

COUNCIL CONNECTIONS

Issue #1

December 2004

COUNCIL CONNECTIONS RETURNS



The New Council Connections - Online

Council Connections is returning. At the meeting to revise Council Guidelines, it was decided that Council Connections would return. We want to keep Parent Mentors connected and informed about what is going on.

The planned format for the new Council Connections will mainly highlight regions, showcase agencies, and share successes. Sharing resources will remain a top priority of the newsletter, and you can expect a few surprises too!

The big difference is that the newsletter will be online now. Parent Mentors will get an e-mail letting them know when a new issue is “hot off the presses” with a link to the newsletter. Council members will make sure that anyone in their region who doesn’t have Internet access gets a copy.

The success or failure of this newsletter will depend on the support it receives from all the Parent Mentors. If you want more information on anything, resources you want to share or anything else, please contact me at pat@linkhornllamas.com or call me at 740-439-3558, ext. 30 (work) or 740-638-5041 (home). A few people can write the newsletter, but the contents need to come from the readers. **LET’S MAKE THIS WORK!!**

BCMh NURSES – A GREAT RESOURCE

The Bureau for Children with Medical Handicaps has nurses in every county in Ohio. The mission of the Bureau for Children with



Medical Handicaps is to assure, through the development and support of high quality coordinated systems, that children with special health care needs and their families obtain comprehensive care and services which are family-centered, community-based, and culturally sensitive. BCMH is a state-

administered program which operates within the Ohio Department of Health. The Bureau receives funding for services from the federal Maternal and Child Health Block Grant, state general revenue funds, county tax funds, third party reimbursements, and donations. The Bureau promotes early identification of children with handicapping conditions and treatment of those children by appropriate health care providers. Major components of the program include: conducting quality assurance activities to

In This Issue

- [Council Connections Returns -1](#)
- [BCMh Nurses - 1](#)
- [Regional Review - 2](#)
- [Interview with Debbie Swinehart - 6](#)
- [Words from Lee Ann Derugen - 7](#)
- [Resource Review - 5](#)
- [Success Story - 6](#)
- [Ask Edna - 7](#)
- [Up & Coming - 8](#)
- [Suggestions - 8](#)
- [Logo & Photo Contests - 8](#)

BCMH Nurses - continued

establish standards of care and to determine unmet needs of children with handicaps and their families; funding services for the diagnosis and treatment of medically eligible conditions; collaborating with public health nurses and local health departments to assist in increasing access to care; supporting service coordination for children with selected diagnoses; and assisting families to access and utilize appropriate sources of payment for services for their child.

Many Parent Mentors have working relationships with the BCMH nurses in their communities. A BCMH nurse can be an invaluable resource at IEP meetings when a child has a unique disorder that the school may not be familiar with. They can help explain a child's limitations due to certain illnesses and conditions and offer insight on physical capabilities.

BCMH nurses can be contacted through your county Health Department. For more information contact the:

Ohio Department of Health
Bureau for Children with Medical Handicaps
246 North High Street
P.O. Box 1603
Columbus, OH 43216-0118

Telephone: (614) 466-1547

Fax: (614) 728-3616

E-mail: BCMH@gw.odh.state.oh.us

[Return to Index](#)

REGIONAL REVIEW - NORTHWEST

The Northwest Region is one of the smaller regions. They have ten mentors in their region, which accounts for about 9% of the mentors in Ohio. Do you know which region has the highest percentage of mentors and which one has the lowest? (You'll find the answer somewhere in this newsletter, in case you're curious.)

They cover the following counties: Williams, Fulton, Defiance, Henry, Wood, Hancock, Allen, Mercer, Sandusky, Seneca, and Wyandot.

And now, in their own words...

LAURIE BETSCHER

I am very excited to be part of the Parent Mentor Project. I was hired into this position in August and am learning the ropes. My husband Jack and I have three children. We have 2 sons and 1 daughter. Our oldest son is 19 and attending college. Our 16 year old son is a sophomore in high school. Our daughter Meghan is our special needs child. She was born with a chromosome disorder called Pierre Robin sequence. We were indoctrinated into the world of special services through our local early intervention program at Blanchard Valley Center. This program was not only a blessing for Meghan but also for us. The networking we received helped us through a very frustrating and scary time. Meghan is now a first grader and is on an IEP for Speech. It has been very rewarding and fun to watch her blossom and her confidence level soar now that people can understand more of what she is saying. This is a far cry from the introverted toddler who needed to learn sign language prior to being able to talk.

In September of 2003, my life underwent some major changes when I was laid off from a position as a Juvenile Parole officer after 13 years. One of the many job duties in this position included integrating teenagers back into their home school districts after they were released from institutions. I sat through countless IEP meetings with school officials, parents and students. In reflection, I guess I was in effect, a type of Parent Mentor, at that time. I am confident that my personal and professional experiences will be a beneficial to the families and schools in Hancock County. I have developed the ability to emphasize with both parents and school officials. My lay-off provided me with the wonderful opportunity to be a stay at home Mom. Also, I got the chance to become involved in numerous school activities that I never had the time to do before. A child's positive school experience and appropriate education is extremely important. I am grateful to be able to work with families and educators to provide services to children who are sometimes overlooked and can "fall between the cracks".

JAN STEYER

I'm married to Leon and we have 8 children - 6 boys and 2 girls. Our youngest son qualifies me for the Mentor position - He has Downs Syndrome and is a senior in high school. He attends a multi-handicapped room at New Riegel High School, attends Senteniel Career center in Tiffin in a food service class and they work at Heidelberg College in Tiffin every day. A fantastic program. Our older kids live from Nashville, Kansas City, Portland, Flint, Port Clinton, Toledo and Alvada. So we travel and visit our 14 grandchildren (and their parents). Our family is blessed with 5 teachers, a psychologist, 2 principals so we have lots of help with educational issues.

JULIE GUNDY

I have been the Parent Mentor for 3 years now in Findlay. What a great job! Helping others and learning as you go is a great reward. With having 3 kids with special needs I understand the importance of having someone to do what we do!

Pat asked if we could share a bit about our families....my FAVORITE subject! I have got to have the best 3 kids anyone could ask for! In 1990 we were blessed with our daughter Chelsea. We didn't realize right away that she was going to have a challenging life. At about 6 months old the doctor suggests we start testing because she wasn't hitting milestones. We came up empty handed, no rhyme or reason for the delays. For years we kept up with PT, Speech and OT. At 3 years old she started preschool at Blanchard Valley Center. She melted hearts left and right. Now, 10 years later, she is still melting hearts!! Chelsea has been diagnosed with Cerebral Palsy. With this have come other health problems including seizures, thyroid issues, Growth Hormone deficiency, etc. Through all this Chelsea has amazed us at how strong she is. She has come out of everything with a smile on her face. She can't talk, walk, or take care of herself but you look at her and her face just shows how happy she is! Chelsea is a Daddy's girl and loves Barney! Chelsea is a Special Olympics Cheerleader; she loves to bowl and ice skate in our local S.A.B.A.H. (Skating Association for the Blind & Handicapped) Chapter.

Our middle son is Nicholas, 9, what a character. Since day one he has made us laugh! As with Chelsea though, we thought everything was fine until we noticed a speech delay. We had him evaluated at 2 years old and he started to receive OT & speech services. We thought he would catch up with his peers by the time he was in kindergarten (sound familiar) which he did make alot of improvement he still had some oddities about himself. We took him to several doctors and just this past year he was diagnosed with Autism. It took so long to pin him down because in so many ways he didn't fit the criteria yet in so many ways he did! One of Nic's strengths in his humor...this guy is hilarious! He can imitate comics with the best of them! Nic is also gifted in music. He started playing the piano in August and is buzzing through the books along with

teaching himself how to play a song just from hearing it a few times! Just recently, the school offered violin lessons so now he is playing that also. What a great kid!

Our youngest is Baby Gaige; yes I still call him my baby! Gaige was born with Agenesis of the Corpus Collusum. This is a rare genetic disorder in which he was born without the fibers that connect your right and left brain cells. There is no way of fixing this. You can actually live a normal life with this, however it is a spectrum disorder and the severity of mental retardation varies by person. Gaige is now 7. He has been receiving services since he was a baby and amazes us everyday! He started walking at 5 years old. We worked and worked with him and one day it just clicked for him and he literally started walking and hasn't quit since! It was the same with crawling. We pray everyday that one day speaking will happen. Gaige loves Elmo, he takes him everywhere. Gaige always wears a smile and will hug anyone who will let him. Gaige also ice skates in S.A.B.A.H. and has volunteers that are goo-goo about him!

A lot of people say the Brian & I "have our hands full" and I do agree but we love our kids and there is not one thing we would change because we would not be where we are or be as strong as we are if it weren't for our fabulous family!

LINDA KAYSER

I am a parent of two children - an adult son with an Autism Spectrum Disorder and a daughter who is a senior in college (Journalism and French major). Next year at this time and in an ideal world, both my children will be working in jobs that they love. My husband and I have just celebrated our 32nd wedding anniversary.

I have witnessed many changes during my ten years of working as Parent Mentor for the Allen County Educational Service Center. One of the most rewarding developments in the field of special education is the early identification and intervention for children with autism and related disorders.

I have learned that listening is sometimes harder than talking but is just as, if not more productive, to accept criticism if it is merited as a growth opportunity and to look for honorable intentions of both parents and professionals. I also realize that God put some people on this earth whose main job is to keep me humble.

KAY KONWICZKA

I guess I would like to share that I recently attended a facilitator's training on Fetal Alcohol Syndrome/Alcohol Related Neurodevelopmental Disorder. We are now organizing a six week training in Sandusky County to address the needs of parents and caregivers whose children have been diagnosed with FAS/ARND.

There are six modules for this training. Module 1 provides facts about the cause, prevalence, and primary disabilities of FAS/ARND as a basis for the rest of the classes. Module 2 includes a discussion on developmental stages comparing the progress of a typically developing child through the stages to that of a child with FAS/ARND. Module 3 is a sensory integration simulation and an introduction to coping skills. Module 4 moves to application of the information on brain dysfunction and behavior to developing appropriate strategies to address the behavior. Module 5 presents information and practice in another critical skill for parents: becoming advocates for their child. Module 6 covers a range of topics of interest.

The goal of this curriculum is that through knowledge, coping skills, and problem-solving practice, participants will be able to access resources, and develop and experiment with strategies to discover which are most beneficial in working with their child's current issues. The long term goal of the curriculum is to decrease the secondary disabilities associated with FAS/ARND.

I have three children, one of whom was identified as Specific Learning Disabled with Attention Deficit Disorder. He has been out of school for awhile graduating in 1998, served 4 years in the Marine Corps, and is working in a full time supervisory position. He is a success story.

I spend a lot of time in meetings with parents just so they know who I am and how I can be of service to them.

PAULA FREY

I am the Parent Mentor for Wyandot county schools, I have been a parent mentor for 10 years in Jan 2005. I have been married to Duane for 27 years and we have twins, Bryan & Melanie. They are 22 years old. Bryan has a learning disability. He works with my husband doing construction. He has his CDL license & operates the large equipment for Construction Services Inc. He lives at home. He is looking at building his own home soon. Melanie graduated from OSU in March of 2004. She has started at Purdue University this fall with a full paid scholarship to get her masters degree in Marriage & Family therapy.

Next Issue: A Look at the Central Region

[Return to Index](#)

RESOURCE REVIEW

www.onlineorganizing.com

This site has great tips on getting organized. There is a "daily tip", free newsletter and resources on organizing your home and office. Check it out!

www.autism-pdd.net The purpose of this site is to guide you to the key issues associated with autism spectrum disorders. It contains info on diagnosing and testing, working with professionals and IEP's.

www.childbrain.com This website has easy to understand info on ADHD and PDD/Autism. A great site for parents.

www.maapservices.org Looking for answers to questions about Autism, Aspergers and PDD? This site is full of great information related to these disabilities. You can subscribe to the Maap newsletter (there is a cost) and locate professional and parent supports by state.

www.schoolpsychology.net A great resource for Psychologists, Parents and Educators. Includes information on specific conditions, disorders and disabilities.

[Return to Index](#)

SUCCESS STORY

Jim is the son of Faith Harkins, Parent Mentor in the Southeast Central Region. Jim graduated from high school in 2001. He was identified as having cognitive delays and spent time in the regular classroom and the special ed classroom. Since graduation, Jim has had several jobs, but has expressed a desire to go to college. His BVR counselor tried to dissuade him from going to college, but Jim had his mind made-up. With the help of his mom, (imagine that!) they were able to persuade BVR to help Jim attend college. In the words of his mother, meet Jim Harkins.

Jim began attending Rio Grande College this fall. He says that he would like to be a high school History teacher, but we are not sure that is logical. We are just testing the waters right now. He is just taking the basic classes now: math, read and learn, intro to writing, freshman success and an art class. They told him next quarter he will begin to take classes that are more geared to his major. We really try to work closely with his advisor and the special class advisor.

Jim drives himself to class every day, which is a 45 minute drive. He would like to live on campus, but his father and I know that he does not manage his time, money, and eating habits well. Jim also has Type 2 Diabetes. We have tried to teach him about these things, but it is still quite a battle at home.

Jim has come a long way in his quest for going to college. I believe that the jobs he's had since graduation have helped him gain more responsibility. He can get himself up and to class on time if I'm not there. In fact, his attendance has been perfect. We are very proud of him. We're taking it one step at a time.

[Return to Index](#)

INTERVIEW WITH DEBBIE SWINEHART

The Parent Mentor Project first struck me as a group of women who cared deeply about special education services. The PM's were able to draw from their personal experiences, and knowledge of working in a district to assist parents, grandparents, and students in accessing the special education services available to them. Many of the PM's had worked through the "bumps in the road" and were able to lead new comers through the special education process.

As I got to spend more time with the Parent Mentors and work with the Coalition I noticed that many of the Parent Mentors were often "working through" difficult situations and trying to get things "resolved" or "settled down" between the parent and the district. After multiple conversations with Parent Mentors, the council, and OCECD we determined that we needed to provide more in-depth training for Parent Mentors so they could approach these difficult situations with additional skills in the area of listening and conflict resolution, along with increased confidence to compliment their present training. Thus, we now have the professional development piece. I believe over the next few years we will see an increase in the opportunities that Parent Mentors have to work with families to build a collaborative relationship with the district. The Parent Mentors touch many families throughout Ohio, and the potential to expand these opportunities will be supported through new training.

[Return to Index](#)

WORDS FROM LEE ANN DERUGEN

I am excited to continue working with the parent mentor network and the 2005 Parent Mentor Council. The council and the committees have been working very hard on the new action plan which they developed. I just reviewed the Professional Development Plans for each parent mentor. They have motivation and drive to improve their knowledge to be able to assist families of children with disabilities to the best of their ability.

I am proud of the dedication, passion and sincerity of the parent mentors to do everything they can to help parents through the special education maze. When you've experienced advocating for a person with a disability to receive the appropriate services they need, you want to help others to make it easier for them than it was for you. I also know because I continue to advocate for my brother's needs as his guardian. We have recently had separate meetings with the district representatives to help them understand the parent mentor role and answer any questions they have. They have said it was time well spent and very beneficial. I look forward to working with Debbie Swinehart, Educational Consultant, Office for Exceptional Children, 2005 Parent Mentor Council, mentors and their district representatives to continue to bring them together as a solid, knowledgeable group who supports Ohio's parents of children with disabilities.

[Return to Index](#)

ASK EDNA

Dear Edna,

I have been trying to figure out what type of shoes to wear to IEP meetings. Should I wear my comfortable, old loafers? Or maybe my new heels? Will I need my running shoes? I have a really nice pair of hiking boots too. What is the proper foot attire for IEP meetings anyway? I've heard that you should always dress nicely for these meetings so you make a good impression, but not once have I seen shoes mentioned! Please help!

Pedi-cally Clueless

Dear Pedi-cally Clueless,

You pose an interesting question. After extensive research, I've come up with some "Shoe Etiquette" for IEP meetings.

1. Comfortable old loafers are better left at home. If they are that comfortable, they are probably pretty old and they just might not smell too good.
 2. Heels are only acceptable if your husband is attending. It may be necessary to get his attention to shut him up if he starts to say something stupid.
 3. Running shoes are acceptable, especially if you plan on bringing up the need for a personal aide again. You may need to leave quickly.
 4. Hiking boots are also acceptable, especially if you think it's going to be a long meeting with some muddy waters to wade through.
 5. Most shoes are acceptable for IEP meetings. My personal advice is wear something simple with no big buckles or chains. If you end up sticking your foot in your mouth, those buckles taste nasty!
-

[Return to Index](#)

WHAT'S COMING UP?

Parent Mentor Council Meeting – January 26, 2004. Ohio School for the Deaf. The Council meeting will be from 10-noon. Amy Freeman and Bob Holl for the Reading sites will be there to work with us from 12:30 to 2 and Skills & Knowledge will meet from from 2-3.

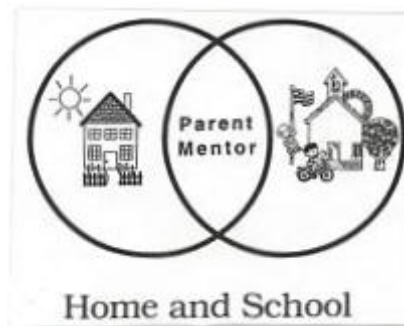
March Statewide Meeting – The Spring Parent Mentor Conference will be March 1 & 2, at the Embassy Suites in Dublin. The registration packet will be mailed the first week in January.

SUGGESTIONS

We're looking for a few good suggestions! Got any? What can we do to make you want to immediately read the newsletter when you get it? What information do you want and need? If you have any, we have a website for the Reading A-Z program where you can also post suggestions or voice your concerns. The address is: <http://www.thelinkto.com/reading/>

LOGO & PHOTO CONTESTS

The Northwest was the big winner all around when it came to contests. They won them both!



[Return to Index](#)

Council
Connections

Until the next time.....

** The Mideast is the largest region with 17 Parent Mentors (apprx. 17%). The East Central Region has 5 Parent Mentors which translates into about 5%.