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EDUCATIONAL SUGGESTIONS FOR CHILDREN WITH ACC: A BEGINNING

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In our work with The ACC Network, Gary and I receive many phone calls and email messages from parents, teachers, and therapists seeking a list of educational approaches which will foster learning in a child with ACC. As a mother of a child with ACC, I can certainly appreciate the desire for such a list. This is precisely what I was looking for when I started my ACC search almost 14 years ago when my son was diagnosed with this condition. However, as a researcher, I recognize my reluctance to create a list. We simply do not have the "hard data" on which to base such a list. Our current work with a group of neuropsychologists will lead, I hope, to more definitive data as to what can be done to help people with ACC educationally. In the meantime, here are some suggestions I came up with when an educator recently pressed me for some educational recommendations. These are based on my experiences with my son Matt who is now almost 23 years old and on communication with hundreds of families of school-aged children with ACC over the last ten years.

Neuropsychological Testing: If I were in a position of advocating for Matt in the public schools at this point, I would urge the school to have a neuropsychological evaluation done. We found such an evaluation to be

invaluable in terms of giving us some concrete suggestions for the teachers working with Matt. My only regret is that it took us until Matt was 15 to figure out that that would be helpful. In our case, after the testing was completed, Gary and I first had a session with the neuropsychologist to go over the results and ask questions. Then we had the neuropsychologist attend a PET (pupil evaluation team) meeting to go over the results. We video-taped this session so that the video would be available for his current teachers to review and new members of Matt's team to view as they started working with him. The school paid for all of this as part of his triennial review.

Occupational Therapy and Speech-Language Therapy: I would also confer with an occupational therapist concerning sensory integration issues and a speech-language pathologist to work on pragmatics. Individuals with ACC typically are weak in these areas.

Nonverbal Learning Disabilities: Some parents of children with ACC have found the information on Nonverbal Learning Disabilities (NLD), in particular the work by Sue Thompson to be very helpful. In case you are not familiar with the term "Nonverbal Learning Disabilities," it does not refer to people who are nonverbal necessarily

but rather to people who have difficulty reading nonverbal cues. The researchers in this area include ACC as one of the conditions which can lead to NLD. Some parents of children with ACC have been ecstatic when they read the NLD literature because they feel it is the first material they have come across that really addresses the issues, particularly learning issues, of their particular child. Other parents, however, are not so sure that the issues for those with NLD completely match the learning issues experienced by those with ACC. Sue Thompson's book The Source for Nonverbal Learning Disorders (\$37.95, East Moline, IL; LinguiSystems, 1997, ISBN 0-7606-0163-1) has been a helpful resource for some parents and teachers. Call 1-800-PRO IDEA to get more information about this book. Here is the url for an article on the internet on NLD in case you would like to check into it further:
www.ldaca.org/gram/thompson.htm

Also, in the book by Byron P. Rourke entitled Syndrome of Nonverbal Learning Disabilities (New York: Guilford Press, 1995, ISBN 0-89862-155-0), there is an appendix entitled Treatment Program for the Child with NLD. In the appendix, Rourke lists 17 general suggestions for working with children with NLD. Although this list is very general, it may provide a useful beginning point in terms of looking at educational issues for a child with ACC.

Here are some specific observations concerning learning issues for people with ACC:

* Typically children with ACC do not handle changes in their routines well. Anything that parents and teachers can

do to prepare the child for routines to be followed or changes in schedule can be very helpful. One kindergarten teacher included photographs of all the different teachers a child with ACC might encounter during the course of his days in school including the music teacher, the gym teacher, the librarian, the lunch room personnel, etc. Each day the teacher included a review of these photos in the order the child would encounter them for a particular day. The teacher found that adding this to her routine greatly helped the other children in her class as well as the child with ACC.

* Children with ACC may also benefit from pre-teaching to help them cope with new material when it is introduced in the classroom. One father wrote the following concerning the benefits of preparation for his son with ACC who was in elementary school underscoring the importance of communication between the parents and teachers: "We are adamant about keeping the lines of communication open with his teachers. We send a notebook back and forth in his backpack every day. We document information they need to know, and the teachers write how well (or poorly) he has done that day. Our best proactive measure has been to have them send whatever is coming up the next day home in advance. We read the stories to him and go over what the day will consist of with him both the night before and at breakfast. It seems to help him a lot to know what will be happening during his day, and have some exposure to it before hand. All of this causes extra work for the teacher and you, but it has been well worth it for us. Fortunately, we have truly caring, wonderful teachers who are willing to really work with us."

* People with ACC often have difficulty with abstract reasoning (e.g., math, certain types of more abstract humor such as irony or word play) so new information needs to be presented as concretely as possible. It is also a good idea to test out different modalities. For example, a child with ACC may be able to take in information much more readily hearing it or seeing and hearing it on video than from someone telling him or her the information or reading it (even though the child can read).

* Repeatedly, parents and teacher report that children with ACC need massive amounts of repetition to learn new skills. Often it seems that they are not making any progress at all towards learning the skill and then "suddenly," they have got it. The message here for parents and educators is not to give up.

* People with ACC tend to absorb far more information than they can demonstrate to others in an educational setting by writing or verbalizing. Teachers need to be creative in finding ways for the child to show what he or she has learned. For example, a five-year-old child with ACC was asked to draw a picture of a man. He took a crayon and scribbled across the page. The teacher came to the conclusion that the child had no concept of what a person looked like. However, shortly afterwards when the child was provided different shapes of paper and pieces of masking tape, without prompting from an adult, that same child produced a face complete with eyes, nose, and mouth, and announced, "This is me." The child clearly understood what a face looked like. He simply could not manipulate a crayon well enough to demonstrate his knowledge. Similarly a few years later,

this same child "wrote" "I LOVE YOU" with blocks without being prompted. His parents were startled by his skill in "writing" this message because at that point no one realized he could spell that well.

* Access to a computer can be essential for a child with ACC. The physical act of writing is much easier with a keyboard. Also, if good educational software is available, a computer can allow for massive amounts of repetition of skills and be fun at the same time. Presentation of information via video can also allow for the repetitions without wearing out the teacher in the process! Similarly, a calculator can be a critical tool for a child with ACC who is having difficulty with math. Using a calculator, the child can demonstrate a acquisition of the procedure for doing a math problem even when he or she is have great difficulty retaining math facts.

* We are finding that many children with ACC need specific social skills training. They don't read social cues well. Sometimes their facial expressions may present a mismatch with the information they are telling, for example, smiling when telling that a classmate's dog has died. As mentioned earlier, speech-language pathologists can help with teaching children the pragmatics of language and verbal social interaction.

* Some children with ACC benefit from having an aide in the classroom in addition to the teacher. Children with ACC often have difficulty sustaining their attention on a task, but with brief reminders and explanations of what they should do, they can keep going on the work at hand. It is difficult for a single

teacher to prompt the child continuously and still keep the classroom functioning as a whole.

* Parents, teachers, and therapists have noted that some children with ACC may fluctuate dramatically in terms of their ability to demonstrate that they have mastered certain skills or information from one day to the next. As one mother wrote about her daughter with ACC, "...their knowledge 'database' is ever changing. Today she can do it, tomorrow she can't, the next day old pro at it and the next, no clue." Quite a few parents have reported similar patterns with their children with ACC.

* Finally, I would urge all teachers and therapists working with children with ACC to be diligent observers of the child's learning patterns. Let the child be the guide to what works and what does not work. Many of us want to reach for a curriculum to tell us exactly what to do in working with our children, but as far as I know at this point such a curriculum does not exist.

This list is just a beginning. Others may have suggestions for additional recommendations. I welcome comments and reactions from others. Such communication among parents, teachers, and the children with ACC themselves will help us begin to create the definitive list of educational strategies that will help children with ACC maximize their learning potential.

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