



ONTARIO ASSOCIATION FOR FAMILIES OF CHILDREN WITH COMMUNICATION DISORDERS

O.A.F.C.C.D. NEWSLETTER

Spring 2006

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OAFCCD Annual General Meeting **Erinoak** **Mississauga, Ontario** **Saturday, June 3rd, 2006**

The Annual General Meeting for the Ontario Association for Families of Children with Communication Disorders (OAFCCD) will be held at Erinoak, North Sheridan Site, in Mississauga. The event will feature a morning workshop, *Parents As Partners, Communicating For Success*, and the formal business meeting and a planning session in the afternoon. (See the enclosed invitation for more details.)

Paid members of OAFCCD are entitled to vote at the business meeting. If you are unable to attend, please sign the enclosed Proxy Form and mail or fax it to the office. As we look to the future of the organization, we would also appreciate your thoughts and ideas about the services and supports that you value or that we should consider providing in the future. Please call Alison Morse at 519-842-9506, or e-mail abmorse@kwic.com with any ideas that you would like to share.

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- 2006 Summer Camp Directory

Calling for Help

Making Effective Phone Calls About Your Child

- Always know with whom you are talking. Keep a note of the name, and the date and time of call.
- Identify yourself and specifically state the purpose of your call.
- Be prepared to offer basic facts about your child which are relevant to the agency you are calling.
- Have records available (with identification numbers, dates, etc) and encourage immediate action.
- Be goal-orientated. Know exactly what you want. Focus on your goal until it has been achieved.
- Be direct and confident, yet positive and polite.
- Convey a sense of cooperation. For example, "How can we work with each other?"
- If you are not satisfied, ask who else you should contact.

*(Source: Presentation by Lynn Ziraldo,
Learning Disabilities Association of Ontario.)*

Learning to Communicate with Children who have Autism

A Mother's Story by Rose Russo

Many people offer differing views about autism and all of its features. It is very difficult to speak about it in a general way as it manifests itself so uniquely in each individual. However, there is universal agreement as to its dire effects on communication and social development.

My son, Felice, and daughter, Cristina, both have autism, and although they do not talk, they can certainly communicate.

I would credit a great deal of their desire and ability to communicate, as well as their understanding of the world around them, to the use of pictures, both within the Picture Exchange Communication System (PECS) and outside of it.

I would suggest to any parent that communication become from the very beginning the number one priority and that it remain so, beginning with simple requests for favourite activities and foods and evolving into basic social conversation using a combination of tools. I recently returned to "More than Words" by Fern Sussman. This book, and the workshop that accompanied it, was our earliest and best resource at a time when we were reeling from a first diagnosis, with a second imminent. My only regret is that I put it away during the turmoil, confusion and the influx of torrents of incoming information and professionals which followed. My experience has since shown me this book is gospel and it is back on my kitchen table for constant reference. (Reference: *More than Words: Helping Parents Promote Communication and Social Skills in Children with Autism Spectrum Disorder*, Fern Sussman, 1999 ISBN: 0 – 921145-14-4)

The other difficulty that has occurred is in the many assumptions that accompany a discussion about autism. That individuals with autism are not interested in "socializing", that the prospects of speaking diminish greatly with age. The course of brain development with autism remains largely unknown. I find that the "developmental timetable" is different, some areas may not fully develop, but much is

happening that our eyes cannot discern. Your children are life-long learners as we all are, needing and wanting friendship. This has become most evident. The importance of early intervention is critical, most definitely, however, we should not allow our expectations and momentum to lapse at any age.

We have tried very hard to achieve vocal language. We have discussed phasing out the use of PECS, however, I do not believe that the use of PECS impedes language development rather quite the opposite. My son has identified oral motor planning issues, my daughter significant sensory integration challenges. They do not do well with verbal imitation approaches and PECS has enhanced their understanding of language. It is the only way that they can communicate. My children enjoy the power that it gives them and it has motivated them to do more. It has also allowed us to work on other skills like joint attention and turn taking.

Communication is very complex and a large component is non-verbal. I would argue that in the earliest days after diagnosis, PECS and pictures enhanced quality of life in a way that other interventions could not do at that time. If anyone suggests to you at any time to start phasing PECS out I would suggest to you that that decision should be made in consultation with a Speech – Language Pathologist. If an Occupational Therapist has been involved, you should consult with that professional as well. We have found in the past that when use of PECS is reduced there is a return to pointing and whining to communicate, frustration and aggression.

We are now struggling with 2-way communication using PECS. By this I mean using it when teaching lessons, playing games and asking questions. We are just embarking on this and it is tricky. We regret that we did not review and update PECS religiously. Now we are struggling to "catch PECS up" and work on its use for social communication and behaviour goals and it is too much. We also did not ensure that it became portable and available at all times and are now doing so. We worried that the children would not understand symbols but in fact they learn the association very, very quickly. Once the symbol was paired with concrete experience the association was learned in a single "trial". Their memories are remarkably strong and this should be used to advantage.

The main point I would like to stress is that both children are trying harder now to say words than they ever did. PECS is the communication medium and I believe, also a visual prompt for words.

To a child who has problems with auditory processing, word retrieval problems and maintaining attention, a picture is a fixed message not a transient message, easier to understand and to learn. The problems with speech and language development in the brain are far from understood. Work with your child's strengths and not your expectations or a timeline imposed by anyone but your child. Use whatever you have to to achieve communication at all times. If some signs are needed in the community, when pictures are not available, use them. Remember also that language has context, associations, and sometimes "double meanings". It is difficult to expect that our children, with all their challenges, can learn language verbally alone. Remember also, that the problems with social development greatly impact language development as well.

I really like the process of "hands on" learning with my children. The more they use their hands, the better they learn. With PECS they are learning the structure of language and "assembling" it. I am now considering whether we should view picture communication as tool for use throughout life, in tandem with an augmentative communication device, some "power signs" and yes, some words, which I believe will come.

The last point relates to the basic idea of turn-taking in communication and this point is very important. As the children age, I am concerned about speaking for them in important matters. They become more frustrated in being unable to control their days. I am unfortunately, a prolific talker (somewhat ironic) and I am becoming very attuned to the fact that I must defer to the children more often, not less, as they get older. We must have conversations as everyone does, about our day and I must be able to discern from them what their choices would be. They must have the tools they need to do this and I must insist that they "take their turn". This implies that communication for them will be mandatory, autism or no.

Autism remains the same enigma to me that it was five years ago. It continues to defy definition and

understanding. While I can neither alter nor control it, nor can I separate it from my children's identity, I can control my response to it. I will be the parent I wish to be, expecting my children to work hard, to face life with courage, and to relish the fleeting moments of joy as they arrive. They will have to work hard to carve a life from their difficulties but "carpe diem" will be the order of each day.

It is not "seeing is believing" but "believing is seeing" for me. It is my job to believe and to teach others to do the same. Let this be the foundation of your life with the individual with autism and it will light your way through it.

What is PECS?

The Picture Exchange Communication System (PECS) was developed to allow children and adults with autism and other communication deficits to initiate communication. With the PECS system, learners use picture symbols to communicate instead of words. Many parents and professionals believe this system can successfully lay the groundwork that leads to using verbal language. PECS has received worldwide recognition for focusing on the initiation component of communication.

Useful Resources:

Free PECS cards Lots of free visuals that you can print off at www.trainland.tripod.com/pecs.html

Pyramid Educational Consultants Inc. An American based company, considered by many as the premier source of training for the Picture Exchange Communication System at www.pecs.com/

Four Points Inc., a Canadian company with an online store offering picture cards, weighted vests and other products and materials at www.fourpointsinc.com/

Use Visual Strategies An online resource providing books, products and information on using visual strategies to improve communication at www.usevisualstrategies.com

Source: The Autism Society, Toronto Chapter Website at: www.asotoronto.org/treat_PECS.htm

Tell Me A Story: Developing Your Child's Language Through Storytelling

WHAT is Storytelling?

Storytelling has existed for thousands of years, long before writing and books. Telling a story is different from reading a book: it is a creative, interactive event that makes connections between people of all ages. It is a wonderful way to teach life lessons and learn about each other.

WHY Tell Stories?

Storytelling helps children develop all communication skills:

- Listening and understanding
- Imagining events when hearing about them
- Building vocabulary, grammar, pronunciation
- Putting thoughts into words
- Putting events into order
- Reasoning and problem-solving with language
- Imagining and creating
- Understanding and talking about feelings

WHO can tell stories?

Anyone can be a storyteller! Encourage all family members and friends to tell stories with your child.

WHEN and WHERE to tell stories?

Anywhere, anytime – at the kitchen table, at bedtime, in the car, on the bus, when you are out for a walk, at family gatherings....whenever you are together!

HOW do I tell Stories?

Tell Stories about your family.

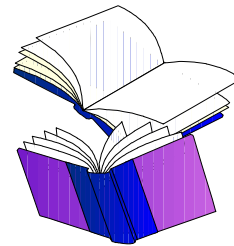
This helps children understand where they've come from and who their ancestors are. Ask other family members and friends to share their stories as well.

Tell your child a story about your day.

Talk about what happened today, and what may happen later. This will help your child learn to talk about the past and the future using correct grammar and sentence structure.

Incorporate books.

Tell a story first without the book, and then read the book. This helps to link stories with print. You and your child can also re-tell or act out a story from a familiar book. Use toys, old clothes, puppets, or anything you can think of to help act out the story.



Whenever you are telling stories:

- Make sure that both the storyteller and the listener are actively involved
- Use words like first, next, finally
- Include all the parts of a story:
 - Who was in the story?
 - Where did it happen?
 - When did it happen?
 - What was the problem?
 - What was the plan?
 - What happened?
 - How did people feel?
 - How did it end?
- Play with language: incorporate rhymes and nonsense words, use words from your culture, try different voices or accents
- Encourage your child to help tell the story – especially the repetitive or very familiar parts
- Connect things that happen in the story with your family's experiences
- Tell stories in the language you are most comfortable speaking
- Most of all, have fun together!

Make up pretend stories together.

Take turns adding to the story. Use your imaginations! Record your stories and your child's stories with a tape recorder so you can listen again and again. You can never tell the same story too many times!

This article has been re-printed with permission from the Toronto Catholic District School Board, Parent News, Full Day Senior Kindergarten, Issue No. 2, January 2005.