silent Sheila speaks with words. The day is sprinkled with gold dust.

Gold dust was in the air one morning when dad greeted our early risen daughter (who usually is the last one to rise) with ‘good morning Honey.’ Sheila replied ‘go somewhere tonight’. Surprised by joy yet feigning casualness so as not to alarm her, dad said ‘where do you want to go?’ Sheila replied ‘McDonald’s. Cheeseburger’.

Ordinarily, such a mundane exchange between child and parent would hardly be worth mentioning. But, for those of us who hunger for the mundane, a few words strung together are wondrous. The worth of that exchange between Sheila and her dad is so extraordinary; it can only be measurable in priceless gold.

The winters of our lives will always be followed by springtime. And springtime is a hopeful season. It will come, it will renew us, and it will give birth to possibilities we never dare to hope for, let alone dream about.

May we all have spring times to be thankful for. There’s always, always, something to be thankful for.

Joyce Krahe McDonnell, M.A.  
*Newsletter Editor*

## “Celebrating The Possibilities”

“Celebrating The Possibilities” is the third annual Art Show sponsored by the Barber National Institute to bring the entire community together in celebration of the artistic achievements of all persons. The Art Show is held during April in commemoration of Autism Awareness Month.

The Art Show will be held in the North Lobby of the Barber National Institute, 100 Barber Place Friday, April 16, 10a.m.-4p.m.; Sunday, April 18, Noon-3p.m. (refreshments and live entertainment); Monday, April 19, 10a.m.-4p.m.

The Art Show celebrates the artistic achievement of all children and adults, families and staff whose lives are touched by disabilities, as well as professional and amateur artists in the community.

Each artist may submit up to two pieces, although only one piece may be selected for the show. Entries will be accepted on Saturday, March 27 from 9a.m.-Noon, and on Monday and Tuesday, March 29 & March 30, from 8:30a.m.-4:30p.m. at the Barber National Institute, 100 Barber Place, Erie PA 16507 (enter off of East Bay Drive). Find directions @ [www.barberinstitute.org](http://www.barberinstitute.org). If you would like a call for entries, please call 814-878-5903 or go to [www.barberinstitute.org](http://www.barberinstitute.org).

## Biking Program will have Kids on the Move

Riding a bike is one of the summertime joys of childhood. Yet for many youngsters, and their parents, learning to ride a two-wheeler can be a very difficult experience. The Barber National Institute is sponsoring a four-week program, “Ready, Set, Ride,” to help children develop independent bike riding skills. The program will be held on consecutive Saturday mornings on June 5, 12, 19 and 26 in the West parking lot. One-hour sessions will begin at 9:45 and at 11 a.m.

The program is developed to meet the needs of children with special needs but is open to any child at least seven years of age who is able to pedal and steer a bike but who has not been successful in riding without training wheels.

The program is ideal for youngsters with special needs including autism, Down Syndrome, mild cerebral palsy, sensory issues, developmental delays, behavioral issues, or any child who is having difficulty with making the transition to riding without training wheels.

The cost for the program is \$85, which may be covered through an FSS allocation; scholarships are also available. Participants should have a bike and helmet, but a limited number may be available for use. For more information, call 864-5671, or visit [www.barberinstitute.org](http://www.barberinstitute.org).

## Planning a Safe Backyard Playground

Your play structure should reflect what your kids enjoy. Are your kids climbers? Do they enjoy pretend play? Is sand the ultimate play experience?

Choose a backyard playground location with proper drainage and some shade. Measure the area.

Equipment taller than 6 feet doubles the possibility of injury. Choose age-appropriate equipment. Preschoolers are often injured on equipment designed for older kids. If you have to lift your child up to use the equipment, it isn't safe.

Allow at least 6 feet of open space around the equipment so children will not swing, jump or fall onto other equipment. Be sure the structure is firmly anchored in the ground to avoid injuries from tip-overs, inspect for sharp edges and rough wood, and be sure S-hooks are closed.

Install appropriate surfacing materials under the structure since falls account for more than 70% of playground injuries. Pea gravel, sand, ground rubber and woodchips are good surfacing materials but need to be 9-12 inches deep to effectively cushion falls.

Treat play equipment like a backyard pool. Both are great fun, but require vigilance. Remember that kids in their own backyard need adult supervision. Children six years and under should have constant supervision and older kids should be checked on frequently.

Find more playground safety tips @ [www.playgroundsafety.org](http://www.playgroundsafety.org).

S: National Program for Playground Safety.

## Steps to Prevent Birth Defects

Worries about birth defects are common in women who are pregnant or trying to conceive. Though some defects are genetic, many are preventable. Learn what you can do to protect your baby before you conceive. Be sure to ask about whether any prescription drugs, over-the-counter drugs or vaccines should be avoided.

- Don't drink alcohol. No amount has been found to be safe during pregnancy.
- Do take a daily vitamin with 400 micrograms of folic acid before and during pregnancy to prevent neural tube defects. Tip: some fortified cereals may supply 100% of your daily folate need.
- Do delegate pet care. Pet rodents (hamsters, guinea pigs) can contract lympho-

cytic choriomeningitis virus (LCMV) from wild mice; cat feces can transmit toxoplasmosis. If pregnant, let professionals handle mice problems and avoid contact with pet rodents; let someone else clean the litter box.

- Don't smoke. May cause premature births, cleft palate, limb, heart defects.
- Don't use street drugs – all can cause serious birth defects.
- Do avoid harmful substances, including lead, solvents and arsenic.

S: March of Dimes.

### **Things We Like to Know...**

The Social Security Administration (SSA) oversees two disability benefits programs: the Social Security Disability Insurance (SSDI) Program and the Supplemental Security Income (SSI) Program. SSDI and SSI provide non-medical benefits based on disability. SSDI and SSI are funded and administered differently.

The SSDI Program is funded by Social Security taxes. Your unmarried child (18 or older) with a disability that started before age 22 may qualify for SSDI benefits based on your work. A person receiving SSDI will automatically be enrolled in Medicare after receiving 24 months of SSDI.

The SSI Program is funded by general tax revenues (not Social Security taxes). SSI makes monthly payments based on financial need (even those who have never worked) to people who are age 65 or older or blind or disabled. A person receiving SSI is automatically qualified for Medicare without a waiting period.

## **Family and Community Support Services Support Groups**

### **Monthly Meetings**

Family and Community Support Services offer a variety of support groups for individuals with special needs, and parents and caregivers of children with special needs. Parent/caregiver support groups provide members with opportunities to meet with other parents both of younger children and adult children with special needs in an atmosphere of emotional support, education, and friendship. FSS also facilitates groups specially designed to meet the needs of children and young adults with developmental disabilities.

## **The 21+ CLUB**

The 21+ CLUB will launch the 2010 Spring Season on April 7<sup>th</sup> with a presentation by Dianne Allaire, Director of Adult Day Services at the Barber National Institute. Ms. Allaire will talk about the variety of day services available to adults with disabilities. She will explain how the menu of day services offered is personalized to each individual's needs and abilities.

THE 21+ CLUB is an advocacy group of parents, caregivers, and other persons who are interested in the needs of adult children (over the age of 21) with developmental disabilities. Membership is open to anyone interested in services for adults with developmental disabilities. Parents of younger children are invited to join now to help ensure that services will be in place for their children as they mature.

The goals of THE 21+ CLUB are threefold: (1) Educate local, state and national legislators to the unmet needs of adults with developmental disabilities. (2) Explain the various programs and services available for adults with disabilities and inform parents and caregivers about issues affecting adults with developmental disabilities. (3) Develop sociability opportunities for adults with disabilities.

For more information about the group, please call Joyce Krahe McDonnell, MA, Family Support Services @ 814-878-5905 or the FSS Office @ 814-878-5961.

### **Asperger's Support Group**

The Erie Chapter of GRASP, the support group for adults with Asperger's Syndrome, meets monthly on the 4<sup>th</sup> Saturday of each month at the Barber National Institute. GRASP stands for 'Global & Regional Asperger Syndrome Partnership'.

The group, facilitated by Mark Haller, will meet March 27th and April 24th in the Emerald Room, located in the back of the cafeteria, from 1-3pm. Guests are asked to enter from the gated lot on East 3<sup>rd</sup> Street. Please contact Mark Haller to check the most current information for scheduled meeting dates, reservations, and information. You may reach Mark Haller @ 814-864-8770 (between 10am & 1:30pm). You may also email [mentatmark@gmail.com](mailto:mentatmark@gmail.com).

## Autism Support Group

The Autism Society of America Northwest PA Chapter ([www.nwpa-asa.org](http://www.nwpa-asa.org)) Support Group meets to discuss issues related to children with Autism and Asperger's Syndrome. Meetings are scheduled for the 3<sup>rd</sup> Tuesday of the month.

The group will meet in the Emerald Room, Dr. Gertrude A. Barber National Institute, March 16th and April 20th from 7-8:30pm. Sitter services in Room 120. Make free sitter service reservations with Diane @ FSS office 814-878-5961.

## Down Syndrome

The Down Syndrome Support Group of Erie County will meet March 9<sup>th</sup> and April 12<sup>th</sup> at St. Paul's Lutheran Church, 3108 Sterrettania. Regular meetings take place at St. Paul's Lutheran Church, 3108 Sterrettania. The group meets the 2<sup>nd</sup> Tuesday of each month @ 6:30pm. For more information about the group, please call Jackie Lupo @ 833-2143 or email [DownSynErie@yahoo.com](mailto:DownSynErie@yahoo.com)

## FSS Grandparent Autism Support Group

The next FSS Grandparent Autism Support Group meeting will take place April 8, 2010 at the Barber National Institute. Cindy Priester, Education Program Coordinator for Children & Youth and Occupational Therapist will speak to the group about "The Best Classroom Setting for My Grandchild". The meeting will be held in the Breakout Rooms from 6pm-7:30pm. (Note: No meeting will be held in March.)

Registrations are requested to Diane Sanfilippo, FSS Office @ 814-878-5961. For more details about the upcoming meeting or to learn more about the FSS Grandparent Autism Support Group, please call Joyce Krahe McDonnell, MA @ 814-878-5905.

Family Support Services offers support for grandparents and other caregivers to better understand how a developmental disability affects their grandchild. Grandparents also share personal experiences in an atmosphere of support and friendship. Meetings are scheduled the 2<sup>nd</sup> Thursday of each month in the Breakout Rooms, Barber National Institute, from 6-7:30pm.

## SIBSESSIONS

Family Support Services offers monthly SIBSESSIONS for brothers and sisters of individuals with developmental disabilities. SIBSESSIONS include time for sharing, lunch, and games. The group will meet at the Barber National Institute from 10:30am to 1:00pm on the following dates:

- **March 20, 2010: March Madness Party @ Barber National Institute.**
- **April 17, 2010: Spring Fling Party @ Barber National Institute.**

SibSessions offer a supportive setting for the expression of feelings and concerns and the development of new friendships for siblings ages 5 to 16. Participants share the positive aspects of having an affected sibling. Participants enjoy arts and crafts, recreational events, sharing time, and a free lunch.

Sessions are offered free of charge. Most sessions take place at the Barber National Institute, 100 Barber Place. For more information about SibSessions, please call Jennifer Dennehy, FSS @ 814-878-4117.

## Time for Me

"Time for Me" participants will gather March 13, 2010 and April 10, 2010 at the Barber National Institute from 1:30 to 4:00pm. "Time For Me" is a unique program offered to children ages 4 to 10 who are developmentally disabled. Participants engage in structured activities including swimming, arts & crafts, and gym.

This program also provides parents with their own "Time For Me" knowing that their children are in a safe environment, having fun and are well supervised by trained staff. TSS are welcome to attend.

Space is limited to 12 children per session and registration is required. Sessions take place the 2<sup>nd</sup> Saturday of the month. Reservations may be made until the Wednesday prior to the session. For further information regarding dates, fees, and registration, please call Jennifer Dennehy, FSS office @ 878-4117. Guests are asked to please enter through the gated parking lot on E. 3<sup>rd</sup> St.

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## Janet's Jokes

**Question: What did one plate say to the other plate?**

**Answer: Lunch is on me!**

## Things To Do, Places To Go

### FRIENDSHIP MINISTRIES

The Friendship Ministry Groups share God's love with teens and adults with developmental disabilities. Guests may attend any of the meeting locations.

- **FIRST ALLIANCE CHURCH**

First Alliance Church, 2939 Zimmerly Rd., Monday evenings from 7-8:30pm. Contact Alex and Mary @ 734-8553.

- **ST. JOSEPH CHURCH**

St. Joseph Church, 147 W. 24 St., the 2<sup>nd</sup> and 4<sup>th</sup> Monday of month. Contact Diana @ 899-6194.

- **TRINITY UNITED METHODIST CHURCH**

Trinity United Methodist Church, 3952 Pine Ave., the 1<sup>st</sup> and 3rd Monday of the month. Contact Diana @ 899-6194.

### EXPERIENCE CHILDREN'S MUSEUM

Toddler Story Time every Thursday @ 10:30am. Parents & children enjoy a story and hands-on craft. Dates & info @ 814-453-3743. [www.eriechildrensmuseum.org](http://www.eriechildrensmuseum.org).

March 5

#### ERIE PLAYHOUSE

Jane Austen's classic novel "Pride & Prejudice" comes to life. 7:30pm curtain time tonight. More info @ 814-454-2852. [www.erieplayhouse.org](http://www.erieplayhouse.org).

March 6

#### WARNER THEATRE

Verdi's Requiem opera featuring Pittsburgh Opera artists, Erie Phil choir & Grove City Touring Choir tonight @ 8pm. Ticket info @ 814-455-1375. [www.eriephil.org](http://www.eriephil.org).

March 10

#### EXPERIENCE CHILDREN'S MUSEUM

St. Patrick's Day Crafty Corner today and March 13<sup>th</sup> (10am-Noon) for hands-on activities and art projects. Reservations & info @ 814-453-3743.

March 14

#### WARNER THEATRE

Erie Civic Music Assoc. presents Wyaland Pickard

and Deborah Johnson, composers and singer-pianists in concert @ 3pm today. Ticket info @ 814-864-5681.

March 24

#### EXPERIENCE CHILDREN'S MUSEUM

Easter Theme Crafty Corner today (10am-Noon) and March 27<sup>th</sup> (12:30-2:30pm). Reservations & info @ 814-453-3743.

March 27

#### WARNER THEATRE

Erie Phil Pops presents "That 70's Show" with the music of Abba, Bee Gees, Jeans 'n Classics tonight @ 8pm. Ticket info @ 814-455-1375.

April 2

#### WARNER THEATRE

Erie Broadway Series brings the Riverdance Farewell Performances. Special shows April 2 & April 3 at the Warner Theatre. Ticket info @ 814-452-4857.

April 7

#### EXPERIENCE CHILDREN'S MUSEUM

Spring Fling for kids to explore plants, animals & thunderstorms (9am-Noon). Reservations & info @ 814-453-3743. [www.eriechildrensmuseum.org](http://www.eriechildrensmuseum.org).

April 14

#### WARNER THEATRE

The "Rat Pack is Back" in a spirited tribute to Frank Sinatra, Sammy Davis, Jr., Dean Martin & Joey Bishop. Show time & ticket info @ 814-452-4857.

April 16

#### ERIE PLAYHOUSE

The hilarious battle of the "Dirty Rotten Scoundrels" will entertain you. Performance tonight @ 7:30. More info & ticket info @ 814-454-2852. [www.erieplayhouse.org](http://www.erieplayhouse.org).

April 17

#### EXPERIENCE CHILDREN'S MUSEUM

Children will be Going Green to help the environment (9am-Noon). Reservations and info @ 814-354-3743. [www.eriechildrensmuseum.org](http://www.eriechildrensmuseum.org).

April 23

#### WARNER THEATRE

Enjoy "Sesame Street Live" at the Warner Theatre. Show dates are: April 23 @ 7pm; April 24 @ 2pm & 5:30pm; April 25 @ 2pm. Ticket info @ 814-452-4857.

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# **FAMILY SUPPORT SERVICES**

The Dr. Gertrude A. Barber Center, Inc.  
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