

Valley Region Community of Practice in Autism Minutes April 22, 2009

Introductions:

Alisa Fernez, Mary Ellen Chewning, Amy Roy, Sherry Bouigeois, Cori Hill, Dianne Kootz Lowman, and Amy Russell-Yun.

Definition of Community Practice:

A Community of Practice is a group of people who share a concern or passion for a particular issue. The group interacts regularly to deepen their knowledge and expertise on the issue. The mission of our CoPA is to share knowledge and information about evidence-based strategies in natural environments, focusing on infants, toddlers, and young children diagnosed or suspected of having autism Spectrum Disorders. We will focus on guidelines for educating parents and professionals about effective strategies and using the strategies to meet IFSP/IEP goals. Our CoPA has been funded by the Department of Mental Health, Mental Retardation and Substance Abuse Services, the Part C Integrated Training Collaborative, and the Virginia Department of Education.

Goals for Our CoPA This Year:

1. develop our knowledge, skills and abilities related to autism
2. develop a resource list for families and providers
3. develop handouts of strategies and information about autism to give to families and other caregivers
4. develop an overall strategy/list of things to consider when working with a family who has a young child with autism
5. have our members who attend our CoPA be a resource to others in our communities who are unable to attend
6. develop strategies to balance research recommendations with the current practices in Part C and Part B, recognizing that placing the responsibility for intervention on the family can increase their stress to sometimes an unmanageable level
7. develop a network of support and information sharing among CoPA members that will exist between and beyond our CoPA meetings

Announcements:

1. Strategies for Supporting Young Children, Birth to Age Three, with Autism Spectrum Disorders will be held on May 4 and May 22 in Charlottesville, Virginia. This ~~two~~-day workshop will be conducted by

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Dana Childress and Carol Burke. Registration is \$30 per person. Register online at www.eivac.org.

2. Shenandoah Valley Autism Partnership is having a screening of “Ethan & Jennifer”, a film by Jo Sittenfeld at Court Square Theater in Harrisonburg on Thursday, May 21st at 7pm. *Ethan and Jennifer* follows two children on two very different points of the autism spectrum, and it provides an intimate and honest glimpse into the lives of their families as they tackle everyday life. The event is free and open to the public.

Review of Past Meeting Notes:

Dianne Koontz Lowman reviewed the minutes from the first CoPA meeting on March 25th. Mary Worley, from the Matthew’s Center, presented on Applied Behavioral Analysis. The following resources were recommended,

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Children and Autism: Time is Brain (2004). Aquarius Health Care Videos, Sherborn, MA.

This 28 minute documentary featured two families faced with the challenge of raising a child with autism. Discussion included identifying the signs and symptoms of autism and Applied Behavior Analysis. The DVD can be purchased at <http://www.disabilitytraining.com/caad.html> .

The VB-MAPP Set: The Verbal Behavior Milestone Assessment & Placement Program.

The VB-MAPP by Mark L. Sundberg, PhD, BCBA is an assessment tool, curriculum guide, and skill tracking system that is also based on established developmental milestones, and research from the field of behavior analysis. The VB-MAPP provides a clear and accurate picture of an individual child’s abilities, as well as potential language and learning barriers that may be hindering progress (<http://www.avbpress.com/vbmapp-set.html>).

Agenda:

1. What is “Infant mental health”?

Amy Russell Yun from James Madison University Occupational Therapy Program presented “Infant Mental Health”. See attached slide set.

Amy also reviewed, “Sensory-Motor Preference Checklist (For Adults), taken from,

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William, MS, & Shelenberger, S. (1994). "How does your engine run?": A leader's guide to the alert program for self-regulation. Albuquerque, NM: Therapy Works.

and . . .

| Sensory Processing Disorder Checklist, which has sections broken down into an infant/toddler checklist, pre-school checklist, school age, and adolescent/adult. <http://.spdfoundation.net/library/checklist.html>

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| **2. Problem of the Month: How can we reduce the behavior of head banging?**

| Amy emphasized d the importance of ruling out medical problems first.

We also reviewed the following handout on head banging,

Head Banging

While head banging looks frightening, it is important to remember that it can be part of typical development. According to Dr. Greene, up to 20 percent of healthy children are head-bangers at some point in time. Typically, head banging appears in the latter half of the first year of life and generally ends spontaneously. All infants are rocked by their mothers when they are carried about in utero. Later on, they enjoy being held and rocked in parents' arms. For some children, head banging is a way to release tension and prepare for sleep. Some kids head-bang for relief when they are teething or have an ear infection. Some kids bang their heads out of frustration or anger. Head banging can be an effective attention-seeking behavior. The more reaction children get from parents or other adults, the more likely they are to continue this habit (<http://www.drgreene.com>).

Head banging may give a child who is hyposensitive the sensory input he needs to wake up his system, while it can calm the child who is hypersensitive to sensory input. Lindsey Biel and Nancy Peske (2005) suggest the following ways to approach head banging:

- Check for an ear infection, vision problems, headache, or teething. In rare cases, this behavior could be the only noticeable sign of a seizure. Talk to your pediatrician.
- Talk to your occupational therapist about the sensory input the child might need to provide in a sensory diet.
- Speak to the OT about using a weighted hat.
- Give the child something to suck or chew on (depending on the child's age) before going to bed.
- Pull the crib or bed away from the wall and place it on a thick rug. Use a padded crib bumper, securely attached, that goes all the way around the crib.
- Encourage your child to push her head into a pillow or bean bag chair.
- Massage her face with your hands.
- Let her push items with her forehead, such as a pillow-filled box or a dust mop across the floor.
- Playfully push your child over with your hand against his forehead as he sits on a soft surface, such as a bed, cushion, or large pillow (pp. 155-156)

Biel, L., Peske, N (2005). Raising a sensory smart child: The definitive handbook for helping your child with sensory integration issues. New York: Penguin Books.

3. What is our meeting schedule for the remainder of the year?

The Valley CoPA will be held on the 3rd or 4th Wednesday of every month, from 1:00 to 3:00 pm at the Verona Government Center. A distribution list was obtained from last year's CoPA; announcements and invitations will also be distributed to the Shenandoah Valley Autism Partnership distribution list.

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1. Completed March 25th, Applied Behavioral Analysis, Mary Worley of the Matthew's Center
2. Completed April 22nd, Sensory Processing Disorder and Infant Mental Health, Dianne Koontz Lowman and Amy Russell Yun, OT
3. Scheduled May 20th, Video Modeling, Sally Chappel, T/TAC

The following topics were suggested for future CoPA meetings:

1. Developmental Pediatrician
2. Biomedical Intervention
3. Alternative Therapy-Music therapy, Art therapy, RDI, therapeutic horseback riding, etc . . .
4. Medicaid Waiver
5. How to support the family that is first diagnosed?
6. How to support other siblings in the family
7. Social Skills

4. How can we increase participation at CoPA meetings?

The following needs assessment was sent out,

Dear CoPA Members,

We need your help. Attendance at the CoPA this year has not been at the same level as last year, and we would like to know why. Please take a moment to answer the following questions.

I am not coming to the CoPA because:

___ I cannot leave work on Wednesdays. What day of the week would be better for you? _____

___ I cannot leave work from 1:00-3:00. What time would be better for you? _____

___ The location in Verona is not convenient for me. What would be a better location?

___ The topics have not meet my needs. What topics would be of interest to you? _____

___ I will not be able to attend any CoPA meetings this year.
Why? _____

Other comments or suggestions?

Thanks so much for your help! And thanks to all of you that have attended a CoPA this year!

Karen S. McCormick

The following things will be implemented to increase participation at CoPA meetings:

- Reminders of the meeting will be sent out every week
- Everyone will be invited 15 minutes early for snacks
- “Door-prizes” will be given out. Small items, such as books or sensory equipment that can be used with families.
- Water bottles and candy/gum will be provided for snacking during the meeting (You can’t have food in the room we currently have reserved).
- If possible, we will reserve the room upstairs in the Verona Government Center, so we will be able to have food throughout the meeting.

5. Is there anyone that would like to be on the CoPA Leadership Team?

The following people will serve as the leadership planning team:

- Karen McCormick-Parent and President of Shenandoah Valley Autism Partnership
- Dianne Koontz Lowman-James Madison University, Region 5T/TAC, Early Intervention Coordinator
- Alisa Fernez-Parent
- Kelly Peters-Valley Service Coordinator
- Cheri Knick-Speech Language Pathologist, Infant and Toddler Connection of the Rockbridge Area

6. Thanks to Alisa Fernez who provided snack for this CoPA.

Karen McCormick and Kelly Peters will bring snacks to the next meeting

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7. Is there anyone that would like to take minutes at the next meeting?

8. Activity Evaluation

An evaluation will be completed at the end of every CoPA meeting

9. Certificate of Attendance:

All members received a Certificate of Attendance

The next meeting will start at 12:45 on May 20th, 2009 at the Augusta County Government Center in Verona!