

GETTING STARTED in ABA/AVB -- Long Version

This file is in the process of being created as a guide to getting started in ABA. Please note that the superscript numbers refer to appendices. Feedback and suggestions will be welcomed.
Reg Reynolds, 4 December 2001

Autism is what is called a Pervasive Developmental Disorder, one of a number of conditions which are given that general label.¹ It exists on a continuum (i.e., some autistic children are less autistic than others) and it is independent of intelligence (i.e., some autistic children are bright and some are "intellectually challenged").² Autistic spectrum disorders are characterized by deficits in language and social interaction, and by restricted, repetitive and stereotypical patterns of behaviour, interests and activities. There are no treatments which are accepted by everyone as "the" approach to use³, but the ABA (Applied Behaviour Analysis)⁴ approach to teaching language and social skills, useful in any condition for which precision teaching⁵ is required, seems to be meeting with considerable success.

See www.autism.com/ari/editorials/aba.html for an editorial about ABA by Bernard Rimland,⁶ founder and director of the Autism Research Institute⁷ (and www.autism.com/ari/dan.html for a reference to information about some of the medical treatments that have worked for some children.⁸). This editorial by Dr. Rimland is important for another reason as well: While an enthusiastic supporter of ABA, Dr. Rimland is opposed to the "ABA is the only thing that is any good" fanaticism of some/many ABA advocates; thus, his article helps to place this particular treatment method within the wider context of other helpful approaches to treating autistic spectrum disorders.

Some proponents of ABA have incorporated into their programs B.F. Skinner's⁹ writings about Verbal Behaviour,¹⁰ and these approaches are sometimes referred to as AVB.

For getting started in ABA (should you choose to do so, and you should):

1. Obtain a copy of "A Work in Progress" by Ron Leaf and John McEachin. This is standard ABA (Applied Behaviour Analysis) -- in this case, precision teaching via DTT (Discrete Trials Training). This is what is called "Lovaas-style ABA," named after Ivar Lovaas, the clinician who engineered the first successful scientific demonstration of an approach that would work with autistic children. At the moment, it is considered by many to be somewhat outdated, because of the advances introduced by Sundberg and Partington by their inclusion into ABA of Skinner's analysis of verbal behaviour (see the following book). In addition to being the current "ABA Bible," however, it contains extensive information on dealing with/unlearning the undesirable behaviours which so many autistic spectrum children have learned, i.e., teaching more acceptable behaviours to replace the unacceptable ones.
2. If at all possible, obtain the services of a consultant who is trained in ABA and, preferably, and ABA approach that incorporates B.F. Skinner's analysis of Verbal Behavior. Preferably also, hire a senior or lead therapist with this training. Either they or you will have to ensure that the therapists/teachers which you hire are adequately trained. The Geneva Centre, which is located in

Toronto but which, so I understand, conducts training in other locations as well, offers courses such as an "Autism Intervener" Certificate Training Program and a "Behaviour Management: A Positive Approach" Certificate Training Program. Although neither of these courses places any particular emphasis on Verbal Behaviour, they do provide a good foundation for working with the autistic spectrum disorders.

3. Obtain a copy of "Teaching Language to Children with Autism or Other Developmental Disabilities" by Mark Sundberg and James Partington.¹¹ IMO, it is essential that you have this book to work from. You should be able to obtain both of these books from Different Roads to Learning (www.difflern.com) or from Parentbooks, located on the south side of Harbord Street just east of Bathurst Street in Toronto. They are not cheap, but they are worth it. The current edition of Teaching Language to Children with Autism or Other Developmental Disabilities is actually the 7th version of a manuscript more than 25 years in the making, and it is based on research and experience accumulated during that time.

At the back of the book, there is an appendix providing important background information about Skinner's (1957) model of Verbal Behavior, as well as information from more recent publications related to this model.

4. The ABLLS ("The Assessment of Basic Language and Learning Skills" by Sundberg & Partington and available from them at www.behavioranalysts.com or from Parentbooks) is the schedule used for assessing functional language and is the basis for whatever program you develop to teach language. It is a more-or-less essential part of the whole process since, at any given point in time, it will tell you what your child has to be taught next. Like the rest of the books which I have suggested, it is expensive, but you might as well "bite the bullet" and get it and start using it to begin defining your communication goals for your child. All that will become clearer when you read Sundberg and Partington's book "Teaching Language" and the Carbone workshop notes referenced below.

With respect to the actual teaching, I understand that the Language Builder flashcards available from Different Roads to Learning (www.difflern.com) are worth it, even at \$150 U.S.

5. On the internet, go to <http://groups.yahoo.com> and subscribe to the DTT-NET group. In the archives of that list -- the "Files" section -- you will find notes written by Bridgit Platts for a workshop given by Dr. Vincent Carbone¹² (www.DrCarbone.net). It is called VB Intro notes.doc Download it and read it. It is provided here as part of Appendix 12, along with some comments on manding for information by Norrah Whitney (with the assistance of Jenn Godwin and others), ideas from Kelly Wiggins on high-intensity manding and, from Rhonda Miga (ramiga@earthlink.net), comments on "Workshops about DTT NET / Verbal behavior."

6. There is a new video available from www.behavioranalysts.com called "Teaching Verbal Behavior: An Introduction to Parents Teaching Language." According to the promotional literature, "This 50 minute video, narrated by Dr. Jim Partington, follows the first ten months of an intensive language intervention program conducted by the mother of Dani, a young girl diagnosed with autism. Dani's

progress demonstrates the importance of parents learning to capture their child's motivation, as we see Dani's family teaching her how to ask for items and activities that she enjoys ("mand" training). Dr. James Partington reviews the process for the identification of initial skills to be taught, and presents an analysis of effective teaching strategies.

Dr. Partington additionally describes the progression of a language-based curriculum that focuses on the development of specific expressive language skills and other basic learner skills. Through the development of these skills, Dani, like many other children with language delays, gradually becomes more able to learn from less structured teaching activities. With Dr. Partington's clear and systematic presentation, parents and professionals can learn the essential elements of programs like Dani's, designed to help children with language delays be successful participants in the learning process."

At approximately \$70 U.S.(including shipping), it isn't cheap, but it may be worth it to see how the experts do it, particularly given the emotional and economic costs of not getting it right.

7. You may want to get a copy of "Help Us Learn" by Kathy Lear¹³. This is a set of manuals, available through www.helpuslearn.com describing how to set up an ABA program -- ABA stands for Applied Behaviour Analysis -- which is the current standard for teaching autistic children and the approach adopted by the Province of Ontario in their IBI program¹⁴. Among other things, it contains information about recruiting teachers/therapists and obtaining required equipment/materials. As an example of the latter, it references (on page 8) the Flash Pro 2 CD_ROM's¹⁵ from which you can print flashcards for use in your ABA program.

This Help Us Learn material may not be essential but it can be very helpful, particularly if you are just getting started.

CONTINUING TO FINE TUNE YOUR ABA KNOWLEDGE

8. Subscribe to the Me-list, the main ABA discussion group. To do this, send an e-mail message to LISTSERV@LISTSERV.IUPUI.EDU and in the message section put: subscribe me-list Dr. Peter Zwack maintains the ME-list archives.¹⁶ Once you have joined the me-list, you can access the me-list confidential files which Peter has collected over the years. Go to <http://people.sca.uqam.ca/~sqa/prive/> (Use prive as the ID and george as the Password.).

9. Subscribe to the Autism list. To do this, send an e-mail message to LISTSERV@MAELSTROM.STJOHNS.EDU and in the message section put: subscribe autism This list is a bit too general for my taste, but it will give you a pretty good idea of the breadth of interests and/or approaches within the autism field.

10. Subscribe to the DTT-NET list. To do this, go to <http://groups.yahoo.com> and <Search> for DTT-NET and subscribe to it. DTT-NET, which stands for Discrete Trial Training - Natural Environment Training, is one of the main discussion groups concerned with teaching communication skills.

11. Subscribe to the Verbal Behaviour list. To do this, go to <http://groups.yahoo.com> and <Search> for VerbalBehavior and subscribe to it. This list is for discussion of ABA/AVB, or ABA with a verbal behaviour emphasis.

12. As soon as you can, attend a workshop by Dr. Vincent Carbone (You can find a schedule of his workshops at www.DrCarbone.net). You cannot help but catch his enthusiasm for the Sundberg and Partington materials and the value of a Verbal Behavior approach to ABA. One of the most inspiring things about Dr. Carbone's workshops is the "before-and-after" videos which he shows. This is a reminder that it will be very helpful to you to begin videotaping your child from the very beginning, if at all possible, so that you have a record of what is being accomplished as treatment progresses. This is important for a couple of reasons: (1) It is important because it is one of the best indicators of the effectiveness of whatever program is being provided for your child, and (2) It may become important for funding purposes.

13. Join your local Autism Society chapter/group. You will find that the other parents are exceedingly supportive and generous of their time and expertise to help you get started on a program for your child. For a list of Autism Society of Ontario (ASO) chapter presidents, see <http://www.autismsociety.on.ca/> or Appendix 17 (2001/2002).

14. Have a look at www.wrightslaw.com This is an American website, so the law regarding entitlement to education will be different than it is here, but it is a good start just the same.

If you happen to live in Ontario (where this file originated), you may want to get in touch with Lindsay Moir at Comhnadh Consulting, 92 Cumberland Crescent, London, Ontario, Canada N5X 1B6 (519) 660-0493. His e-mail address is l.moir@sympatico.ca if you would like to write to him. He is Ontario's expert on dealing with school systems in order to get the services which your child should be getting. And take a look at the Comhnadh website: <http://www3.sympatico.ca/l.moir/> and catch one of his workshops (regularly sponsored by one of the Autism Society chapters or by one of the learning centres) if you get a chance.

15. On the internet, go to <http://www.people.virginia.edu/~nak9k/signs/signindex.htm> Read what she has to say and download The Lexicon (sign images). You may find that you want to start using signing with your child. You don't have to learn signing all at once; all you have to do is stay one sign ahead of your child.

Another interesting but more expensive source of information about signing is the signing videos available through sites such as www.cerformedia.com. I particularly like this site because of their children's songs and their Christmas songs videos. They will even produce a song for you in sign language if you want them to.

16. A few more potentially useful websites are given in Appendix 18.

16. One of the books reference on the CTFEAT website referred to above is "Teach Me Language" by Sabrina Freeman and Lorelei Dake (SKF Books, Canada, 1996 and available

through Different Roads to Learning www.difflearn.com 1-800-853-1057). For a look at what one list participant (Norrah Whitney) has had to say about it, see Appendix 19.

17. "Shadow Syndromes," by John Ratey and Catherine Johnson, which is about "The mild forms of major mental disorders that sabotage us," quotes Lovaas to the effect that "Social ineptness is the definition of autism; it's the one thing all autistic children have in common. They don't have IQ in common, they don't have problems with emotional attachment in common. But they all have social delays." (p. 215).

Thus, you might pay particular attention to the Melinda Smith website (<http://melindasmith.home.mindspring.com>) because it is your gateway to information about teaching social skills. As you may surmise, language is important in socializing, but it is not always sufficient in itself. Sometimes, and probably more often than we would wish, social skills have to be taught directly. There are lots of social skills materials, but this stuff is even more basic and you should probably acquaint yourself with it.

18. You might also like to purchase a copy of "Making a Difference," the recent book edited by Catherine Maurice, Gina Green and Richard Foxx, especially for its chapters by Bridget Taylor on "Teaching Peer Social Skills to Children with Autism" and by Bridget Taylor and Suzanne Jasper on "Teaching Programs To Increase Peer Interaction." Dr. Taylor, Director of Educational Programming at the Alpine Learning Group in Paramus (Sorry; I don't know where Paramus is), under the aegis of FEAT of Oregon (<http://www.rdrop.com/users/feator>), taught a course entitled "Strategies to Increase Social Initiation." In Appendix 20, there is a description of it from someone (Melinda) who attended. It is given here to give you some idea of the strategies that Dr. Taylor would employ to teach social skills.

Another book about social skills which comes highly recommended and which you should consider purchasing is "Autism/Asperger's: Solving the Social Relationship Puzzle" by Steven Gutstein.

19. Paradox: Language Acquisition vs. Social Inclusion -- One issue that will need to be faced is what to emphasize in your ABA program. I *think* that the Verbal Behaviour approach is probably the most powerful habilitative/rehabilitative program to date for most children, but that it is also important that attention be directed toward social skills training fairly early on. Dr. Tony Attwood, author of "Asperger's Syndrome" (personal communication to Celeste Littek, March 16, 1996), highlighted this paradox/conflict that "although communication is of paramount importance to enable needs and wants to be expressed and met, so too is the well-being and self-esteem essential to learners' success through social inclusion."²¹

20. Don't forget about "Establishing Operations," those "operations" which you perform on the environment to establish the reinforcement value of a particular consequence of a particular child behaviour. Remember that the reinforcement value of any consequence varies from time to time (e.g., water is more reinforcing when someone is thirsty than when he is not), and remember to keep the reinforcement value of individuals (such as therapists and other children) in the child's life high by ensuring that they are frequently paired with reinforcement.²²

21. Have a look at <http://www.stanfield.com/index2.html> IMO, this is THE source for social skills videos (mainly because it is the only one that I know about). You may want to have your local Autism group order some of them for use by your children and adolescents.

NOW FOR A SOMEWHAT DIFFERENT PERSPECTIVE

22. For a different perspective on the whole process, go to the website of the Interdisciplinary Council on Developmental and Learning Disorders (www.icdl.com) and have a look at their Clinical Practice Guidelines, i.e., download it if possible. It isn't even sympathetic to the ABA approach, but it does contain a ton of potentially useful information, particularly as it is related to socialization within the context of therapy, and how social interaction with your child can become an excellent learning experience for him.²³

23. Because some autistic symptoms either result from or are exacerbated by food allergies and/or food sensitivities, subscribe to the GFCFKids list. To do this, go to <http://groups.yahoo.com> and <Search> for GFCFKids and subscribe to it.

For GFCF recipes, have a look at <http://geocities.com/danaatty/gfcfkids.htm>

Also, acquaint yourself with the writings of Bernard Rimland, one of the pioneers of autism research, and the "biological perspectives" point of view regarding autism, by exploring the Autism Research Institute's website, which you will find at www.autism.com/ari

And here are a couple of other gfcf (gluten free/casein free) websites which you may wish to explore:

<http://www.gfcfdiet.com/> (The name says it all)

<http://home.att.net/~pediatricaac/main.html> (Dr. Megson's gfcf, etc. website. You will find it quite informative.)

You might also have a look at the use of digestive enzymes in the treatment of autistic symptoms (which you can explore by subscribing to the [enzmesandautism](http://groups.yahoo.com) list on <http://groups.yahoo.com>) although, frankly, I don't find the discussions on this list very enlightening, probably because this is a relatively recent development and most people exploring the use of enzymes still seem to be stumbling around in the dark.

24. January, 1995, the Autism Research Institute (ARI) convened a group of about 30 carefully selected physicians and scientists in Dallas, for the express purpose of sharing information and ideas about defeating autism as quickly as possible. One major goal of this DEFEAT AUTISM NOW! (DAN!) Conference was to produce a document that could be used by physicians as a guide for the clinical assessment of autistic patients, leading to appropriate treatment. This document, representing a consensus statement of the state-of-the-art alternative medical approach to the diagnosis and treatment of autism, is now available through ARI. The 40-page manual is titled *Clinical Assessment Options for Children with Autism and Related Disorders: A Biomedical Approach* and costs \$25.00 (U.S. Funds). A list of DAN! Doctors can be found on the ARI

Website: www.autism.com/ari There are a couple of DAN-trained doctors in the Toronto area: Dr. Josef Krop and Dr. Rex Verschuren.

25. If you live in Ontario, get a copy of the Directory of Services for Individuals with Autism in Ontario (from the Geneva Centre for Autism, Toronto) and, regardless of where you live, get yourself a copy of the “Best Practices for Designing and Delivering Effective Programs for Individuals with Autistic Spectrum Disorders” document, which you can download from the California Departments of Education and developmental Services. My copy came from the following website (although, unfortunately, it doesn’t seem to work for me any more):

<http://www.bunt.com/~hageng/California%20Best%20Practices.htm>

26. Finally, as just one more step towards rounding out your understanding of some of the current thinking regarding autism, have a look at the Neuro Immune Dysfunction Syndromes (NIDS) Medical Advisory Board and Research Institute draft proposal of a neuro-immunology hypothesis concerning autism²⁴ and a related statement by NIDS Board Member, Dr. Michael Goldberg²⁵ of the Avalor Medical Group in Tarzana, California. NIDS dietary suggestions are given in Appendix 26.

Appendix 1

299.00 Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) qualitative impairment in social interaction, as manifested by at least two of the following:

(a) marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) failure to develop peer relationships appropriate to developmental level

(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) lack of social or emotional reciprocity

(2) qualitative impairments in communication, as manifested by at least one of the following:

(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

(c) stereotyped and repetitive use of language or idiosyncratic language

(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted, repetitive, and stereotyped patterns of behavior, interests,

and activities as manifested by at least one of the following:

- (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
- (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements)
- (d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

299.80 Asperger's Disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

- (1) marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
- (2) failure to develop peer relationships appropriate to developmental level
- (3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
- (4) lack of social or emotional reciprocity

B. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

- (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- (2) apparently inflexible adherence to specific, nonfunctional routines or

rituals

- (3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
- (4) persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific pervasive developmental disorder or schizophrenia.

299.80 Rett's Disorder

A. All of the following:

- (1) apparently normal prenatal and perinatal development
- (2) apparently normal psychomotor development through the first 5 months after birth
- (3) normal head circumference at birth

B. Onset of all of the following after the period of normal development:

- (1) deceleration of head growth between ages 5 and 48 months
- (2) loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (i.e., hand-wringing or hand washing)
- (3) loss of social engagement early in the course (although often social interaction develops later)
- (4) appearance of poorly coordinated gait or trunk movements
- (5) severely impaired expressive and receptive language development

with severe psychomotor retardation

299.10 Childhood Disintegrative Disorder

A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.

B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:

- (1) expressive or receptive language
- (2) social skills or adaptive behavior
- (3) bowel or bladder control
- (4) play
- (5) motor skills

C. Abnormalities of functioning in at least two of the following areas:

- (1) qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
- (2) qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
- (3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypies and mannerisms

D. The disturbance is not better accounted for by another specific pervasive developmental disorder or by schizophrenia.

299.80 Pervasive Developmental Disorder, Not Otherwise Specified

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific pervasive developmental disorder, schizophrenia,

schizotypal personality disorder, or avoidant personality disorder. For example, this category includes "atypical autism" --presentations that do not meet the criteria for autistic disorder because of late age of onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

Diagnostic and Statistical Manual, 4th Edition, ©1994, American Psychiatric Association

Appendix 2

Stedman's Concise Medical Dictionary for the Health Professions, 3rd Edition (1997) defines intelligence as follows:

- (1) An individual's aggregate capacity to act purposefully, think rationally, and deal effectively with the environment, especially in meeting challenges and solving problems.
- (2) *Psychology* An individual's relative standing on two quantitative indices, measured intelligence and effectiveness of adaptive behavior; a quantitative score or similar index on both indices constitutes the operational definition of intelligence.

Typically, "intelligence" is measured through the administration of an "intelligence test," while effectiveness of adaptive behaviour is measured through

Intelligence and I.Q. (Intelligence Quotient) testing are subjects of great importance to the autistic spectrum community for a couple of reasons:

First, a child's intelligence, as represented by I.Q. score, establishes a certain expectancy regarding learning potential, and expectancy plays a very strong role in determining achievement. Research has shown, for example, that if you administer an intelligence test to a classroom of Grade One children, divide them randomly into two groups and tell the teacher that one of these groups contains the more intelligent children while the other group contains the less intelligent children, the group which has been labelled as "more intelligent" will make an average of two years' progress in reading during the year while the group which has been labelled as "less intelligent" will make an average of half a year's progress during the year.

There are limits to what can be accomplished simply with expectancy, of course. If you tell the teacher that a normal child is brain damaged, the child will begin to function as if brain damaged. On the other hand, if you tell the teacher that a brain-damaged child is normal, the child will still function as if brain-damaged. On the other hand, that doesn't rule out the role of expectancy since the teacher may be using other clues to determine for herself that the child is brain-damaged.

Second, since society values reading and, to some extent, mathematics -- most jobs require a certain amount of reading and mathematics -- school tends to emphasize those two particular abilities, often to the exclusion of the 130 or so other abilities which people can have -- things like spacial and mechanical abilities, music, art, finger dexterity, verbal fluency, and so on. Because school tends to emphasize reading comprehension and mathematical ability, intelligence test (and particularly the older intelligence tests) tend to sample for performance in those particular areas; and if your child's strengths don't happen to fall into the areas sampled, his true potential may be misrepresented in the teacher's eyes, with the kind of expectancy effects described above.

Although newer intelligence tests sample a wider variety of achievements, they are still relatively specific to the kinds of abilities needed for success in the typical classroom; and that is all right given

that the school personnel are relatively sophisticated regarding the meaning of any test results which are obtained. Unfortunately, that is not always the case, and you may need to do advocacy work on behalf of your child which should actually be being done by the school.

Appendix 3

Effective Therapies for Autism and other Developmental Disorders

An article by [Lewis Mehl-Madrona, MD, PhD](#)

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Introduction

During my medical training, I learned that [autism](#) and its related disorders were essentially incurable, a finding certainly confirmed by our dismal experience. Our autism clinic was an exercise in diagnosis and no treatment; what little we did for children was largely ineffective. While we had come a long way from Bettelheim's refrigerator mother theory of autism (in which a cold, unresponsive mother was the cause of the condition), we were stuck in a genetic-biochemical hypothesis allowing no possibility for cure or improvement. We were confident that the unknown genetic defect was buried deep in the biochemistry of the brain. We were excused from searching for treatments, thereby leaving this crucial journey to the parents.

The parents of autistic children convinced me that everything I learned was wrong, to everyone's benefit. Freed from the fetters of training and pessimistic professors, I discovered that children with developmental disorders are interesting, and have rich social and communicative lives, though different from their so-called normal counterparts. Attentive parents naturally learn this secret language of their autistic children without even realizing this amazing feat.

Autistic children do communicate and do respond, but as if they live in a parallel universe, which can nevertheless be accessed by those who want to reach them. They respond to many [treatments](#), including just receiving attention and being cared for. They respond to [nutritional therapies](#) and body therapies, such as reiki or craniosacral therapy. They respond to acupuncture. They respond to biofeedback and to behavioral educational therapies. What don't they respond to?

Can autistic children become indistinguishable from so-called "normal" children? I have seen it happen sufficiently often to believe, though - in every case - the parents invested significant time and money to their child's treatment: far above what school systems and insurance carriers would have paid. To what can we attribute these successes? No one treatment seems to out perform all the others, and no clear signposts exist to tell parents what to do. Despite this, there are therapies with which I begin.

Nutritional Therapy

Nutritional therapies are first on my list. The [gluten-casein free diet](#) has helped many children and is where I begin. The diet can be difficult. Gluten, a major constituent of wheat, and several other grains, is hard to eliminate. Gluten can be found in soy sauce, for example, in the form of whey. Gluten can be found in the coatings of pills used for medicine. Eliminating dairy is almost as hard. Nevertheless, excellent cookbooks exist and are found on our [web site](#).

The theory behind gluten-casein free diet is based on the [opioid hypothesis of autism](#). In this hypothesis, defective intestinal enzymes (especially [dipeptidyl-dipeptidase IV](#)) allow large molecules to "leak" through the gut. Gluten, and the structurally related casein from dairy, are incompletely digested and pass through the gut as molecules with opioid-like properties. In larger doses, these molecules cause hallucinations. The effect of [opioid-like compounds](#) are, in part, the symptoms seen in autism, Asperger's, and other developmental disorders.

While the diet is difficult to follow, one month is usually sufficient to determine if following the diet will help. After one month, if any question exists, challenging the child with a grilled cheese sandwich on whole wheat bread helps to determine if symptoms will worsen after exposure to gluten or casein. Sensitive children become clearly worse after this meal. At least half of my patients improve significantly after starting the gluten/casein free diet.

Second on my list of interventions, after "GF/CF diet" or variants of it, is vitamin supplementation.

Vitamin Therapy

Enthusiasm over particular vitamins appears in waves. Recent candidates include individual B-vitamins (B6, B12, thiamin), vitamin A, and [essential fatty acids](#). Dr. Patricia Kane has promoted awareness of fatty acid metabolism among autistic spectrum children. Through BodyBio, she offers analysis of fatty acids on the red blood cell membrane to determine their relative levels. Fatty acid metabolism can be directed toward a pro-inflammatory state or an anti-inflammatory state, the former being worse for autistic children.

Supplementation with specific fatty acids (especially omega-3 and omega-6) can alter pro-inflammatory tendencies toward anti-inflammatory. While the details of fatty acid therapy can become quite intricate, three oils provide almost all of the compounds needed: evening primrose oil, borage seed oil, and marine lipids. We can broadly speak of an inflammatory theory of autism, in which nerve cell membranes are irritated and nerve transmission is affected. The inflammation can come from a variety of sources, including [viral infections](#), auto-immune phenomena (in which the body's immune system attacks its own nervous system), post-vaccine reactions, abnormal molecules in the nervous system (coming from the [leaky gut](#) and deficient enzyme activity in the gut), and abnormal fatty acid metabolism. The inflammatory theory can explain the role of some vitamins as anti-oxidants (preventing and reversing cellular damage from inflammation) and as direct anti-inflammatory agents (vitamin C, omega fatty acids).

[Vitamin supplementation](#) alters metabolism of the nervous system and provides an abundance of resources for healing within the brain. Getting children to take vitamins can be difficult, but can be overcome by blending vitamins into palatable drinks or by mixing the vitamins into foods that the children will eat. Stevia is a

sweetening herb that makes these concoctions more palatable without causing the adverse side effects sometimes associated with simple sugars. My basic supplement program includes vitamin C, trace minerals (vanadium, germanium, selenium, tungsten, tin, etc.), common minerals (zinc, manganese, magnesium, calcium), B vitamins (with extra thiamin, B6, and B12), vitamin A, evening primrose oil, marine lipids, OPC-3's, and vitamin E. Recent enthusiasm has centered around vitamin A followed by doses of urecholine. I have not yet tried the urecholine, but suspect that urecholine may not be the essential element of the treatment.

Pygmalion Effect

A major problem in autism treatment is separating what could be called the "Pygmalion Effect" from true biological efficacy. The problem is complicated by the possibility that true biological activity without an emotional and environmental context for a treatment doesn't really exist. The Pygmalion Effect is named after George Bernard Shaw's play in which a lower class, "uncultured" woman from the slums of London is trained to be a "lady," and becomes every bit as sophisticated as one born to this position. The effect has been demonstrated in elementary school classrooms. In the classic experiment, children's IQ's were measured and the children were ranked as higher or lower IQ. Teachers were told the opposite from what was found. High IQ children were presented to teachers as lower IQ. Low IQ children were presented to teachers as high IQ. One year later, the teachers' expectations were much more important in determining children's performance than their actual IQ. Knowing this, we could never ethically repeat this experiment, for we are so much more aware of how people's expectations for others determines performance.

A confounding problem in evaluating any therapy for autism, including vitamins, is this Pygmalion Effect. Because of this, many conventional physicians dismiss the potential value of alternative therapies in favor of pharmaceutical treatments. Drugs are always better studied than alternative treatments, because 1): they are easier to study, 2): more money exists to study drugs because of the potential profitability, and 3): it is more respectable as a researcher and a physician to study drugs.

Until sophisticated clinical trials are completed, any of the alternative therapies I will discuss could be explained partially or completely by the Pygmalion Effect. What is exciting about this is the realization that expectations can alter behavior. If parents expect strongly that their autistic child will improve, the child does. I am not afraid to try safe therapies that may only work because they activate this Pygmalion Effect. This type of healing is just as real as that produced by drugs, and probably much safer!

While we struggle to find biologically active treatments for autism, we cannot err too greatly by supporting parents' enthusiasm for safe, new treatments. We know from research on the placebo effect that an enthusiastic doctor whose patients believe in him or her has a 70% success rate regardless of the effectiveness of the treatment. An unenthusiastic doctor has only a 30% success rate with an ineffective treatment. Therefore, we should never discount enthusiasm.

I continue to believe that vitamins are an important part of treating autism, the above considerations aside. Nevertheless, the Pygmalion Effect may be very important in another popular therapy - that of [secretin](#).

Secretin

[Secretin](#) is a 27 peptide hormone, produced in the intestines, and commercially marketed as an aid to endoscopy. The interest in secretin began in 1996, when Dr. Karoly S. Horvath, director of the pediatric gastrointestinal and nutrition laboratory at the University of Maryland, Baltimore, administered intravenous secretin while examining an autistic child with chronic diarrhea. Several weeks later, the child's mother, [Victoria Beck](#), called with surprising news: her 3-year-old son, Parker, had started to talk and had good eye contact ¹. Subsequent infusions, obtained by the parents - against medical advice - led to further gains. Dramatic improvement has been reported for some autistic children who receive secretin. Typically a dose of 2-3.5 International Units per kilogram of body weight is administered intravenously every 3-7 weeks, depending upon the child's response and when the effects of the secretin appear to wear off. Victoria Beck switched to transdermal administration for her child in which the secretin is applied daily to the skin and soaks into the body through a vehicle such as DMSO. Typically a dose of 3 to 7.5 International Units is used each day.

[Dr. Horvath](#) and associates gave secretin while assessing gastrointestinal complaints in two other autistic children, and reported "a dramatic improvement in their behavior, manifested by improved eye contact, alertness, and expansion of expressive language," in the next several weeks along with relief of gastrointestinal symptoms ².

In December 1999, Dr. Bernard Rimland of the Autism Research Institute in San Diego, California, reported that one-half of 100 treated children improved in behavior, sleep, and/or digestive symptoms - based on questionnaires returned by self-selected parents.

In another series, 70% of 200 children responded positively, according to the treating physician, with a dramatic effect among 10%. These reports did not control for concurrent treatment, nor was diagnosis rigorously established.

The results of a randomized, controlled trial of one dose of [secretin](#) was reported in the New England Journal of Medicine's December, 1999, issue by Dr. Sandlin and colleagues. Children were randomized to receive either secretin in an appropriate dose or placebo. Change was measured on the Autism Behavior Checklist. Both placebo and treatment group improved equally over the course of one month. Opponents of secretin have used this study to argue that secretin is ineffective in autism. Secretin proponents have argued that the study was of insufficient length to draw serious conclusions and that important variables that change in response to secretin were not measured.

The Autism Behavior Checklist, for example, changes more slowly than one month. We administer it every six months. This study showed no adverse reactions to secretin, which was suspicious to me, since I see about 15% of children reacting to secretin infusion with increased hyperactivity or aggression. Reducing the dose or giving the secretin at longer intervals usually corrects this.

I have presented a case series of secretin infusions lasting over one year among 35 patients. About 70% of patients improved - some quite dramatically - again, a figure within the range of what could be expected with enthusiastic placebo. What is more remarkable to me is how much some of these children improved. If secretin is working only because of a change in parental expectations, we have good news. Such a finding could open a new awareness for the need to expect more from autistic children.

If secretin is not biologically active, then what do parents do who believe in secretin to foster such dramatic improvements in their child? Knowing this and being able to train parents in how to influence the course of autism would be as significant as finding an active biological agent. Unfortunately, the developmental disorders community tends to overlook behavioral therapies, much as most illness communities. We modern 21st century people are still searching for pills that will change everything. While autism may respond in this way, it is as likely that it is a complex illness that requires multiple, synergistic treatments, not all of which are biological.

Secretin may open the pathway for searching for other neurohormonal therapies that activate brain receptors. We know that [secretin receptors](#) are found in the brain, especially in the temporal lobe speech areas. Brain-imaging studies in one of Horvath's original cases showed a "marked" post-infusion increase in cerebral blood flow to these areas. Secretin may also activate receptors for a related hormone, vasoactive intestinal polypeptide or VIP, which is more widely distributed in the brain. Secretin also stimulates pituitary adenylate cyclase which increases intracellular [cyclic adenosine monophosphate \(cAMP\)](#), a messenger molecule for brain biochemical reactions. Opioid-like peptides are known to lower levels of cAMP. Perhaps secretin prevents this or replenishes the missing cAMP.

Lectins may also be important in explaining the mechanism of action of secretin. [Lectins](#) are molecules that bind to cholecystokinin (CCK) receptors and other glycosylated (meaning: attached to long-chain sugars) membrane proteins. CCK is another gut hormone with receptors in the brain. Lectins inhibit CCK-8-induced alpha-amylase secretion by the pancreas. This inhibition does not occur after administration of secretin.

There are two divergent opinions on secretin - one that high doses are necessary to obtain binding of secretin to receptors in the brain; the other, that only small concentrations are required. The final verdict on secretin is not

yet out.

Anti-virals

Returning to the inflammatory theory of autism brings us to anti-viral therapy. Proponents of [this theory](#) argue that signs of long-term or chronic viral infection exist among autistic children, and that treatment with anti-viral agents can improve autism. The most commonly used agent is Valtrex, though some also have used Zovirax, which is known best for its use in treating herpes virus infections. Some parents have even reported improvements in their autistic children from the use of [antibiotics](#).

At this time, I know of no trials that show true biological efficacy of anti-virals for autistic children. Nevertheless, we can't yet discount this therapy. It may also be that autistic children have immune defects and are more prone to chronic viral infections. Treatment of these viral infections could relieve some of the physiological stress of infection and result in an improvement.

Chronic illnesses (including autism) are so much more complex that most physicians would like to acknowledge. Once a disease process is started, effects follow upon many other organ systems. Even if viral infection is not the precipitating insult of autism, it may be important once autism is established, and treating chronic viral illness may be helpful. If this is so, however, it would only be helpful for those children who have a chronic virus.

There are risks to anti-viral medications, and there are herbal alternatives. Herbs boost the immune system instead of attacking the virus directly. Common immune boosting herbs include echinacea, astragalus, garlic, plant tannins, uva ursi, and berberis. These herbs can also treat [Candida](#), again by strengthening the immune system.

Immunotherapy

Regarding immunotherapy and IVIG, we know that autistic children have defects in their immunity, especially cellular immunity (the kind that involves the direct action of cells - opposed to humoral immunity which involves immunoglobulin molecules released into the blood stream). The white blood cells (lymphocytes, macrophages, natural killer cells) of autistic children can be sluggish and weak. Antibodies to brain proteins (especially myelin basic protein) are also more prominent among autistic children, suggesting an auto-immune process, in which the body is attacking itself. Autistic children show decreased activation of lymphocytes in response to mitogens (substances known to attract lymphocytes to stream into action) [3,4](#).

Other immunological abnormalities found among autistic children include weakened macrophages and natural killer cells [5,6](#), circulating auto-antibodies to brain proteins [7-9](#), and elevation of agents which activate immune T-cells (interleukin-2 and soluble CD8) [10](#), along with increased levels of other activated cells (DR+) cells [11, 12](#). (Plioplys et al., 1994; Warren et al., 1995).

Levels of substances which indicate excess immune activity directed at the self have been found elevated among autistic children. These include gamma-interferon, alpha-interferon, interleukin 6 and 12, alpha tumor necrosis factor and others.

Immunological studies of autistic patients have revealed features also found in patients with other autoimmune diseases. Autoimmune diseases, including Grave's thyroid disease, rheumatoid arthritis, and insulin-dependant diabetes, show some genetic predisposition. Similarly, autism is higher among identical twins than in the normal population. Autism is four to five times more prevalent in boys than in girls - a gender factor also found in other immune diseases, including systemic lupus erythematosus, Grave's disease, and ankylosing spondylitis.

Autoimmune disease may be triggered by infections with bacteria or viruses. In autism, coincidental findings indicate infections with congenital rubella and cytomegalovirus.

Treatment is more difficult. The most popular treatment is intravenous immunoglobulin G, given in varying

protocols. The most aggressive protocol gives the immunoglobulin approximately every other day, in progressively increasing dosages, starting at 1 gm/kg, and increasing to 5 gm/kg. The more conservative protocol begins with 1 gm/kg, increasing to 2-7 gm/kg at monthly doses. An intermediate intensity protocol is 5 gm/kg, administered monthly.

Several studies have shown benefit to treating children with immunoglobulin, though it is uncertain if all children would benefit, or only those with chronic viral infections, frequent bacterial infections, [fungal infections](#), or other immune deficiencies. Dr. Gupta at the University of California, Irvine, is conducting clinical trials on the use of immunoglobulin therapy for autistic children, and will have more data soon.

Other immune enhancing therapies include vitamin C, oligoprocyanthocyanidins (OPC-3), and anti-inflammatory fatty acids, along with the herbs already discussed.

Homeopathy

I have also used homeopathy to treat the symptoms of autism. Homeopathy is controversial among conventional physicians, but is occasionally very effective in my experience. Is this effectiveness due to the remedy, to the placebo effect, or to the Pygmalion Effect? I cannot say, but have especially used sulfur for hyperactive and aggressive behavior, along with a variety of other remedies as appropriate to homeopathic theory.

Homeopathy has the advantage of having minimal risk. It either works or it doesn't. When it doesn't work, it doesn't harm. The debate will continue for some time about whether homeopathy works, though a recent analysis published in *The Lancet*, reviewed all of the recent clinical studies of homeopathy and concluded that it is significantly more effective than placebo. The downside noted by the review was that homeopathy was not as reliable as some other treatments. This has also been my clinical experience. When it works, it's wonderful, but it isn't always predictable whether or not it will work.

Homeopathic detoxification is popular with some parents and physicians. In this approach, small amounts of toxic substances are used to stimulate the body to heal itself from these substances. The approach may be combined with dietary modifications to facilitate the release of toxins. For example, alkaline diets seem helpful for agitated children, at times, and are thought to aid detoxification. Alkalinizing agents in the diet include spinach, cucumber, carrot, beet, and celery. These are juiced and used alongside food or used instead of food in an alkaline fast. Avoiding acidic foods can also be helpful. These foods include tomatoes, red meats, and simple carbohydrates, to name a few.

Allergic Theories and Treatments

Lurking in the background throughout complementary and alternative medicine lies the question of allergies. Though some physicians feel allergies are over-stressed, the concept is important.

I typically use the ELISA/ACT Test from Serammune Physicians Laboratories in Virginia, to test for food allergies. The acronym stands for Enhanced Lymphocyte Immunostimulation Assay. Blood is drawn and the patient's lymphocytes are incubated with various substances to determine what cell-mediated reactions the patient is having. Cell-mediated reactions are more important for food allergies than humoral reactions (immediate antibody reactions in the blood stream).

Some more alternative physicians use applied kinesiology or an off-shoot called Neuro-emotional technique, or N.E.T., to test for allergies. Others place the substances within the patient's "energy field," and test for changes in Chinese Meridians using pulse diagnosis. Offending substances are identified and eliminated from the diet or the environment. Nambuprihad Allergy Elimination Technique (N.E.A.T.) aims to reduce the patient's allergic reaction by balancing the energy meridians with the offending substances in the patient's energy field.

I have seen these approaches work and not work. We are all impressed when they work. We are not so impressed, when they are ineffective. I know of no rigorous clinical studies of the role of allergy treatment in autism, but suspect that some will some be forthcoming. Certainly eliminating foods and other substances that

produce allergic responses in the autistic child can't be harmful, and may be helpful in other ways, even if these approaches show no effect on autism in rigorous trials. These approaches can help the gastrointestinal problems of autistic children, which is no small feat. Perhaps that will be where their utility will lie.

Body Therapy and Manipulative Therapies

A recent study from the University of Miami showed effectiveness of craniosacral therapy, a form of osteopathic manipulation, for autistic children. In craniosacral therapy, the bones of the skull are adjusted along with subtle adjustments of the spine, all the way to the sacrum. Craniosacral therapy, or CST, is different from chiropractic manipulation in that the adjustments are very subtle and are aimed at improving the flow of cerebrospinal fluid down the spinal canal. This fluid has been demonstrated to cycle with a pulse of 12 beats per minute. This pulse can be felt in the area of the sacrum (near the tail bone).

The goal of craniosacral therapy is to improve the ease with which the cerebrospinal fluid circulates and to help hold the skull bones and the spine in adjustment. The study showed improved concentration, socialization, and less self-stimulation behavior after a course of craniosacral therapy. This has been my experience, as well, watching children receive the therapy.

Chiropractic manipulation has been used for autistic children. I know of no formal clinical studies on its effectiveness, but have referred children for this therapy and been pleased with the results. Naturally, without clinical studies, the results could be due to the parents expecting it to work, so we cannot say for sure that the technique works of its own.

Sometimes techniques work by giving opportunities for natural healers and patients to interact. Unlike drugs, which can be more obviously separated from the prescriber, body therapies are more fused with the person administering the treatment. Some body therapists are more inspired than others. Nevertheless, a developing literature is finding body therapies very effective for many medical conditions.

We have been doing a pilot study of reiki massage for autistic children. The preliminary results are encouraging, especially when the parents are taught to do the reiki along with visualization in between formal appointments with the therapist. The use of reiki by parents and therapist appears to encourage communication, especially non-verbal communication. Children are more calm and have less self-stimulation.

Important to remember with healing methods that are non-pharmacological, is that their effectiveness is a complex mixture of technique, therapist, expectation, and communication.

Naturalistic Behavior Therapy

Most practitioners in the autism world have heard of Lovass' technique of applied behavioral analysis. This approach is based upon teaching the child skills through interaction in discrete trials in which the child is rewarded for the correct response. Rewards often include food, sometimes, unfortunately, foods to which the child may be allergic (M & M candies are frequently used!).

Studies from the Autism Research Center at the School of Education at the University of California at Santa Barbara, have shown that naturalistic behavior therapies are better than the applied behavioral analysis at changing autistic behaviors. This approach incorporates natural situations in which the child is already interacting and rewards the child through creating opportunities to do more of what the child already enjoys doing.

Non-autistic children may be recruited to be part of the therapeutic process. Examples of therapies in the classroom include a teacher developing a game for the entire class when her autistic student was obsessed with maps. The game consisted of the children dividing into teams and drawing states on sidewalks with chalk as fast as possible, including locating the capitol of the state. The autistic student was excellent at this game and was soon desired as a team member, thereby improving his opportunities for interaction with other children.

A book has been published about this approach, entitled [Teaching Children with Autism](#). We are more excited about this method than the applied behavior analysis, though ABA as it is often called, has helped many children.

Other more permission therapies exist such as those offered by the Options Institute in Western Massachusetts, in which parents are helped to appreciate the special talents and uniqueness of the autistic child, and to learn to love the child as he or she actually is. These are often healing for families, especially when coupled with naturalistic behavior therapy and the other therapies mentioned here.

Conclusions

Many options exist within complementary and alternative medicine for the treatment of autistic children. We have not discussed drugs that can help autistic children, but rather have focused upon non-drug therapies. This is not to say that medications cannot be helpful, because they can. But many parents are interested in alternatives to medications, especially when there are side effects, and other parents have found that the medications are not helpful or that alternative therapies can add much benefit beyond what medications can do.

My approach is to present this menu to parents, suggesting that they decide what makes the most sense to try first. If parents don't know or can't decide, I proceed in an orderly fashion through nutritional therapies, to body therapies (craniosacral and reiki, especially), through educational and behavior therapies, and through Chinese medicine. By the time we have reached Chinese medicine, parents have learned more about these alternatives, and typically have definite opinions about what will work. I monitor the outcomes of treatments carefully, asking parents to record daily counts of desirable behaviors (eye contact, appropriate use of language, etc.) and undesirable behaviors (self-stimulations, non-responsiveness, aggression). I use the Achenbach Child Behavior Checklist and the Autism Behavior Inventory on a regular basis also to document progress.

With any therapy, conventional or alternative, accurate data are needed to prove that the treatment is worth the expense and the side effects (if there are any). Fortunately, the majority of the alternative therapies have no side effects.

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Appendix 4

The following description of Applied Behaviour Analysis (ABA) is a slight modification of a definition given on Kathy Lear's website, www.helpuslearn.com

"ABA stands for Applied Behaviour Analysis, and it is a methodology from psychology which has been adapted and applied to teaching children with autism. It is also referred to as 'Intensive Behavioral Intervention' (IBI).

It is a teaching method based on the principles of positive reinforcement, prompting and rapid (sometimes graduated) prompt fading (for errorless teaching), repetition and the teaching of tasks in very small, discrete steps. The program is often done at home, using students and other part-time workers as teachers. Studies show that children receiving behavioural intervention generally achieve significant gains."

Another definition is as follows (Sorry, I don't remember where this definition originated):

"ABA is Applied Behavior Analysis. It is a behaviorally-based therapy that typically involves 1:1 interactions between a teacher and student. After a child is assessed and the parent finds an ABA provider, the program supervisor will design a curriculum tailored to the child's individual needs. Target areas are communication, social skills, emotional/affective skills, physical development, school self-sufficiency skills, and cognitive skills. The actual teaching is strict in the sense that the rules that the TEACHER has to follow are very clear, but I think that the best therapists/teachers gauge how best to interact with the child. I personally always treat my kids as kids first. The aim should be to treat the child, not the disorder. After designing a curriculum, therapists generally work in 2-3 hour individual sessions with the child. The teacher runs the programs, giving the child a reinforcer (something they like, such as food, a toy, a short break -- whatever is fun for him) if he gives a correct response, or giving the child a correction if he gives an incorrect response. The idea is to make correct responses more probable by making the consequences for them very good and positive. But even if the child doesn't respond correctly for a while, giving him the correction (showing or telling him what the right answer is) helps him to learn what to do in future. By strengthening the association between answering correctly and getting something he likes, the child is more likely to learn. Eventually, the goal is for the kids to enjoy learning itself, which has happened fairly quickly with every child I've ever worked with! :) Working together, the therapists and parents analyze the data that is taken on each response to all programs and decide what to do next. In books such as the Catherine Maurice manual "Behavioral Interventions for Children with Autism" or the Lovaas book "The ME Book" (both of which can be ordered through <http://www.difflearn.com>), they provide comprehensive curriculum lists. Most certified or degreed therapists will work within a particular system of ABA for which there is a particular curriculum, though the general curricula are the same."

Appendix 5

In this reference, I have used “precision teaching” in its generic sense – knowing what you want to teach and arranging the conditions for the learning to occur. There is, however, another sense in which the term is used, and this is the sense which I tend to associate with the work of the Standard Celeration Society, “a collegial organization for all persons who use standard celeration charting in education, human services, business, performance management, parenting or child rearing, and science.” The following excerpts are taken from the “Questions and Answers” file on their website -- www.celeration.org – and listed here because I suspect that this approach will provide a yet-to-be-added component to our standard approach to the education of autistic individuals, although I doubt that it will be of much use to you just yet.

Standard Celeration Society Questions and Answers

When was the Standard Celeration Society formed?

1992. While there were earlier informal meetings where forming a Standard Celeration Society was discussed, the Society officially came into being in 1992.

Standard Celeration Charting Question and Answers

What does our Standard Celeration Chart do?

[This question and its answer was contributed by Dr. Ogden R. Lindsley, in a message posted to the SC List on 9-9-2000.]

Hi All: You often hear people ask, "What does our Standard Celeration Chart Do?" Of the many answers, one of the best is, "It simplifies things."

- It simplifies charting so that six year olds can learn it and teach it to others.
- It simplifies chart reading, making it so fast that we can share charts at 2 minutes each.
- It simplifies chart checking so much that you can check for x2 learning on 60 charts posted on a ten foot stretch of wall as you walk past without slowing your pace.
- It simplifies understanding of all growth and decay. An example of this is how our standard chart simplifies the famous Fibonacci series.

In the early 1970's when I worked out "ChartStat" I was amazed to find that almost every mathematical series, that I had learned years ago in calculus, was a straight line on our standard chart. The formulas for harmonic series, and Fibonacci series, and others, were very different. But they were straight lines, just at different angles, different constant multiples, and therefore different celerations. The Fibonacci series, that Owen White finds so interesting in his "Log" and "Power" charts List serv post, where the next number is the sum of the two numbers before it, follows:

1, 1, 2, 3, 5, 8, 13, 21, 34, 55, 89, 144, 233, 377, 610, 987, 1597, 2584, 4181, 6765, 10946, 17711, 28657, 46368, 75025, 121393, 196418, 317811, 514229, 832040, 1346269....

What surprised me, and will surprise Owen, and should surprise you, is that the Fibonacci is merely a times 1.618 series,

$$5 \times 1.618 = 8, 8 \times 1.618 = 13, 13 \times 1.618 = 21, \text{ etc}$$

This means, of course, that it forms a straight line on our Standard Celeration Chart.

Charted on a daily chart, x1.618 per day makes a straight line celeration of about x47 per week.

Charted on a daily chart at x1.618 per week makes a celeration of x1.6 per week. Charted on a yearly chart at x1.618 per year makes a straight line celeration of x10 every five years.

When things are actually only multiplying, we simplify by telling how much they multiply. No need to create puzzles as did Fibonacci, and White, by calling attention to a strange addition formula to describe constant multiple growth. Describing multiplication by addition just complicates and confuses.

Resist being led back to Fibonacci and the year 1228. Think multiply!

We have a good thing going for us. We have multiplication!

Keep it Simple. Keep it multiply. Keep it graphic. Keep it standard.

As ever, Og [Ogden Lindsley, first president of the Standard Celeration Society]

Why do you use the Standard Celeration Chart?

[This question and its answer was contributed by Dr. Rick Kubina, in a private email message.]

People use graphic designs (e.g., graphs and charts) to "make sense" out of quantitative information.

Different graphic designs can lead to different interpretations of the data. Because most graphic designs use "times series*" the Standard Celeration Chart (SCC) offers numerous advantages in interpreting quantitative information. For example the SCC represents data "proportionally" instead of "absolutely." A look at the data from Kubina (1999) shows an example of data represented absolutely ([Figure 1](#) shows an equal-interval or add-subtract chart) and proportionally ([Figure 2](#) shows a Standard Celeration Chart). Vastly different interpretations result from viewing the same data on different graphic designs (equal-interval versus the Standard Celeration Chart).

The Standard Celeration Chart also contains many other advantages. The following lists some of the advantages of using the Standard Celeration Chart:

- A Standard Celeration Chart displays behavioral frequencies, celeration changes, and bounce that correspond to the natural flow of behavior.
- SCC's pre-constructed, standard nature, means individual users will not have to concern themselves with "design variation" issues, or factors that distort the true nature of the data.
- Evidence suggests that Kindergarten children (Bates & Bates, 1971) through senior citizens (Kubina, Haertel, & Cooper, 1994) can learn how to use and understand the Standard Celeration Chart.
- Standard display permits chart readers to react in a similar, and quicker, manner to the same data, lessens the chance of committing interpretation errors due to design variations, and allows those with "differing histories with interpret data effectively" (Johnston & Pennypacker, 1993, p. 320).
- SCC can facilitate new discoveries when placing behavior on a frequency spectrum (Lindsley, 1991).

Please refer to Pennypacker, Koenig, & Lindsley (1972) for other technical details of the Standard Celeration Chart.

*Time series- a graphic design which has "one dimension marching along to the regular rhythm of seconds, minutes, hours, days, weeks, months, years, centuries, or millennia" (Tufte, 1983, p. 28) and another dimension showing the quantitative value of some event or occurrence.

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Precision Teaching Questions and Answers**Why was it named Precision Teaching?**

[Question and Answer contributed by Dr. Ogden Lindsley, September 2000.]

Ogden Lindsley (1972, Page 9) named Precision Teaching because "what was really new in our procedure was precision, we decided to use that as an adjective in front of whatever it was one was doing: hence in our case, "precision teaching." Lindsley (1971) hoped that the standard recording and charting system would be used throughout the behavioral fields as Precision School Psychology, Precision Social Work (Green & Morrow, 1972), Precision Speech Therapy (Johnson, 1972), and so on. The field experts would keep their name as the noun and use the adjective "precision" to describe the method standard to all.

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What is a Chart Parent?

[Question and Answer contributed by Dr. Ogden Lindsley, September 2000.]

Your chart parent first taught you to use the Standard Celeration Chart.

If you are having trouble learning to Standard Celeration Chart from printed handbooks and articles, post a chart parent request along with your home address and telephone number on our 170 member [as of September, 2000] SCListerv. Joining instructions appear here at www.celeration.org. A chart parent living near you will reply to your email request.

Chart parenting, is still our most effective way to spread and share our science. Chart parenting has taught where our handbooks and seminars have failed. Chart parenting provides personal attention, proof that the teacher cares, one on one, and real time immediate feedback and correction. At any, or every point the learner can ask, "How?" or "Explain that over again." We wish there were more efficient ways to teach our SCC, but so far there doesn't seem to be. We need more charters in the X and Z generations! Keep up your chart parenting!

Chart children often invest a day plus three hours commuting to learn. But, the busier chart parent still invests a day! A day invested in one or two learners! Chart parent investment motivates chart children. Should we add a slogan, "Care enough to Chart Parent?"

Chart parents offer continued support after the initial teaching session over telephone and occasional visits. Most all new charters welcome the emotional support of knowing there is someone to call. However, few new charters have to make follow up support calls.

[Note that Michael Maloney's "chart parent" was Eric Haughton who, in turn, was a student of Ogden Lindsley, first President of the Celeration Society.

Doing Precision Teaching: Do I need a baseline?

[Question and Answer contributed by Dr. Ogden Lindsley, October 2000.]

No. You do not need to chart for a week or two before you try a reward or penalty. The slope of our standard chart tells how much what you are doing is working, and will predict when you will reach aim. Of course, about one third of the time self counting and charting alone produce the results you want. So, you don't always need to change anything else.

Doing Precision Teaching: How can I teach social skills?

[Question and Answer contributed by Dr. Ogden Lindsley, October 2000.]

Two ways:

Chart real life counts daily.

Create a practice session for skill and time and chart it daily. Both can be done at once.

An example: Greeting people warmly.

1) Real life count. Post a class list and have students go up and initial beside the name of each student who warmly greeted them that day. At the end of each day each student totals and charts the warm greeting marks they received.

2) Two minute practice session. Have your class form a circle around room perimeter. Start a timer and a student greets each class member in turn working around the circle. The greeting student shakes hands and makes eye contact until the greeted student signals that the handshake and eye contact were warm. The numbers of warm and cold greetings signaled by the greeted students per minute are charted for each greeter student that day. This, of course, requires honesty and cooperation of your students.

What are some basic Precision Teaching resources and where can I find them?

[This question and its answer was contributed anonymously by a long-time Precision Teacher.]

Precision Teaching Resources

• To order Precision Teaching supplies contact:

Behavior Research Company, Box 3222, Kansas City, KS 66103 publishes a number of books,

reports, and articles on Precision Teaching.

• People to Contact:

Elizabeth Houghton is the director of the Houghton Learning Center.[Houghton Learning Center 3166 Jefferson St Napa CA 94558 (707) 224.8863].

Aileen Stan-Spence is a director of the Ben Bronz Academy 139 North Main Street West Hartford, CT 06107 (860) 236-5807.

Kent Johnson is the director of Morningside Academy. Kent is an authority in Precision Teaching, Direct Instruction, and Instructional Design [Morningside Academy, 810 Eighteenth Avenue, Seattle, WA 98122 (206) 329-9412].

Michael Maloney is the director of The Learning Center. He also uses Precision Teaching and Direct Instruction [The Learning Center, 28 Isabel >Street, Belleville, Ontario Canada K8N 5A5].

E. Anne Desjardins is the director of the Cache Valley Learning Center [Cache Valley Learning Center, 146 N. 100 E., Logan, UT 84321 (801) 753-8811].

Claudia E. McDade is the Editor, *Journal of Precision Teaching* and the Director of the Center for Individualized instruction at Jacksonville State University. Claudia has developed computer applications of Precision Teaching and Personalized Systems of Instruction [Editor, *Journal of Precision Teaching*, Center for Individualized instruction, Jacksonville State University Jacksonville, AL 36265-9982].

• Professional Readings to obtain:

Journals:

All issues of the *Journal of Precision Teaching (JPT)* provide important reading. Order *JPT* from McDade--use address given above.

Teaching Exceptional Children, Volume 3(3), Spring issue, 1971.

Teaching Exceptional Children, Volume 22(3), Spring issue, 1990.

These two *TEC* references are special issues on Precision Teaching and contain many outstanding articles. You can buy these issues from the Council for Exceptional Children, Teaching Exceptional Children, 1920 Association Drive, Reston, VA 22091-1589

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- Books:
- Jordan, J. B. & Robbins, L. S. (1971). *Let's try doing something else kind of thing*. Arlington, VA: Council For Exceptional Children.
- McGreevy, P. (1983). *Teaching and learning in plain English* (2nd. ed.). Kansas City, MO: Plain English Publications.
- White, O. R., & Haring, N. G. (1980). *Exceptional Teaching* (2nd ed.). Columbus: OH, Merrill.
- All three of these books give good instruction, but they are dated in many ways. All three of these books are out of print. You should be able to find the Jordan and Robbins and the White and Haring books at most college or university libraries. If a library does not have these two books, interlibrary loan is possible. White and Haring is the most comprehensive book written on Precision Teaching, but it is very dated. I believe it will be difficult to locate a copy of McGreevy's book.
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FAQs page compiled and edited by John W. Eshleman, Ed.D., October 2000.

SCS webmaster: [Rich Anderson](#)

Page updated Monday October 9, 2000

Appendix 6

The ABA Controversy

Bernard Rimland, Ph.D.
Autism Research Institute
4182 Adams Avenue
San Diego, CA 92116

I am a long-time and ardent supporter of what is now called the “ABA” (Applied Behavior Analysis) method of teaching autistic children.

I remember very clearly the day in October 1964—35 years ago—that I first visited Ivar Lovaas in his clinic at UCLA. I met the autistic children Billie, Rickie, and Pam, who resided there. Their speech was sparse and stilted, but the children were miles ahead of where they had been when they were filmed (this was before videotape) at intake. I spent the day with Ivar, and came away impressed. I returned home and started using “operant conditioning” with my then eight-year-old son Mark. He, too, began to improve.

A year later, in November 1965, I spoke to a group of parents in Teaneck, New Jersey, a suburb of New York City, and proposed that we start a national organization, the National Society for Autistic Children (now the Autism Society of America) dedicated to helping, not just baby-sitting, our children. The talk I gave was titled “Operant conditioning: breakthrough in the treatment of mentally ill children.” (I said “mentally ill” because few were aware of the term “autism” then.) I traveled to city after city, giving the “Breakthrough” talk and starting a new chapter of the society in each city. My “Breakthrough” talk was translated into many languages in the ‘60s and ‘70s, and helped educate parents and educators around the world.

In 1987, when Lovaas’ landmark study of ABA was published, we featured it in the ARRI. I wrote dozens of letters of support for parents who wished to obtain ABA for their children, and in ARRI Vol. 8, No. 3, in 1994, I published a generic letter of support (copies available on request) which was helpful, I’m told, to innumerable families fighting to get ABA for their children. As a long-time advocate and supporter of ABA, I take a back seat to no one. Having said that, I must tell you that I am dismayed and appalled at the ludicrous position taking by many other supporters of ABA, who claim that ABA is the only scientifically validated treatment for autism. Not so! That position is not only false, it is absurd. Believe it or not, the Early Intervention Program of the New York State Department of Health has published a series of Clinical Practice Guidelines which makes that claim.

Considering the weight of scientific evidence, there are several treatment approaches which clearly meet the criterion of scientific validation, and of these, at least two surpass ABA in terms of scientific supportability. I will confine my comments here to the treatment modalities which most clearly exceed ABA in terms of level of scientific support (not necessarily in terms of percentage of children helped, nor in terms of the degree to which they are helped, but only in terms of weight of scientifically valid evidence that the treatment effect is real). The New York State Guidelines, which recommend ABA as

the only effective treatment, explicitly reject vitamin therapy, gluten- and casein-free diets, anti-fungal treatment, auditory integration training, sensory integration, and many other interventions.

The Lovaas 1987 study, the centerpiece of the ABA early intervention movement, attracted a great deal of attention because it employed a control group of more-or-less equally impaired children who were given less intensive (fewer hours per week) treatment. This represented an important advance in methodology over no control group at all (the usual approach), but the study did not employ double-blind procedures. Those involved in the study knew how intensive the treatment was for each child. I am aware that it would have been exceedingly difficult, if not impossible, to develop a double-blind evaluation of intensive ABA treatment, but that does not change the fact that a double blind was not used. The results were thus to some extent contaminated by participant bias and expectancy.

Further, all of the methods of measuring the effect of the treatments were to some degree subjective and a source of error. No study of the effectiveness of ABA has used double-blind procedures or scientific laboratory analytical equipment.

In contrast, of the 18 studies showing vitamin B6 and magnesium to be effective, 11 employed the double-blind procedure. Further, in addition to using soft behavioral and observational criteria such as were employed in the ABA evaluation studies, 10 of the studies of B6 and magnesium measured the presence of abnormal substances in the blood and urine of autistic children, and found the B6/magnesium to have improved the children's metabolism. Five studies of B6/magnesium in autism have shown normalization of brainwave activity in the autistic children. These are hard, objective, measurable, scientifically replicable findings. Show me the equivalent of such solid scientific evidence in the ABA literature. It is absent.

The situation is similar with regard to the efficacy of the casein- and gluten-free diet. Study after study has documented the presence of abnormal substances in the urine of autistic children, with improvement in the children's urine and in the children's behavior when the special diets are implemented. There are over 40 such studies, yet the New York State report claims the diets are ineffective. Very strange.

Recently an organization has been formed with the title Association for Science in Autism Treatment (ASAT). Their literature espouses the same nonsensical, counterfactual position as the aforementioned New York State report: ABA is the only scientifically valid intervention for autism. Their position is indefensible: it requires a distorted view of what science is all about, as well as a willingness to ignore all relevant evidence.

The "ABA is the only way" folks are wrong, not only because of their lack of information about research on the validity of other interventions, but because of their failure to recognize that parents have a right and an obligation to consider all possible forms of intervention, including those which may not yet have won the stamp of approval of whatever person or committee feels qualified to pass judgment on candidate interventions.

A case in point: ABA itself. I can't help but wonder how the ABA-only folks would view my efforts

to have ABA accepted between 1964 and 1987. Though there were no control group studies, and certainly no double-blind studies to point to, the evidence was clear enough to compel me to fight for ABA. Should I have abandoned my efforts for more than two decades while waiting for a control group study to appear? I'm glad I didn't.

It is a major mistake to think of ABA as being competitive with, rather than complementary to, many other interventions, particularly such biologically based interventions as vitamin B6 and magnesium therapy. For years, our publications have urged parents who are about to undertake megavitamin therapy to refrain from mentioning the new intervention to teachers, therapists, grandparents, sitters, etc., so they would be able to obtain objective input from these "blind" observers. Each such case is a mini double-blind single-subject experiment. We have heard from hundreds of parents who have reported, "Our therapist, who did not know about the B6 we started last week, said our child has made more progress in one week than in the prior three months" (see letters sections in back issues of the ARRI).

If you really want to be scientific, do a mini double-blind trial on your child.

Appendix 7

The following information is taken from the Autism Research Institute's website:
www.autism.com/ari

The Autism Research Institute (ARI), a non-profit organization, primarily devoted to conducting research, and to disseminating the results of research, on the causes of autism and on methods of preventing, diagnosing and treating autism and other severe behavioral disorders of childhood. It provides information based on research to parents and professionals throughout the world.

A great deal of information is available from the ARI office, and may be ordered from our publication list (see below). New information is published in our quarterly newsletter, [*The Autism Research Review International*](#), available by subscription. A limited amount of the information is available from this web site.

ARI is a non-profit organization which provides its services free of charge, except for nominal fees to cover postage and printing. ARI depends for its support upon charitable contributions from concerned individuals and organizations.

The founder and director of ARI is Bernard Rimland, Ph.D., an internationally recognized authority on autism and the father of a high-functioning autistic son. Dr. Rimland is the author of the prize-winning book *Infantile Autism*, and the founder of the Autism Society of America. He served as chief technical advisor on the film *Rain Man*. He has earned many awards for his work.

Appendix 8

DEFEAT AUTISM NOW! (DAN!)

The Autism Research Institute convened a group of about 30 carefully selected physicians and scientists in Dallas in January, 1995, for the express purpose of sharing information and ideas toward defeating autism as quickly as possible. The participants, from the U.S. and Europe, represent the most advanced thinking by some of the best minds in the autism world. The participants continue to work together toward the goal of finding effective treatments.

One major goal of the DAN! Conference was to produce a document that could be used by physicians everywhere as a guide for the clinical assessment of autistic patients, leading to appropriate treatment. After a year of strenuous work the document, representing a consensus statement of the state-of-the-art alternative medical approach to the diagnosis and treatment of autism, is now available. The 40-page manual is titled *Clinical Assessment Options for Children with Autism and Related Disorders: A Biomedical Approach* and costs \$25.00 (U.S. Funds)

Parents and physicians who do not regard psychotropic drugs as the best or only means of treating autistic patients will welcome this advanced manual on clinical assessment.

If you would like to purchase the 40-page manual, see the ARI Information Request Form. You can also write to ARI for more information on DAN!, such as a list of doctors, future DAN! Conferences, and audiotapes.

[Click here](#) to view the list of practitioners who have attended one or both DAN! conferences and have agreed to assist families with autistic children in pursuing the DAN! approach.

Appendix 9

The following biography is from A Science Odyssey, People and Discoveries and available at the website: <http://www.pbs.org/wgbh/aso/databank/entries/bhskin.html>

B.F. Skinner **1904 - 1990**

Burrhus Frederic (B.F.) Skinner majored in literature at Hamilton College in New York. He went to New York City in the late 1920s to become a writer, but he wasn't very successful. "I had nothing important to say," he later explained. So he decided to go back to school, and went to Harvard to study psychology, since he had always enjoyed observing animal and human behavior. For the most part, the psychology department there was immersed in introspective psychology, and Skinner found himself more and more a [behaviorist](#). He worked in the lab of an experimental biologist, however, and developed behavioral studies of rats. He had always been a tinkerer, and loved building Rube Goldberg contraptions as a kid; he put that skill to use by designing boxes to automatically reward behavior, such as depressing a lever, pushing a button, and so on. His devices were such an improvement on the existing equipment, they've come to be known as Skinner boxes.

Skinner received his PhD in 1931. In 1936 he took an academic position at the University of Minnesota where he wrote *The Behavior of Organisms* and began his novel *Walden II*, about a commune where behaviorist principles created a new kind of utopia. He also began development of his controversial "baby box," a controlled-environment chamber for infants (his second daughter spent much of her babyhood in one). Pigeons roosted outside his office window at the University of Minnesota, which gave him the idea to use them as experimental subjects -- they became his favorite.

With pigeons, he developed the ideas of "operant conditioning" and "shaping behavior." Unlike [Pavlov's](#) "classical conditioning," where an existing behavior (salivating for food) is shaped by associating it with a new stimulus (bell ringing), operant conditioning is the rewarding of a partial behavior or a random act that approaches the desired behavior. Operant conditioning can be used to shape behavior. If the goal is to have a pigeon turn in a circle to the left, a reward is given for any small movement to the left. When the pigeon catches on to that, the reward is given for larger movements to the left, and so on, until the pigeon has turned a complete circle before getting the reward. Skinner compared this learning with the way children learn to talk -- they are rewarded for making a sound that is sort of like a word until in fact they can say the word. Skinner believed other complicated tasks could be broken down in this way and taught. He even developed teaching machines so students could learn bit by bit, uncovering answers for an immediate "reward." They were quite popular for a while, but fell out of favor. Computer-based self-instruction uses many of the principles of Skinner's technique.

Skinner expressed no interest in understanding the human psyche. He was as strict a behaviorist as John Watson, and he sought only to determine how behavior is caused by external forces. He believed everything we do and are is shaped by our experience of punishment and reward. He believed that the "mind" (as opposed to the brain) and other such subjective phenomena were simply matters of

language; they didn't really exist. Skinner was known for making audacious statements on this matter (and others), following in Watson's tradition of being provocative, controversial, and an excellent publicist of his ideas.

After nine years in Minnesota, and three years as head of the psychology department at Indiana University, Skinner returned to Harvard in 1948 as a professor and remained there for the rest of his career. In 1971 he wrote *Beyond Freedom and Dignity* which suggested the ceding of individual freedoms to further the goals of an ideal society. He died in 1990.

"Education is what survives when what has been learnt has been forgotten."

Appendix 10

The book, “Teaching Language to Children with Autism or Other Developmental Disabilities” which is discussed at some length in this introduction to Getting Started in ABA/AVB, is based on Skinner’s functional analysis of verbal behaviour (Verbal Behavior, New York: Appleton-Century-Crofts, 1957), which is described in some detail in its Appendix.

Appendix 11

The following comments regarding “Teaching Language to Children with Autism or Other Developmental Disabilities” are from a book review written by Mariele Koenig published in the CT FEAT Newsletter in the fall of 1999:

... Now for a review of the book’s content: Teaching Language to Children with Autism or Other Developmental Disabilities is based on the conceptual framework of Skinner’s (1957) Verbal Behavior. Its 315 pages include four divisions and an appendix. The first division (chapters 1-4) describes an assessment protocol for children at the earliest stages of language development. The protocol utilizes a combination of interview and direct observation to identify a child’s typical performance levels in several natural settings. Observations are focused on the following types of behaviors: 1) cooperating with adults, 2) requesting (manding), 3) motor imitation, 4) vocal play, 5) vocal imitation (echoic), 6) matching-to-sample, 7) receptive language, 8) labelling (tacting), 9) receptive identification by function, feature and class (RFFC), 10) conversations (intraverbal), 11) letters and numbers, and 12) social interaction.

A child’s performance is rated in each area relative to five behaviorally defined proficiency levels. A form is provided to document the ratings and to profile the child’s repertoire. Intervention goals are selected in consideration of the profile. Five model profiles are provided to illustrate the translation of performance patterns to IEP Objectives. Also included are guidelines for the selection of an appropriate communication modality (e.g., speech, sign language, picture system). While the long-range focus remains on speech for all children, augmentative systems are recommended as a supportive interim step for some.

The second division (chapters 5-9) describes specific procedures and a curriculum for establishing early language skills in nonverbal children. Specific procedures are described for establishing rapport, requiring a response, establishing positive alternatives to negative behavior, and teaching a child to request (“mand training”). Mand training is the first form of direct language instruction in this protocol, and it is reinforced as the program progresses. Specific procedures for mand training vary depending on a child’s assessment profile.

Detailed instructional sequences are provided for four types of learners: 1) children who are non-echoic and non-imitative; 2) children who demonstrate imitative skills and are candidates for sign language; 3) children who demonstrate echoic skills and are candidates for vocal mand training; and 4) children with physical impairments who are candidates for learning a pointing response. The manual also provides guidelines for the selection of first words as mands, for establishing a mand through multiple prompts, for fading each prompt, for thinning the reinforcement, for expanding the mand repertoire, and for supporting the use of mands in the natural environment. This systematic approach to early mand training distinguishes the Sundberg and Partington approach from some behavioral approaches (e.g., Maurice, Green & Luce, 1996; Leaf & McEachin, 1999) but not others (e.g., Bondy, 1996).

A number of related language skills are targeted following initial mand training, including imitation, echoic responses, receptive discriminations, and matching-to-sample. Strategies are

given to support the instruction of each related skill to learners with different profiles. Trials targeting these skills are interspersed systematically with mand trials, resulting in a "mixed verbal behavior" (aka "mixed VB") format. This is different from behavioral approaches that rely heavily on massed discrete trials during the early intervention phase.

Tact training and receptive identification of common objects are introduced concurrently following the successful acquisition of 5 to 10 mands and some success on related skills. Work in all areas continues and is interspersed with trials targeting tacts, thus continuing and expanding the mixed VB format. Again, different strategies for teaching each new skill are provided to accommodate learners using different communication modalities (e.g., speech, sign, picture exchange). Criteria are provided for the selection of specific words to expand the receptive and expressive repertoire. A sample vocabulary sequence for tact and receptive language training is provided to illustrate the selection criteria.

The identification of receptive [labels] by function, feature, and class (RFFC) is initiated following the acquisition of about 50 words in previous language training. Targets include only those items that the child can already tact and receptively discriminate. Specific examples are provided. Once the child can perform this skill with a large number of targets, the skill is brought into a mixed VB format.

The last set of targets included in the beginning language curriculum is intraverbal skills (e.g., word associations, word sequences, fill-in-the-blank items, etc.) These are introduced at about the same time as the RFFC targets. As with the other skill sets, the authors provide detailed behavioral descriptions of strategies for selecting and establishing initial intraverbal skills. Again, strategies vary depending on a child's communication modality (speech, sign, pictures). Detailed shaping and fading procedures are also tailored to modality.

Division three (chapters 10-12) presents advanced language training as a continuation of the procedures and curriculum described in division two. The materials and procedures are considerably more complex than those involved in the first two levels. Here is a small sample of some of the skills targeted at this level: use of phrases, simple sentences, and more complex syntactic forms; use of language for describing experiences gained through different sensory modalities (e.g., touch, vision, hearing) and verbalization of private events (feelings); responses to a variety of Wh-questions; expansion of previously stated information; responses to a sequence of questions about a single topic; verbalization of event sequences; definition of words; narration of stories; description of current events; discussion of politics, and much more. The goal at this level is to develop fluency in the production and use of language adequate for a variety of social and academic functions.

Division four (Chapters 13-14) covers issues relevant to the implementation of a language program in a child's home and in his/her school environment. Included here is a detailed comparison of discrete trial teaching (DTT) to natural environmental training (NET). When considered from within the conceptual framework of Skinner's model, the authors indicate that each strategy supports a different aspect of verbal behavior. NET primarily benefits mand training

while DTT primarily benefits tact, receptive, echoic, and imitating training. The importance of NET and DTT may also vary at different points in developmental time. NET may exert a greater influence during initial acquisition and peer social interaction while DTT may exert a greater influence on academic work.

Also covered in division four are characteristics of an effective educational program. Specific issues addressed under this umbrella are home-based ABA programs, intensive school-based programs, traditional special education classrooms, inclusion, procedures and checklist for evaluating potential programs. Included within the checklist is a consideration of staff philosophy, acknowledgement/use of basic behavior modification, augmentative communication, language analysis and teaching, the classroom environment, staff-student ratio, length of the instructional day, number of school days in the academic year, classroom's daily schedule, physical layout of the classroom, parent education and involvement, skill acquisition data, and disruptive student behavior.

Appendix 12

The Behavior Analyst Certification Board (www.bacb.com) is a nonprofit corporation established as a result of credentialing needs identified by behavior analysts, agencies within several state governments, and consumers of behavior analysis services. Its main purpose is to develop, promote, and implement a voluntary national certification program for behavior analyst practitioners. As of August 2001, its website did not list any Canadian Board Certified Behavior Analysts (For an introduction to Functional Behavioral Assessment, have a look at the document at the Center for Effective Collaboration and Practice: <http://cecp.air.org/fba/>).

Dr. Vincent J. Carbone is one of an elite group of Board Certified Behavior Analysts who have incorporated Skinner's analysis of verbal behaviour into the ABA programs which they provide. The workshops which he and his associates provide are in high demand, and rightly so.

Bridget Platts attended an introductory workshop given by Dr. Carbone, and the notes which she took at that workshop are given below:

TO INTRODUCTORY CARBONE WORKSHOP

by Bridgit Platts

Introduction

Many ABA programmes ignore Skinner's analysis of verbal behaviour, although there is much empirical research that supports this work (e.g., Rate of Acquisition/Amount of Maladaptive Behaviour during Mass Trialing versus Acquisition/Maladaptive Behaviour using short ITI's and fluent responses). In fact, there is an ABA Journal that lists all the research that has been done around Skinner's work. On the other hand, there is no research as yet which compares a traditional Lovaas programme with a VB model, nor is there any research that compares 1:1 intensive work (of an eclectic nature) with 1:1 therapy using a VB model.

Sundberg and Partington have renewed interest in Skinner's work, and it is their research which Carbone and McGreevy use in setting up an ABA Programme.

Carbone and McGreevy believe that it is contradictory to the nature of an ABA programme to use a cognitive approach to language, but that it makes more sense, and is actually essential, to use a VB model when teaching language to children with autism, within the context of an ABA programme.

Furthermore, there is a developmental sequence to learning the various aspects of language, and it is upon this sequence that a VB model bases its process of learning language.

Instructional control

There were a huge number of videos shown which showed very unwilling/uncooperative learners change to kids who made multiple responses, and who seemed very happy to do so! Vince

emphasised, on a number of occasions, that it is a less than ideal teaching environment when the child is talking/working **so as to get away**. He pointed out that it is highly unlikely that a child who does this will later initiate any type of communication; as it is this lack of initiation which makes autistic kids different from their peers, this situation needs to be addressed. The child should be working and talking because it is something that they enjoy and which is, in itself, reinforcing.

It is therefore important that this potential for enjoyment/reinforcement is established quickly. Without this (instructional control) it will be almost impossible to effectively teach the child. Compliance is a very different issue and one that is addressed in the context of everyday life. For teaching purposes, it is instructional control that one is after, as it is through this that the most effective teaching can begin.

Video 1: Brittany, age 3, who is/was a SCREAMER.

Vince was doing an assessment of Brittany (i.e., he wasn't trying to demonstrate effective teaching procedures) and the purpose of this was to ascertain WHY Brittany screamed (the function of the maladaptive behaviour) and HOW she learnt to do this.

Every time Vince took Brittany near the table her screams went from loud to deafening. Through repeatedly moving from table to the door (where B could get out), Vince determined the how and why of Brittany's screams. The function of the behaviour (why she does it) was socially mediated negative reinforcement, that is: Brittany learnt that by screaming, the task that was to be completed would be removed.

As far as Brittany was concerned, every time an adult took her to the table, she had to do something that she didn't want to do AND something enjoyable that she had previously been doing was taken away.

SO: Vince brought in the video (Barney, which Brittany loves), put it on and sat at the table. The intention behind this was PAIRING -- Vince wanted Brittany to associate him with something reinforcing for her, as the presence of an adult had previously been a predictor of something negative; this had to be changed and so pairing was required. Vince had no intention of placing a demand on Brittany but merely wanted her to come to the table independently, albeit so that she could watch the video (the video was entirely non-contingent).

Without saying a word, Vince placed the puzzle on the table and this immediately resulted in Brittany starting to scream! As the function of this behaviour was socially mediated negative reinforcement, under **no** circumstances was the puzzle to be removed in response to/as a consequence of Brittany's screaming (or any negative behaviour); if this happened B would again learn that by screaming, any demand placed on her would be taken away. An extinction procedure was then required: the extinction procedure for socially mediated negative reinforcement is to keep the task present (versus the extinction procedure for socially mediated positive reinforcement where the object is removed) and the video is turned off. Vince now had to say "No screaming" and as soon as there was a pause in the scream (B was basically just taking a breath), the video was turned on and the puzzle was removed. B was now learning that if she screams, the task remains but if she stops screaming, the task is taken away and she gets a video.

Vince tells us that at this point in the assessment he is not only thinking about pairing himself with the video but also the pairing of the table to the video AND of his voice to the video. The latter point was illustrated by the fact that when Vince said "Good job, Brit" (because she was at the table watching the video without screaming) this immediately resulted in B starting to scream. He hadn't placed any

demand on her but as soon as she heard his voice, she screamed. For Brittany, a voice meant “demand” and so V explains that it is important to slowly start using one’s voice while the child is getting his/her (non-contingent) reinforcer so that one’s voice is also associated with something nice.

When Vince next brought the puzzle on to the table, he did so very slowly and very coyly (without looking at her or talking to her) and removed one of the pieces (the video is still on at this stage). He gently prompted her to put the piece in place, which B did WITH NO SCREAMING; this was the first response to a task without a scream. Vince had therefore established the lowest common denominator, that is, the maximum demand that could be placed on Brittany before she screamed. Vince then slowly increased the demand placed on her (from 1 piece to 4 pieces), increasing the amount that he talked (always using very natural language, e.g., “How about this one, Brit”) and decreasing the amount of prompting. Vince explained that what he was now doing was slowly fading back in the steps involved in making a demand -- the SD, the task, prompt fading.

Vince then continued this process of fading in by switching off the video and asking Brittany to place one piece of the puzzle correctly. Even though the video was off, B happily completed the task with no scream, WHY? Because Vince had successfully paired himself with good things.

Vince explained that when one is working with these children, one is in constant competition with other types of reinforcement -- the value of escape and/or the value of stimming needs to stay low while the value of the reinforcing item (e.g., video) needs to remain high. How does one keep the value of the latter high? By limiting access to it to teaching sessions and by good teaching procedures (Errorless teaching, Fluency, Appropriate level of demand, etc.)

Vince suggests that when one is first taking away the reinforcer (this is especially pertinent when the reinforcer is a toy or food) one should return it to the child very quickly, but not if they are screaming. Furthermore, one should use very normal language (“Give me the toy, please”) rather than flowery “would you mind” language. Also, one is not expecting the child to mand for the object as, at this point, the emphasis is on instructional control, not on manding.

I asked what one does if a child appears to have very limited interest in an object or appears to be into multiple reinforcers, so that as soon as they are expected to do something for the object, they no longer want it. Vince explained that this is not actually because of limited interest on the part of the child, but rather the result of “Too much too soon.” In other words, one’s teaching procedures need to be re-evaluated, as the value of escape is high and the value of the reinforcer is low.

THEREFORE: For instructional control to occur, one needs to ascertain the HOW and WHY of a behaviour. There are 3 main types of reinforcement

- Socially mediated positive reinforcement: The child learns that a maladaptive behaviour will result in the presentation of something that they want. The extinction procedure for this is the removal of that item.
- Socially mediated negative reinforcement: The child learns that a particular maladaptive behaviour will result in the removal of an aversive. The extinction procedure here would be to keep the object/demand present, and only remove it once the maladaptive behaviour stops.
- Automatic positive reinforcement: This is the feelings that the child gets from his/her own body, in other words “stimming.” This is a difficult one to compete with but can be dealt with by providing the child with something that is of greater reinforcement, and also by the appropriate teaching procedures (fluency is essential for those children who tend to stim).

Video 2: David, age 7, who is/was very aware of his body and its sensations

This video showed the Before and After scenario, the difference being amazing (of course!). In the “Before” component, David (who was non-vocal) was sitting at the table and as soon as a demand was placed on him, his stimming began and it was obvious that the value of escape was enormous. In the 5 minutes of therapy, David independently answered about 1 thing fluently, while the rest was either very slow or was incorrect (the NNP procedure was being used).

The “After” included the first session that Vince ever worked with David and the emphasis was therefore on pairing and instructional control.

Vince sat at the table and just watched David while he flew around the room. Vince then put on his favourite video (David’s favourite, not his own!) and just sat there. The video was strategically placed so that the best view of the video was from the table. Vince waited. David went and stood in front of the TV at which point Vince turned the TV off. David immediately turned and looked straight at Vince, at which point Vince knew that he had become the second most important thing in the room (the video being No.1). It is this that Vince was trying to achieve. He had established the beginning of a relationship because David had associated the video (a very strong reinforcer) with Vince; the pairing had begun.

Vince then asked David to sit down, which he did, and the video was immediately put on. If David tried to get up, the video was switched off and Vince used a gestural prompt to get David to sit down. After about 5 minutes of this, David would start to get up (he seemed almost hyperactive due to his amount of stimming) and would immediately sit down again (independently).

Vince started some NVI’s (initially with the video on but very quickly with the video off) and David became a speed machine in his imitation. Initially this was to get the video back on but by the end of the session, even with the video on, David was constantly looking at Vince. At one point Vince scratched his ear, and David immediately did the same! There was no doubt that Vince’s presence was a reinforcing one to David and he really couldn’t wait to do whatever was required of him.

At the advanced workshop we saw a later video of David (after about 2 months of VB Therapy) and he was vocal, on an Early Learner Profile (explained in later notes) and incredibly fluent. Basically, there was an enormous difference in his attitude to the tasks (he seemed to be enjoying the work) and he was very fluent.

For a child who does a lot of stimming, long ITI’s (Inter-Trial Intervals) really interfere with the teaching process; logically, the child has a longer amount of time for the value of automatic reinforcement to increase. Furthermore, prompts should not be a correction, not only because the child has to unlearn the error (this is especially true for those items on acquisition) but also because when an error is made, the value of the reinforcer is decreased, while the value of escape/stimming is increased.

Someone queried eye contact (using “Look at me”) which Vince explained is necessary but is not specifically taught. He explains that eye contact is a natural by-product of manding and pairing; this was very evident in David who couldn’t take his eyes off Vince. Furthermore, if eye contact is fading, Vince recommends bringing it back by using folding hands as an NVI. This not only brings the child’s attention back to the task, but one does not want to have to constantly interrupt the teaching process by having to say “Look at me” or “Hands down.” These instructions are not only never faded but really interfere with the task at hand.

Every task that the child does becomes a conditioned reinforcement and is a step closer to larger reinforcement (the video or food). The next SD becomes a reinforcer for the previous response. To ensure that this is always the case, one should use a Variable Response Rate. In other words, one should constantly vary the number of responses required before the video is given (20, 80, 5, 40 etc.) The reason for this is that if the number of responses is always the same, the result will be a peak in response rate at the beginning and end, with a lull in the middle. Imagine if one knew that one had to pull the one-arm-bandit exactly 80 times before one got one's money. At about 30, one would feel slightly daunted by the fact that one wasn't yet half-way through and so speed of performance might lull as one looks for distraction (looking around, taking a drink, etc). As one approaches the 80 mark, performance would then increase as one realizes that it is soon to be over. If, however, one isn't aware of when the money will fall, but one knows that it is coming, one's speed of response would probably be very rapid.

Classification of language

Language is frequently divided into the Receptive (Listener repertoire) and Expressive (Speaker repertoire) components. *Skinner looked at language as having more than just these two aspects. He saw the Listener repertoire as having a receptive language component and a RFFC component while the Speaker repertoire includes the mand, the echoic, motor imitation, the tact, and the intraverbal.*

There is a brief description of each below, but they are described in greater detail under the heading of "teaching procedures."

Receptive Language: the ability to comply with someone else's instructions, which should result in reinforcement. Strong receptive understanding benefits the teacher/speaker more than it benefits the learner.

RFFC: *the ability to understand a receptive instruction when given information about an item, namely the feature, function and class of that item (i.e., Receptive: Feature, Function, Class).*

The purpose of the RFFC is a bridge to the intraverbal repertoire. One teaches the RFFC so that one can remove the pictures without inhibiting the child's ability to answer questions about the item. Most children can begin RFFC training once they have mastered about 50 words as mands, tacts or receptive discrimination.

Echoic: *repeating precisely what is said*; this develops naturally in "normal" children at about 6-10 months but if the ability to echo doesn't develop then it has to be taught.

If the echoic isn't strong it is then appropriate to decide on a form of augmentative communication. In many cases the use of sign language does result in improved echoic and, in fact, for many vocal children (whose speech is unclear to the majority of listeners) signing is taught as a way to improve their speech.

Furthermore, for concepts that the child finds difficult (one child - Sarah - who was shown on video had great difficulty in learning her colours) the sign is taught as well, as it can become a kind of self-prompt in helping the child to learn. When Sarah was asked the colour of the object, we saw her signing the colour first and this really helped her in then being able to vocalise it!

Motor Imitation: *repeating/copying a movement*; this is obviously very important to children who sign as it forms the basis of their communication. Vince reminded us that signing is still verbal behaviour; children who speak are described as vocal.

The use of motor imitation within a VB programme for a non-vocal child is obviously important but we need to remember that the ability to imitate a movement is NOT a pre-requisite to the mand training; the reverse of this (mand signs transferred to the NVI programme) can also happen. Just like an echoic won't spontaneously become a mand (the two verbal operants are distinct) so the signed mand and the ability to imitate remain distinct. Therefore, one shouldn't think that a sign for a reinforcing item cannot be used because the child hasn't yet mastered it as an imitation; shape it through physical prompts while the EO (Establishing Operation = natural motivation) is strong and transfer it to the NVI programme to practice it. The EO is the most powerful motivator and if the child has a strong EO to make the sign, the chance of it being well shaped is very high.

Mand: *a verbal instruction to provide a desired reinforcement*; the mand (from the word demand) is the only verbal operant that directly benefits the speaker; it is for this reason that it is a powerful motivator in getting a child to communicate. Furthermore, during normal development, the mand (initially through crying) is the first component of language that develops.

Mand training occurs in the Natural Environment and is the very basis on which spontaneous communication is built.

The quantity of mands being introduced is limitless (if the echoic is strong) because one is NOT teaching a label. What you are teaching is that talking is good because it gets one things; the child's voice becomes a conditioned reinforcer. The normal 60% - 40% ratio (60% acquired skills, 40% on acquisition) does not apply with mands.

Tact: *the tact (from the word contact) is the labelling of aspects of ones environment and includes objects, prepositions, adjectives, pronouns, etc.*; the tact is an independent verbal operant and so the ability to say "juice," because one wants some, does NOT mean that the child will then be able to tact juice upon being asked "What is it?" As with all the verbal operants, they need explicit training through DTT.

Tact training would begin when the child has a reasonably strong manding repertoire by taking pictures of the child's mands to the table and teaching them as tacts. One would then take items that have some relevance to the child (shoes, book, teddy bear, scissors, etc.) and teach these as tacts. When the child can fluently tact about 50 items, one would begin teaching receptive identification of these items based on 5 facts about them (2 features, 2 functions and 1 class).

Intraverbal: *the intraverbal is the ability to answer WH questions about an item when that item is absent*, that is, it is the ability to have a conversation. Most conversations are combinations of mands and intraverbals.

The intraverbal repertoire is taught through RFFC: one asks the child to receptively identify an object based on information about that item. One then removes the non-verbal stimulus (the picture) and repeats the question (moving from a fill-in → WH question → reversal → WH reversal).

The idea is that once the child has mastered the ability to talk about an object even when it is not present, "stories" can be created through enlarging one's carrier phrases. In this way, the skill of listening/answering/listening/answering can be learned without being inhibited by scripted sentences with rote responses.

Rote responses are indicative of a learner not having been taught all the meanings of a word (a word as mand, echoic, tact, receptive, RFFC and intraverbal.)

NET

When I first heard about NET (natural environment training), I immediately envisioned lessons in the garden, but NET is not about a geographical location, nor is it those things that are taught away from the table. NET refers to using the child's EO (i.e., natural motivation) as a lead to what is to be talked about. So, if one is at the table but using the video as a topic of conversation, then this is NET.

Mand training, therefore, is done using NET as the child is asking for something due to the presence of a strong EO.

One uses DTT (discrete trial therapy) to teach the child those aspects of language that they wouldn't learn through the environment.

Video 3: Andrew, age 4, who found the table very aversive

Andrew, an Early Learner, found the experience of DTT very aversive, so Vince suggested spending some time using NET as a way of teaching. Once this pairing was strong, a transition to the table would occur. This is a very effective way of avoiding screaming and uses a method of strong pairing so that, in time, the teaching procedures could be transferred to the table.

The most important thing for Andrew to learn at this stage was: I TALK → I GET. Everything that was done during his session was based on Andrew's lead and, where appropriate, his mands were extended to include RFFC and Intraverbals. He was sitting on the ground eating some banana and so questions were geared around this EO, for example: "What is this?" (banana); "Something you eat is...." (banana); "A banana is something you...." (eat).

After following Andrew around the room, taking his lead, and getting him to talk about the various things that he found reinforcing, the next step was to try and pair some cards (which had previously been aversive) with the NET (which he was controlling). A few questions were asked about the cards, interspersed with his EO's.

Andrew had a history of negative experience at the table, so the intention was to pair the NET (following his lead) with cards and the table. In time, the table was no longer an aversive as it had become conditionally reinforcing (i.e., a conditioned reinforcement) through NET.

For an Early Learner, NET means manding + reinforcer (you ask, you get).

Video 4: Sarah, age 6, an Intermediate Learner

Sarah had been doing a lot of DTT at the table and had acquired a good repertoire of verbal behaviour skills through fluency, errorless teaching and manding. Instructional control had been achieved through pairing and, because of this, Sarah seemed to be a very willing learner.

NET formed about 50% of Sarah's ABA programme and its purpose was to give meaning to the language skills that she had acquired at the table. The video was used to provide a topic of conversation so that her mastered skills could be put into a context.

This use of the video (NET) differed from Video 3 where Andrew's programme used predominantly NET as a means of pairing so that they could extend his learning to the table.

Augmentative communication

One would choose an augmentative communication system for a child who has no accurate echoic repertoire, that is, they cannot be understood by unfamiliar people; this would mean the vocal repertoire would not be particularly functional.

It is used to replace maladaptive behaviour that has previously been functioning as mands (e.g., screaming). When choosing a response form for a non-vocal child, one should choose a form that will most likely lead to vocalization, and one which represents the rich tapestry (full linguistic system) of spoken language.

Pictures (e.g., PECS) is a selection-based system while sign language is topography based. From the perspective of the speaker, these two forms are very different, although they look the same from the perspective of the listener.

One should choose a signing system that is highly iconic and one which is syntactically arranged; if a certain “logic” exists to the signs, it is more likely that they will hold meaning for the child (and for the teacher).

The advantage of using PECS is that one doesn't have the limited audience that a signer potentially has, because PECS don't require the learning of any additional skills on behalf of the listener. Furthermore, the use of PECS is based on the skill of matching which, once learned, makes the process of using pictures relatively easy.

The disadvantage of a PECS-type system is that one has to carry the pictures around with you; the effort required in using the system is therefore quite high. In addition one has to scroll through all the options until one finds what one is trying to say. This effort could potentially translate into an increased desire to scream as the value of the reinforcement may decrease as too much effort is required in attaining that reinforcement.

Furthermore, it is easier for the teacher to use a PECS system but actually harder for the child. It is interesting to note that the picture for beautiful, for example, is actually a picture of someone signing the word beautiful!

It is very common for signing to lead to vocalization, and this seems to occur more frequently than vocalization occurring from using pictures. Part of the reason for this is that the “feeling” of each sign is very different; there is an amount of evocative control in using the sign that can often lead to control of vocalization. On the other hand, when one is presenting a picture, the response is always the same – the action of giving.

In connection with this, it is very good to use motor imitation and echoic training simultaneously. For example: 2 NVI followed by 1 echoic. This appears effective for 2 reasons: first, the control of the motor movement seems to lead to greater control of the echoic; and second, this process of interspersal is very good at bringing the child's attention back to the task at hand.

Interspersal is actually an integral part of any effective VB programme and ideally one would intersperse all aspects of the child's learning; initially one may intersperse only motor imitation with the main task, but as soon as possible, one should intersperse tacts, intraverbals, echoics, imitation, etc.

Another disadvantage of pictures is that there is no tacting or intraverbal repertoire; in the case of the former, the child is actually matching, rather than labelling. For the latter, the repertoire would actually be RFFC and not intraverbal.

If a child is using signs as his/her main form of communication, one should remember that the goal is to get the child to be vocal. For this reason, if a child is manding for something (e.g., video), the therapist would say the word “movie” (or “video”) in an attempt to get the child to try to say the word. If the child makes a good approximation of the word [or, thinking in terms of shaping, even a poor beginning of an approximation of the word], then the video would immediately be given. If, after the therapist has said the word three times, the child still hadn’t been made a good approximation, the video would still be given; under no circumstances would one continue saying the word without giving the child the item they were manding for.

One should bear in mind when doing any form of echoic training, that there are certain developmental constraints in vocalization. Bilabials, for example (b, p, m), are far easier than velars (k, g) or laterals (l, y). BUT (just to complicate matters) words and sounds that are close to the child’s reinforcers are better targets than words that have no importance/meaning in the child’s life; use the child’s mands as a basis for signs and echoics.

Teaching procedures

The teaching procedures discussed below will be explained in greater detail in my notes from the advanced workshop, but these are a good starting point.

Mands: For an Early Learner (a child who is just starting out on a VB programme, irrespective of their ability), it is necessary for situations to be contrived so as to get the child to mand 500-1000 times per day.

If the child has some echoic ability then one would target **vocal** manding, where initially (through the process of prompting) the child will be using part echo/part mand.

The reason for a mand is a strong EO (i.e., intrinsic motivation) and this motivation can be manipulated so as to increase (and shape) the mand. One can manipulate a demand for food, for example, by withholding it so that the child becomes hungry. Furthermore, if the motivation for food is strong, one could put it in a container so that the child would have to mand for you to open it. As the child progresses to more advanced mands, the manner in which one manipulates the EO becomes more complicated. For example, if one is trying to get a child to mand for information using the question “Which,” one could hide a desired item in one of your hands and prompt the child to ask “Which hand is it in?”

Contriving situations for increased manding, and the manipulation of the EO, is an integral part of any VB programme. Most of this training will occur in the natural environment and needs to be done hundreds of times per day.

The whole process begins with the echo-to-mand transfer; this process will only start after pairing has been done. The prompt used is “What do you want?” which, initially, will immediately be followed by the name of the item that the child wants -- he/she will then echo the item (hence part mand/part echo). If the child is repeating the SD as well, then one would drop the SD and just name the desired item. Either way, the SD/prompt should be dropped as soon as possible. For both mands and tacts,

the SD “What is it?/What do you want?” is a prompt and should be faded as soon as possible so that the child is spontaneously requesting and spontaneously manding. Mands are actually “talking in response to an inner motivation” (i.e., an EO) and so the SD can and needs to be dropped. Spontaneity is a characteristic that autistic children lack, and what we are working towards is for these children to initiate interaction; manding is one way in which these children will talk first.

The teaching procedures for mand training differ slightly to the procedures for the other verbal operants. First, one can use a more mass-trial approach due to a strong motivation, and second, it is often advantageous to pause before jumping in with a prompt, since one wants to provide the child with the opportunity to talk (although the EO must be high in order for the child to do so).

Once the child has about 15-20 mands that are reliable (spontaneous requests with little/or no prompting), one can start to prompt the use of carrier phrases (I want, Can I have, I would like, etc.). Use a number of carrier phrases simultaneously as one doesn't want the child to get stuck on using just one.

The next step is to teach “yes” and “no” as a mand (yes and no can also be a tact and intraverbal). The way to teach these as a mand is to manipulate a strong EO (for example, a love of being in the shower), and contrive a situation where one can appropriately manipulate the use of yes and no: the child is in the shower and you ask if they want to get out, prompting “no.” One could use the same motivation and take the child out of the shower and ask them if they would like to get back in (prompting “yes.”)

When using this teaching procedure, it is important to remember that one would NOT ask the questions so that the yes and no immediately followed each other. One would rather run the sequence of: “Do you want this cup?” (no), “What do you want?” (shower -- prompted); at a later stage one would then ask “Do you want to go in the shower?” (yes -- prompted).

Remember that if one has good instructional control, it is a good idea to give some reinforcers for “free.” The idea is to be as natural as possible, and we all often snack while having conversations.

The next step in mand training is to teach the advanced mand, namely manding for information (which, why, how, where, when, etc). As mentioned previously, manipulating the EO for advanced manding is an essential part of the training and one needs to contrive situations where this type of manding will occur.

Video 5: Stephen, age 6, learning to ask for information using the question “how.”

Vince was teaching Stephen to mand for information using the question “how.”

Vince used toys to get Stephen to mand, as he finds these motivating and, therefore, a strong EO exists. While Stephen watched a video, Vince played with one of the toys (while it was hidden) so that it made a very strange noise; he then prompted S to ask, “How did you do that?”

Remember that one needs to immediately answer the question by explaining how one did it. For this reason, one can't keep on using the same toy, because once the child knows how the task was performed, the EO to ask the question again is very weak. One also needs to remember that one shouldn't only use one thing to get the question (e.g., toys) but rather generalize across various opportunities. One could, for example, place a cookie in a container that is very hard to open and give it to the child. When he/she can't open it, one could open it for him and then prompt him to ask how you did it; again, one would immediately answer the question by showing him/her.

Vince also pointed out that one wouldn't drum away at practicing these questions during an echoic drill; there is no motivation for the child to ask them, due to a lack of context. He also pointed out that in the video of Stephen, it might have looked as if the question was being mass-trialed but this is only because it is in the context of manding where a strong EO exists.

For questions using "where," one needs to contrive an EO for location. One could take a desired item that is always found in the same place (juice in the fridge) and wait for the child to mand for it. A tiny bit would be given, so that the EO remains high, and one would repeat this a couple of times in order for an idea of location to be built up. One would then hide the juice in a different place and prompt the mand, "Where is it?" after the initial mand for the item.

One child I worked with loved being tickled and so, after tickling him a few times on his request, I then hid behind a door and prompted him to ask, "Where are you?" His EO for the tickle (and then for location) was so strong that he soon was pushing me behind the door so that he could ask where I was!!

For "which" questions the EO needs to be contrived for choice. One way of doing this is to establish what the desired item is and to then hide it (assuming it is small enough!) in one of your hands. When the child then mands for that item, one prompts him/her to ask "Which hand is it in?"

For "why" questions, the EO is curiosity. One can make the situations funny by putting things in strange places, or doing things in funny ways, and then prompting the child to ask, "Why did you do that?" Remember that it is important that one actually answers the question, otherwise there is no reason for the child to ask it again.

A very effective way of answering the "why" question is to ensure that the answer you give is better than the current EO. One could for example, switch off the television while the child is watching a video and then answer the "Why did you do that?" question by saying that you did it because you wanted to take the child into the kitchen so that you could eat ice-cream.

For "when" questions the EO is time. However, the child does NOT need a knowledge of time (minutes, seconds etc.) to ask the question.

When one has established what the child wants, as they have manded for that item ("I want cookie."), one could say "yes, okay" but not immediately give it to them. One would then prompt them to ask: "When can I have it?" and one would answer by saying "When you have told me how old you are." One wouldn't give the answer as "x minutes", as this will kill the question.

For "who" questions the EO is curiosity for a person.. There are two ways that this EO can be manipulated. Firstly, one could pair an unfamiliar person with something that the child really wants and then prompt the child to ask: "Who is that?" so that they are then able to ask that person for the reinforcer.

Secondly, if an unfamiliar person is not present, one could give the item that the child really wants (cookie) to one person, get them to hide it behind their back and then prompt the child to ask "Who has cookie?"

As with all these questions for information, it is imperative that the "who" questions are immediately answered so that the EO to ask in future is strong.

When teaching mands for information, Vince said that there are no hard and fast rules as to how many one would teach at one time. The child will let you know whether they are able to handle learning all

of them at more or less the same time. These teaching procedures are all conducted during NET as the EO for the item has to be high.

If one is teaching these simultaneously (i.e., not waiting for one to be mastered before moving to the next one), it is very important that one teaches them in different places; the geographical difference really helps in avoiding confusion while they are on acquisition. Furthermore, the EO for each should also differ.

One begins mand training for information when the child has achieved the following: spontaneously: manding for reinforcers; mands for actions, attention and missing items; mands using yes and no; mands with carrier phrases. Following manding for information, one would get the child to mand using adjectives, prepositions, adverbs and pronouns.

Tacts: When the child can mand for reinforcers spontaneously (but before one has worked on manding for actions, attention, missing items, using yes and no, using carrier phrases, manding for information, etc.) one would move to the verbal operant of tacting.

One would start with tacting the child's reinforcers but it is important to note that the transfer of an item from mand to tact does NOT occur automatically; it needs to be taught (using DTT).

Tacts form the foundation of conversation and the echo is used to teach them.

The transfer procedure from echo to tact is that initially the echo is controlling the response but then the item itself begins to control the response. So, if one is teaching the tact for "cup," one would start by saying "What is it?/cup" (child echo's "cup") and this would immediately be followed by "What is it?" with a 2-second delay so that the child has the opportunity to answer "cup." If after 2 seconds no response has occurred, one would immediately say "cup" as an echoic prompt. One would NOT continue doing this procedure immediately but rather ask for an acquired response (e.g., motor imitation), thus avoiding mass trialing, as well as keeping the child successful. One would then return to the tacting of "cup," beginning at the prompt stage that one was last at to get the response, i.e., "What is it?" with a 0-second delay echoic prompt; another teaching opportunity for cup is then given.

The goal at this stage is for the response to be controlled by the presence of the item (and the question, "What is it?"), rather than by the existence of the echoic. Remember, however, that the question, "What is it?" is a prompt and needs to be faded as soon as possible.

It is important to note that the teaching of a tacting repertoire should coincide with the teaching of the receptive discriminations such that these two skills are taught together for each word. Using DTT, both the receptive repertoire and the tact repertoire should be taught simultaneously.

The first tacts that are taught should be nouns; these include objects that the child can mand for (as well as pictures of these acquired mands) and familiar objects and people.

When the child can tact about 25-50 nouns, one would start teaching the tacting of on-going actions. Vince pointed out that one would NOT begin with the tacting of pictures of actions, but rather use objects to perform an action, e.g., a teddy bear jumping, a ball rolling, etc. Once the response becomes strong using the moving object, one would then use pictures of that action for generalization trials.

Unlike the tacting of nouns, there is always an SD for actions; one is aiming for the child to spontaneously tact the objects/nouns that he/she sees, but one would use an SD ("What is the teddy bear doing?") for actions. One would teach as many actions as possible at one time.

Again, one would conduct receptive training trials simultaneously. For example, after a tact trial on clap, the tutor could then say “Show me clapping” or, in the case of pictures, “Touch the girl clapping.”

After teaching the tacting of nouns and actions, one would then move on to teaching Noun-Noun combinations and Noun-Verb combinations. The SD would be, “Tell me what you see” (or a variation of that) with a prompt so as to let the child know what is expected. The idea is that the child is beginning rudimentary sentences and is making multiple responses.

Again, receptive training should be interspersed with the tact training by asking the child to touch two objects from an array of several objects.

Once the child can tact 75-100 nouns and verbs, one should then move on to the teaching of adjectives; these are more difficult to acquire than nouns and verbs.

If teaching colours, for example, one would begin the procedure by using identical cards that differ only by virtue of their colour. One would NOT teach the colours one a time (Mass Trial) but teach all simultaneously using both the receptive and tacting repertoires.

When moving on to the colour properties of objects, one would choose items that are known to the child (something that they can reliably tact) and, for the teaching of the (colour) tact, ask the child “What colour is this ball?” One would use the prompting procedures used when teaching any new concept.

Alternatively, one could do the receptive component by saying to the child, “Touch the one that is red” and, after they have receptively identified it, ask “What colour is the ball?” Therefore, one is first receptively identifying the colour, and then tacting the property of the object. The receptive and tact repertoires are reciprocal.

If one is teaching big and little, one would start using identical objects and then move on to non-identical objects. The SD/prompt for this property would be, “Let’s talk about size.” Again, the tact and receptive skills would be taught alongside one another; one is expecting the child to find by dimension and tact by dimension.

One then works to build the length of the child’s utterance so that the child could tact what he/she sees using Noun-Verb-Adjective combinations. A very important thing to remember is that one is working towards getting the child to tact what they see; the responses are NOT scripted.

Once the child can tact nouns, actions, noun-noun combinations, noun-verb combinations, adjectives and noun-verb-adjective combinations, one would then move on to teaching prepositions and pronouns.

In the case of prepositions, bear in mind that they are more complicated than nouns and verbs due to the fact that they are not tangible -- they cannot be touched or picked up as they provide spatial information about a tangible object.

Again, receptive and tact trials should be run simultaneously. When choosing which prepositions to start training with, contrasting ones such as “in” and “out” may be the simplest way to begin. For the receptive trials the therapist would present the child with two known objects and ask the child to place one of the objects “in” the other. One would use the prompt procedures that are used when introducing any new skills. One would then repeat the trial, following a correct (unprompted) response but using “out.”

Once the child is successful with this discrimination task, one would add tact training by placing the object “in” (or “out”) and asking the child “Where is the (ball)?” When the child is successful with these trials one would then intersperse the receptive trials with the expressive trials.

The next step is that of generalization for these two prepositions by changing the items, the location of the trials and the person conducting them. It is also very beneficial to conduct the trials in the natural environment (when the EO is strong).

New prepositions should be introduced slowly and in a similar way to the above explanation. Again, one would choose contrasting prepositions such as on and off, above and below, behind and in front, etc. Furthermore, one would run these using both tact and receptive trials, and slowly begin to intersperse the prepositions with each other.

For pronouns, it is effective to begin with receptive trials first, using the pronouns “my/mine” and “your/yours.” Using a stimulus that is known to the child AND which clearly belongs to a particular person (e.g., a body part) one would ask the child to “Touch your nose,” prompting the initial response to avoid an error and then fading the prompt. As with any DTT, one would use differential reinforcement.

One would then ask the child to “Touch my nose” using the appropriate prompt procedures. Interspersal of the two trials should then occur to ensure the discrimination, and then one would generalize the two pronouns to other items.

When moving to the tacting of pronouns, IT IS VITAL THAT THE REINFORCEMENT OF THE TACT USES THE **SAME** PRONOUN. So, if one has asked the child “Whose nose is this?” (while pointing to the child’s nose) and the child says “It’s my nose” one would NOT reinforce with “Yes, it’s your nose”; one must reinforce by saying “Yes, it’s my nose.”

This pronoun reversal problem means that one would only introduce one pronoun at a time (“my”) and in the context of a strong EO. So, one could ask the child “Whose video is it?” with a prompt to ensure the child says “my video” ensuring that the verbal reinforcement of a correct response is “Yes, it’s my video.” One could pretend to take the video away while asking whose video it is, and then reinforcing the correct (pronoun) response by returning the video.

For “your” one could get a group of children to hand out a reinforcing item (e.g., a biscuit) saying “Here’s your biscuit.” Each child would have a chance to do the same, eventually getting the “target” child to have a turn as well.

One would then return to the table setting and practice “my” again. Slowly one would bring the two separate situations together.

RFFC: This is the identification of objects by their feature, function and class. As mentioned above, most children can begin RFFC training once they have mastered about 50 words as mands, tacts or receptive discrimination. Also, the child should be able to respond when different carrier phrases are used.

The first set of words to target for the RFFC should come from their mastered list of tacts. One would place two known items on the table, which differ from each other and which come from a different category, for example, an animal vs. a toy. One would initially ask the child to tact and receptively discriminate between these two items to ensure that they are secure.

One would begin with a simple RFFC instruction such as an animal sound and an action. For example: “Touch the one that says oink” (pig) and “Show me the one that you kick” (ball). One would then gradually introduce more items, again asking the simpler kinds of questions (common phrases, common associations, synonyms, animal sounds).

Once the child is successfully identifying (receptively) several items based on the information provided to them, the teacher could then move on to verbal phrases that are more complex, for example, “Touch the one that lives on a farm/has a curly tail.”

It is important to note that while the child is learning the RFFC skills, he/she should still be acquiring more facts and receptive responses. In this way, by the time that the child is learning the classes of items (animal, transport, toy, etc.), he/she will have hundreds of facts.

Therefore, when beginning the RFFC repertoire, one would begin by starting with two known facts and asking the child to receptively identify these items based on information about them. The information given would be that which is most likely to evoke a correct response. So, if a child has often heard the word “animal” or “woof” in conjunction with the word “dog,” then it is most likely that using these bits of information will lead to the child touching the picture of the dog. Likewise, if “tail” and “legs” have seldom been heard by the child in the context of a dog, then it is unlikely that the child will associate these aspects.

Once the child can identify several items based on a couple of bits of information about each item, one would then begin to introduce more complex stimuli about those items to evoke the response.

Another way in which the complexity of the task can be increased is to increase the visual field. One could begin with 2-3 items and then gradually increase the field to 10-20 items.

Furthermore, different carrier phrases can be used so as to teach the child to respond to a variety of verbal instructions. Also, the tutor could request that the child perform different motor behaviours in the RFFC discrimination, for example, “Pick up, Point to...”

There are no set rules about when to make the RFFC repertoire more complex (by type of information, size of visual field, type of carrier phrase). If the child is successful with the simpler stimuli, shown by a quick response time and minimal need of prompting, then it is likely that they are ready to move on to more complex tasks. If, however, the child is attempting to escape and is requiring a lot of prompting, then it is likely that the task is too difficult.

An important way of reinforcing the RFFC repertoire is to use it as much as possible in everyday life. One could, for example, request that the child gets the thing that they like to drink or runs to the thing that has branches and leaves.

Another important aspect of the RFFC procedure is to intersperse it with the other skills that the child is learning. Within the context of doing the RFFC, using an array of pictures, one could also ask the child to tact the item, receptively identify it, echo the name of the item (thereby improving articulation), mand for the item, etc.

The RFFC repertoire is used as a bridge to the intraverbal, and the reason for teaching the child to receptively identify something based on the information provided is that this is the foundation for conversation. The procedures used to achieve this will be described below.

Intraverbal: The intraverbal repertoire is the conversational repertoire wherein what someone says is determined by what another person says, but the two responses do not match each other; if they did match, then it would be an echoic.

For the teaching of a beginning intraverbal repertoire, it is best to begin in the natural environment. If the child is watching a video, one could join in with the singing of a song and leave out the last word: “Postman Pat and his black and white ___”

These fill-ins are an important way to begin the intraverbal training and should be included in everyday situations as much as possible (“You wash your ___”/ “You watch a ___”)

The RFFC repertoire is used as a bridge to the intraverbal and the basic procedure is to fade out the picture following a correct RFFC response, and then to develop the verbal stimulus to a question. So, once the child has been asked to: “Touch the one you eat”, the picture (of the cookie) is then removed (or you work towards removing the picture, beginning by removing it on occasion) and the instructor says: “You eat a ___” (this is an intraverbal fill-in); one would then develop the question to “What do you eat?” (WH question). At this point, the response that is required is the same, namely the child is required to say the word “cookie.”

A reversal then occurs “A cookie is something you ___” (reversal, fill-in) followed by a WH question: “What do you do with a cookie?” (WH reversal).

The procedure described above is not necessarily one that is done all at one time. The fill-ins are easier to do than the answering of the WH questions, so they are used as a prompt to get the child to be able to answer the WH questions. The answering of WH questions is a more advanced type of intraverbal and thus the child should be relatively confident with the intraverbal fill-ins prior to attempting to transfer these to the answering of the WH questions.

It is important to remember that training in the RFFC and Intraverbal repertoire needs to be done on a daily basis since, without this, these more complex verbal behaviours will not be successfully taught. It is also important that a lot of natural environment training is done so that if a child is requesting a cookie, for example, the opportunity to use this interaction to have a conversation should be taken.

Furthermore, it is imperative that interspersal is occurring so that the child is experiencing mixed VB. One would include mands, tacts, imitation, intraverbals, etc. during a session.

As already mentioned, the answering of WH questions is a more complex intraverbal; and so, once the child can reliably answer fill-in-the-blank questions, a transfer to the WH question should occur. This transfer would occur once the child can answer several fill-ins including fill-in reversals.

For example, if the child has just answered “You eat a ___” (cookie), one would immediately ask: “What do you eat?” As the child has just answered “cookie” it is highly likely that he will repeat the word. One would then use a distracter trial (“Touch your tummy”) and then return to “What do you eat?” If the child requires a prompt to answer the question, then one would return to the fill-in the blank (which you know is reliable).

One would intersperse the target trial with other distracter trials until the child can reliably answer the WH question. It is ideal to vary the question as soon as possible so that rote responding is avoided.

Once the child is successful with this question, one would move on to another WH question (using the RFFC and the fill-in as a bridge to success with the questions). The goal is for the child to be able to

respond to a number of simple questions (What do you eat, Name me a colour, Tell me an animal, What do you sit on, Tell me something you blow, etc).

One then wants to increase the length of the child's utterance so that they can respond, for example, to the question "Tell me some colours."

The way to teach this skill is to place three colour cards on the table (colours that the child can reliably tact) and use these as a prompt for the child to answer the question: "Name me some colours." After this is done successfully, one would then turn over one of the cards and repeat the question, pointing to the overturned card to remind the child to still label that "missing" colour. This process continues until the child can tell you the three colours even when they are not present. It is important to remember that one would NOT mass trial this procedure but would rather intersperse the learning of this task with distracter trials.

One also needs to work on getting the child to answer questions about an item. If, for example, the child is shown a picture of juice, one could then proceed with a number of questions about that item. "What is it?" "What do you do with it?" "Where do you keep this?" etc.

The above two procedures need to be done in order to extend the child's intraverbal repertoire, but the order in which they are done is not important.

The next step in the teaching of an intraverbal repertoire is to extend the amount of information that is given in the question, thereby increasing the amount of information that the child has to attend to. Again, one would use the prompting procedures explained above, ensuring that the information that is in the question is that which the child can reliably respond to. So, one would include attributes such as "hot" and "cold" if the child can reliably tact those concepts.

In the workshop, we were given vital information about compliance training vs. instructional control, dealing with maladaptive behaviours, toilet training etc. I am writing these notes as a separate set (I think these are sufficiently long!!!!!!!!!!!!!!!!!!) and will post them soon.

Norah Whitney's Notes on Manding for Information

From: "N.WHITNEY" <nwhitney@olsusa.com>

Please note that NOT all material is mine, a great deal came from the help of the lovely Ms. Jenn Godwin and ideas from Dr. Carbone and a few very imaginative parents I have adapted it to fit my son's interests

Manding for information is absolutely crucial to the development of conversational skills. If one thinks about what a conversation is between two people, it is a series of questions and statements.

My child with autism needs to learn the power of information and move it from a HIGH interest re: getting something he REALLY wants to a more natural context which I deem in this instance to be "social reinforcement". Since Social Reinforcement in my child is low with other children and or seeking information for the pleasure of an answer and nothing more, I have developed a LEVEL 1

Program that uses HIGH reinforcement to my son , to get him to WANT to ask questions. Once he is spontaneously using these across many environments we will introduce what I consider LEVEL 2 manding for information which is much more socially based., e.g., Instructor: “ I went to see a movie.” Child: “What did you see?” or “Which one?” Instructor (initially choosing HIGH interest topic of child): “The Rugrats in Paris” or “Star wars.” From there it would decrease so that the instructor’s answer MAY NOT be a particular area of interest to the child but decreasing level of interest slowly to not compromise attending.

I will send separate posts on each question. **Please remember that this may not suit all children with autism and above all please remember I am a parent not a professional.** I always advocate having your consultant review material that may be of interest to you from the ME list and or other autism lists.

Subject: Manding for info LEVEL 1 using Who

Program Objective: Manding for information using questions -- Using NET in contrived or non-contrived learning opportunities, the Instructor will teach Lucas to mand information by asking “WHO” using the following:

1. EO (Establishing Operation = natural motivation) HIGH

- Have three people in the room and present the Sd: “Someone has a gummie for you” or other desired item
- Prompt IMMEDIATELY “Who?” , “Who does?”
- Then give the name of the person (try to use a peer if possible). Luke goes and gets reinforcement
- Fade prompt at next given opportunity

2. EO LOW

- Instructor presents pictures of known people, e.g., mom, dad, grandparents and unknown (non-professionals, e.g., Cindy Crawford)
- The instructor holds up one picture at a time
- The Sd is given only once at the beginning of teaching opportunity: “Who is this?”When an unknown person is held up
- Prompt IMMEDIATELY: “Who is that?”

Note: The stimulus should be presented in this manner and not placed on table so that in early training Luke will not confuse the “What is it “ program with the “Who is it “ program and overgeneralize mands

- Fade prompt at next given opportunity.

3. EO LOW to MEDIUM

- Using toys that are reinforcing to Luke the instructor will quickly hide a toy character, e.g., buzz lightyear behind a barrier
 - Present the Sd “Guess who is behind here”
 - Prompt IMMEDIATELY: “Who?”
 - Show and tact item and deliver it as reinforcement
- Note: That is why is it critical to establish figure as EO
- Fade prompt at next given opportunity.

4. EO MEDIUM

- Instructor takes Luke into observation booth or uses other appropriate door.
- Someone knocks.
- Prompt IMMEDIATELY: “Who is it?” “Who’s there?”
- Fling door open to reveal identity
- Deliver reinforcement
- Fade prompt at next given opportunity.

Program Objective: Manding for information using questions LEVEL 1 -- conditioned EO’s -- Using NET in contrived or non-contrived learning opportunities the Instructor will teach Lucas to mand information by asking “When,” using the following;

Teach WHEN, when there is an EO for a reinforcer that is inaccessible at the time.

1. EO HIGH

- Instructor will place highly desired item/reinforcer on the table.
- Luke will mand for it.
- Instructor will say “Not right now” , “Not now”
- Prompt IMMEDIATELY: “When?”, “When can I have it?”
- Note: Fade prompt as soon as possible.
- Instructor says “After you clap your hands” or “After you do this” (and models clapping hands)
- Desired reinforcer is delivered as soon as Lucas claps. “Now you can have the gummy”

2. EO HIGH

- Using a peer and a HIGHLY desired reinforcer
- Give peer the reinforcer
- Prompt Luke IMMEDIATELY: “When can I have it?”, “When is it my turn?”
- Note: Fade Prompt as soon as possible.
- Instructor “After Camilla is done with it.”
- Prompt Peer to put it down. REINFORCE PEER with other desired reinforcement
- Instructor to Luke “Now you can have it.”

Initially the time between the mand and the deliverance of the reinforcer should be VERY short less than 15-30 seconds, gradually build up the time to have to wait for reinforcer

3. EO HIGH

- Instructor presents Sd “We’re going to eat some candy.”
- Prompt Luke: “When?”
- Fade Prompt as soon as possible.
- Instructor “After you say CANDY.”
- Instructor “Okay, lets eat candy now.”

4. EO HIGH

- Instructor says “We’re going to the store/snack bar.”
- Prompt IMMEDIATELY: “When are we going?”
- Fade Prompt as soon as possible.
- Instructor “Right after you put on your shoes.”
- Larger time delay “Right after we make a picture.”
- Deliver reinforcement of “going” to the snack bar/store

Subject: Manding for information LEVEL 1 using WHAT

Program Objective: Manding for information using questions -- Using NET in contrived or non-contrived learning opportunities the Instructor will teach Lucas to mand information by asking “WHAT” using the following;

1. EO HIGH

- The instructor will bring in a paper bag with things Lucas likes inside the bag, e.g., marshmallows, little toys, gummies, lego books
- The instructor will look in the bag and with exaggerated expression (facial) give SD which will be “Wow look what I have”, “Wow you should see this”
- Prompt Luke IMMEDIATELY “What is it?” , “What’s in there?”
- Instructor promptly removes EO and delivers it
- REPEAT above
- Prompt IMMEDIATELY: “What ELSE is in there?”
- Fade prompt at next given opportunity

2. EO LOW

- Instructor presents a field of three or more stimulus using 2d cards and 3d objects
- Present SD “ tell me what is on the table” , “What do you see?”, “What are these?”
- With UNKNOWN item placed within the field Prompt Luke IMMEDIATELY as soon as he is finished tacting last known item: “What is this?” , “What is it?”
- Instructor will label item
- Reinforcement is delivered
- Fade prompt at next given opportunity

3. EO HIGH

- Instructor presents Sd “ I have a surprize for you”, “ I have something for you”
- Prompt IMMEDIATELY “What is it?” “What do you have?”
- Deliver reinforcement while tacting it, e.g., a gummie
- Fade prompt at next given opportunity

4. EO HIGH

- Instructor presents Sd “ I feel like playing” , “ I want to play”
- Prompt IMMEDIATELY “What?” , “Like what?”
- Instructor yells “ CHASE! RUN!”
- Fade prompt at next given opportunity

5. EO MEDIUM to HIGH

- With several stimulus placed on the table including desired items, e.g., marshmallow
- The instructor gives the Sd “ give me that” but is NON specific nor prompts in anyway either visually or with gesture
- Prompt IMMEDIATELY “What?” , “Give you what?” “What do you want?”
- Instructor specifies the DESIRED item and delivers reinforcement and says “Ah, thanks, but you can eat it for me”
- Fade prompt at next given opportunity

6. EO MEDIUM to HIGH

- From a distance the Instructor will call Luke’s name
- Prompt IMMEDIATELY “What”
- Instructor says “ here I have a marshmallow for you” or some other desired item
- Note: Make sure the reinforcement is MORE reinforcing then present activity and that it is TRULY desired

Subject: Manding for information LEVEL 1 using WHERE

Program Objective: Manding for information using questions -- Using NET in contrived or non-contrived learning opportunities the Instructor will teach Lucas to mand information by asking “WHERE” using the following;

1. EO UNSPECIFIED

- Present Luke with a closed box with a PRE identified EO, e.g., marshmallow in it
- SD “This is for you”, “Here, this is for you”, “There is something in the box for you”
- This will be done two times, but on the third the box will be empty.
- Prompt Luke IMMEDIATELY “Where is my marshmallow?” , “Where is the marshmallow?”
- Deliver the EO/marshmallow “Oh, here it is”
- Repeat a fourth time or as many times as necessary until you reach an independant
- Fade the prompt as quickly as possible

2. EO UNSPECIFIED

- While doing an activity, e.g., a puzzle, the instructor will abruptly end the activity with no warning and stand up and say “Come on”, “Let’s go”, “Hurry”, etc.
- The instructor will prompt Luke IMMEDIATELY “Where are we going?”

- The instructor will make sure the answer, e.g., outside to play is MORE reinforcing than the previous activity.
- Note: If choosing an activity with some distance, e.g., outside, the instructor will then find an even more reinforcing activity to avoid a behaviour, e.g., “Let’s go back in and do a cool Lego.”

3. EO UNSPECIFIED

- With increased increments of distance (to ensure compliance) the Instructor will give the SD “Get the _____”, “Give me the _____”, “Go get your_____” , requiring Luke to find an item necessary for another function, e.g., Go get your shoes” EO “so we can go outside” , “Go get your back pack” EO “so you can go home”, “Go get your swimsuit” EO “so you can go swimming”, “Go get your toothbrush” EO “so you can brush your teeth”
- The necessary item will NOT be available.
- Prompt Luke “Where are my shoes?” “Where is my backpack?” “Where is my swimsuit?” “Where did my toothbrush go?”

4. EO UNSPECIFIED

- Have Luke come to sit, but have no chair for him.
- Prompt “Where is my chair” , “Where did the chair go?” , “Where is the chair?”
- Act like “Oh, I forgot your chair.”
- Fade prompt as quickly as possible at next given opportunity

5. EO UNSPECIFIED

- Have Luke sitting and suddenly get up and say “ I’ll be right back”, “Hang on a second”
- Prompt “Where are you going?”
- Answer “To get this gummie for you”
- Fade prompt as quickly as possible at next given opportunity

6. EO UNSPECIFIED

- Instructor will deliver lunch with no utensils
- Prompt “Where is my spoon?” , “Where is my fork?”
- Fade prompt as quickly as possible at next given opportunity

7. EO UNSPECIFIED

- Instructor will present crafts with one necessary item missing, e.g., glue
- SD “Okay, put some glue on it”, “Get the glue ready” “Let’s glue it now”
- Prompt “Where is the glue”
- Fade prompt as quickly as possible at next given opportunity

8. EO UNSPECIFIED

- Have Luke come to the table for preferred activity, e.g., LEGO, but have ONLY one piece on the table
- Prompt IMMEDIATELY “Where is the rest”, “Where are the other pieces”
- Fade prompt as quickly as possible at next given opportunity

Subject: manding for information LEVEL 1 using WHY

Program Objective: Manding for information using questions -- Using NET in contrived or non-contrived learning opportunities, the Instructor will teach Lucas to mand information by asking “WHY” using the following;

1. EO UNSPECIFIED

- The Instructor will put Luke’s chair on the table while Luke is engaged.
- When Luke returns to the table the instructor will Prompt IMMEDIATELY: “Why did you do that?”
- “Why is the chair there?” “Why is the chair on the table?”
- Instructor answers with something that makes sense, e.g., I was cleaning the floor and look what I found under your chair
- Instructor delivers reinforcement
- Fade Prompt as soon as possible.

2. EO UNSPECIFIED

- Instructor delivers Sd “ I am going outside to play”
- Prompt IMMEDIATELY: “Why can’t I go?”
- Instructor “ YOU CAN!!!! Follow me”
- Instructor takes Luke out to play one game of chase

3. EO UNSPECIFIED

- At Lunch the Instructor puts a NON food item on Luke's plate
- The Sd is presented "Here ya go; eat" , "Here's your lunch" , "Hope you're hungry"
- IMMEDIATELY prompt Luke: "Why did you do that?"
- Instructor acts as if they got it mixed up and presents Luke with proper plate

Note: At this time the "Where" program could be chained "Where is my fork"

4. EO UNSPECIFIED

Instructor pretends emotional states

- Instructor cries
- Prompt IMMEDIATELY: "Why are you crying?"
- Instructor: "Because I'm sad and need a hug"
- Prompt Luke to HUG and begin tickling and or deliver other appropriate reinforcement

- Instructor laughs
- Prompt IMMEDIATELY "Why are you laughing?"
- Instructor: "Because I saw something funny" , "Because I feel happy"

- Instructor acts mad and says "Darn" [Grrr]
- Prompt IMMEDIATELY "Why are you mad?"
- Instructor: "Because I broke my Lego; will you help me fix it?"
- EO is built in here since Luke loves Lego, so reinforcement is already there by fixing it with him

5. EO UNSPECIFIED

- Luke is doing a reinforcing activity, e.g., watching TV
- Instructor turns it off with no warning
- Prompt IMMEDIATELY: "Why did you do that?" , "Why did you turn it off?"
- Instructor so we can go to the playground for a bit.

Note: NEVER EVER CHOOSE THE COMPUTER FOR THIS YOU MAY TRIGGER A SEIZURE WITH TURNING IT OFF QUICKLY. Instead, choose TV , music, a remote toy

Note: Remember the instructor must pick an answer that is MORE reinforcing to Luke than what he was just doing

From: "Kelly Wiggins" <sparky8199@earthlink.net>

Subject: Re: 1,000 mands a day

Hi all,

I use every single thing in Connor's life to get him to mand. We have to do at least a thousand mands a day though I have never actually counted them.

Example of part of his day:

Morning

He asks for milk and I tell him he first has to pick out the pants he wants to wear. (I usually try to get him to do something else before getting the reinforcer, in this case it is the milk. This delays the reinforcer. He knows from this routine the he has to do something else before getting to the reinforcer. this works well with him since he is easy to make deals with). I ask him what color he wants. "What are you doing?" "...putting my pants on." Then I ask, "Now what do you want?" He then tells me, "I want milk please mama." Then I ask him what we put the milk in...cup...Where is the milk?...refrigerator...What do we put the milk in?...cup...What color is the cup?...blue....What am I doing?...pouring the milk.....What is in the cup?...milk...What color is the milk....white....What are you going to do with the milk?...drink the milk.

Through out the entire day I do this for everything he wants. I try not to let any opportunity pass to get him to mand.

If he wants to play a game on the computer or playstation (strong reinforcer for him) we go through everything we can about what he wants before he gets it. It helps that he has many strong reinforcers.

It might be easier for me though, since I stay at home with him and am the one being trained in ABA DTT. I have no staff so it makes for a long, but very rewarding day :)

I hope this helps a bit. I am only 3 months into training, still rather new to all this.

From: "Rhonda Miga" <ramiga@earthlink.net>

Subject: RE: Workshops about DTT NET / Verbal behavior

Hi Caroline, I am glad that you have added the component of VB to your already existing ABA program. I would like to make sure that you do not do a 100% switch. As the founder of DTT-NET, it has been very difficult for me to get across to our readers that VB is a "component" of a good ABA program (in many cases the missing component), not a methodology within itself.... for our children on the autism spectrum.

There are many other components that do not pertain to language that need to continue. (We made this mistake and stopped everything else.... it hurt my son's progress greatly).

Drs. Sundberg and Partington have the best explanation for using VB in an ABA program (and the best training through the STARS school that I have seen). The first day of a workshop, the STARS staff make sure that participants know that "good teaching" is the backbone of any program. Follow

through and providing the child with a clear understanding of what is expected is key. (Sd -- R -- Rd).

If you do not already have S/P's book "Teaching Language to Children", it will be a wonderful investment for you. Read chapter 13 first, so you have an understanding of how DTT and NET work together for success.

I have always been taught if you are too tired to follow though, if the child does not respond, then do not ask. (example: "pick up your toys", if you are too tired to prompt the child then do not ask because your "words" will lose meaning to the child.) By making sure that there is a reinforcement or consequence for the child's actions will also strengthen the meaning of language to him/her.

How often have many of us told a typical child to "come here" while sitting on the couch watching tv and the child runs the other direction and we do not go get them. We just say it again "come here", getting louder and louder and more frustrated. But if a child learns early on that there is no choice in the matter, they are more likely to come when they are told. (thus, the need to physically prompt and gradually fade the prompt).

Appendix 13

Kathy Lear's "Help Us Learn" Training Manual and Program Manager's Guide are available through her website, www.helpuslearn.com

Appendix 14

The Ontario Government's Program for Autistic Children is available at:

<http://www.gov.on.ca/CSS/page/services/autism.html> The following information is taken from that website:

“Autism is one of the most severe developmental disorders of childhood, occurring in at least 1 in 1000 children. Many people with autism have severe relationship and communication problems, in addition to motor, sensory and cognitive difficulties.

Until recently, only a small proportion of children with autism were expected to achieve independent functioning as adults. Most were expected to require life long health, education and social services. That expectation is now hanging with evidence that outcomes for many autistic children can be dramatically improved when they receive intensive early intervention services.

The Ontario Government is providing new funding for intensive early intervention services for autistic children age across Ontario. The Ministry of Community and

Social Services, through the Office of Integrated Services for Children, is proceeding with implementation of this initiative.

This is the first time specialized funding for intensive early intervention services for autistic children has been made available in Ontario. Five years ago, no province was funding these specialized services. Today, Ontario is one of the provinces taking a lead in this area.

The program will augment services already in place for children with autism by providing new funding for:

- Individual service plans

- Intensive behavioural intervention services

- Training for professionals in best practices in early identification, diagnosis, assessment and behavioural intervention for children with autism

- Training for parents so they can support their child's treatment at home

- Evaluation that will ensure the program is effective

The Intensive Early Intervention Program will be provided by regional service providers throughout the province. The regional programs will be expected to either provide these services directly or through a purchase of service arrangement with another organization. They will also be required to give each family the option of direct funding to purchase intensive behavioural intervention services privately.

This investment in intensive early intervention services for children with autism addresses an important service gap and offers the opportunity for a better quality of life for children with autism and their families.”

Preliminary Program Guidelines and Curriculum Outlines are available for download as PDF files.

Appendix 15

The Flash! And Flash! Pro2 CD's are available through:

<http://www.iusastore.com/cgi-bin/ePages.storefront/EN/ePages/Customer/HomePage/5126>

The Flash! CD-ROM has 5000 Photos in 50 Categories, while the Flash! Pro2 CD-ROM has all the pictures of Flash! plus 15 extra categories with a total of over 8500 pictures. Cost is about \$50 U.S and \$75 U.S., respectively. Shipping is free to any address worldwide.

Appendix 16

The last time I looked the ME-List archives contained the following files:

ABATestimonials1.html 08-Jan-00 14:23 271K
ABATestimonials2.html 01-Jul-01 07:51 85K
ABA_methods.html 13-Jun-01 11:39 35K
ABA_older_kids1.html 13-Jun-01 10:05 100K
ABA_older_kids2.html 10-Jan-01 22:53 101K
ABAreferences.html 25-Feb-01 17:23 55K
ActivitySchedules.htm+ 20-Aug-01 08:47 21K
Apraxia.html 27-Oct-98 08:36 7K
Asperger.html 09-Feb-00 10:18 54K
AutismPrevalence.html 26-Oct-00 10:06 62K
AutonVsBritColumbia.p+ 20-Aug-01 20:38 73K
BiomedProtocol.html 15-Feb-01 12:02 28K
CF_GFDiet.html 23-Sep-98 17:34 12K
Cost_Benefit.html 08-Sep-98 10:38 15K
Cotazym.html 26-Feb-99 10:24 4K
DirectInstructDistar.+ 13-Aug-01 12:41 12K
Disneyland.html 15-May-01 13:40 4K
Dolphin_Therapy.html 20-Sep-98 21:15 20K
Drills_1.html 12-Aug-01 07:59 117K
Drills_2.html 12-Aug-01 08:00 151K
Drillssocial.html 18-Aug-00 13:23 11K
Eikeseth99paper.html 26-Oct-00 10:10 31K
EpsomSalts.html 05-Nov-00 06:49 62K
Extended_year_ed.html 29-May-00 09:46 115K
Facilitate_Communicat+ 22-Feb-00 12:48 96K
FlowchartLovaas.pdf 08-Jun-00 14:59 7K
Giant_Steps.html 30-May-98 08:38 27K

GoingToSleep.html 16-Jul-98 11:25 14K
GreenspanFloortime.ht+ 03-May-01 09:08 196K
HarrisHandlemanJADD00+ 22-Dec-00 17:50 20K
HidingDiagnosisDebate+ 06-Jul-01 13:25 106K
IEP1.html 02-Oct-00 09:01 122K
IEP2.html 08-Nov-99 12:09 116K
Images/ 07-Jan-01 18:08 1K
JADDBehav10_00.html 29-Nov-00 20:44 41K
Jurisprudence.html 13-Feb-99 09:42 178K
Landau_Kleffner.html 08-Apr-01 12:39 133K
LeakyGutTheory.html 03-Nov-00 17:28 40K
Lovaas98Conf.html 07-Jan-99 18:56 27K
LovaasReplicPrelResul+ 01-Nov-00 13:05 69K
Lovaasdescrip1.htm 22-Feb-00 16:08 126K
Lovaasdescrip2.htm 22-Feb-00 16:08 163K
Melatonin.html 14-Apr-00 14:31 40K
MillerMethod.html 18-Dec-00 19:21 17K
Montessori.html 22-Jun-00 09:59 55K
MostFreqwords.html 27-May-01 16:33 22K
Naltrexone.html 05-Oct-99 10:28 33K
NoNoPromvsErrLess.htm+ 14-Jun-01 09:50 27K
Option.html 24-Feb-00 21:32 111K
PEC_Method1.html 01-Jun-01 10:49 86K
PEC_Method2.html 26-Oct-00 09:30 111K
Parentparticip.html 09-Oct-98 15:53 31K
Playdates.html 26-Oct-00 09:28 64K
PosExtinctBehav_DRO.h+ 20-Jun-01 16:42 58K
PostABAPrograms.html 27-Mar-01 14:49 15K
Predicting_recovery01+ 03-Nov-98 16:56 14K
PromptStrategy.html 03-Mar-01 07:33 70K
RecoveryStories1.html 30-Jun-01 17:42 137K

RecoveryStories2.html 16-Aug-01 10:14 64K
Regression.html 05-Dec-00 09:00 10K
Reinforcers.html 11-Jul-01 11:29 130K
ReplicationPapers/ 07-Jan-01 22:22 1K
Resource_BooksForABA.+ 20-Apr-00 20:07 88K
ResultsTherapyPoll.pd+ 01-Mar-01 16:41 8K
RimlandPoll.gif 20-Dec-00 20:18 234K
SI_AIT1.html 15-Jan-01 21:23 89K
SI_AIT2.html 05-Feb-01 19:50 111K
SchoolProg.html 02-Jul-01 19:41 11K
Secretin1.html 12-Aug-99 13:53 89K
Secretin2.html 12-Aug-99 13:55 106K
SmithLovaasReplic.htm+ 07-Jan-01 22:18 2K
SocialSkills.html 12-Jul-01 09:51 66K
SocialStories1.html 15-Feb-01 10:10 127K
SocialStories2.html 13-Aug-99 11:16 140K
Speech_Lang_Pathol.ht+ 18-May-01 09:24 142K
StartingABA1.html 02-Jul-01 10:21 84K
StartingABA2.html 18-May-01 09:18 77K
SumlinNotes1_28.html 05-Jul-01 10:13 236K
SumlinNotes29_40.html 05-Jul-01 10:13 86K
TEACCH.html 20-Feb-00 13:11 108K
TEACCH_Lovaas.html 05-Dec-00 09:05 84K
TheoryofMind.html 23-Nov-98 07:21 63K
ToiletTraining.html 17-May-01 17:19 45K
Tokensystem.html 17-May-99 12:31 14K
TreatmentOptions.html 05-Jul-01 10:10 44K
VerbBeh_NETVsLovaas.h+ 21-Aug-01 09:38 116K
VerbalBehav_NET.html 16-Aug-01 10:09 121K
VideosABA.html 26-Feb-01 08:57 20K
VisionDrills.html 13-Sep-99 09:33 19K

VisionTherapy.htm 13-Oct-99 13:08 3K

WiscLovReplicRes.html 07-Jan-01 21:35 53K

Yeast_Candida.html 02-Oct-98 17:30 35K

Zelazo.html 15-Dec-00 21:07 46K

Appendix 17

Autism Society Ontario Chapters and Presidents¹

Brantford, Ontario Area

Brant & County Chapter

Clifford B. Gowan, President

Tel: 519-759-8891

e-mail: ktgowan@hotmail.com

Web site: www.asochapters.org/brantford/

Cambridge, Ontario Area

Cambridge Chapter

Ray & Chantal Brazil, President

Tel: Res: 519-653-8222

Work: 519-621-4800 ext. 259

Fax: 519-621-7793

e-mail: randcb@sprint.ca

Web site: www.asochapters.org/cambridge/

Chatham-Kent Area

Office Tel: 519-352-7827

e-mail: ckasfrn@netrover.com

Tony & Marianne Knox, Presidents

Tel: 519-352-7945

Web site: www.asochapters.org/chatham/

¹ Since this information changes yearly, this is obviously out-of-date. The update can be found at www.autismontario.com

The Chatham-Kent Chapter serves families located in the Municipality of Chatham-Kent. They offer information and support for families with a child/children diagnosed with Autism Spectrum Disorder. The office has a resource library available to the community.

Orangeville and Area

Dufferin Chapter

Kim Armstrong, President

Tel: 519-941-9737

e-mail: kym_armstrong@hotmail.com

Web site: www.asochapters.org/orangeville/

Pickering, Whitby and Area

Durham Chapter

Lynn Kyneston, President

Tel: Res: 905-839-3768

Work: 416-657-2673

Fax: 905-839-3768

e-mail: lyn@ca.ibm.com

Web site: www.asochapters.org/pickering/

Port Elgin-Owen Sound Area

Grey-Bruce Chapter

Mary Rich, President

Tel: Home: 519-794-4430

Work: 519-373-1986

e-mail: gb.aso@bmts.com

Web site: www.asochapters.org/port-elgin/

Oakville Area

Halton Chapter

Cindy Faria, President

Tel: 905-825-1344

e-mail: asohalton@home.com

Web site: www.asochapters.org/oakville/

Hamilton Area

Hamilton-Wentworth Chapter

Kelly Anderson, President

Tel: Home: 905-627-9168

Fax: same

Web site: www.asochapters.org/hamilton/

Kingston and Area

Kingston Chapter

David Parkhill, President

Tel: Home: 613-389-2285

e-mail: parkey@cicable.net

Web site: www.asochapters.org/kingston/

London Area

London & Middlesex Chapter

Patricia Gallin, President

Tel: Home: 519-473-5999

e-mail: gallins@primus.ca

Web site: www.asochapters.org/london/

Toronto Area

Metro Toronto Chapter

Dr. Russell Tanzer, President

Tel: Chapter office: 416-489-0702

Web site: www.asochapters.org/toronto/

Niagara Region

Niagara Region Chapter office

Tel: 905-682-2776

Fax: 905-682-5609

Kathy Rubino, President

Tel: 905-735-509

e-mail: autismsocietyniagara@on.aibn.com

Web site: www.asochapters.org/niagara/

Support to families, information to parents and the community, act as spokespeople, hold monthly membership and executive meetings and fundraising events.

North Bay and Area Chapter

Yvette Bellefeuille, President

Tel: 705-472-6807

e-mail: belfy@onlink.net

Web site: www.asochapters.org/northbay/

Ottawa Carlton Area Chapter

Elizabeth McRae, President

Tel: 613-230-6305

Fax: 613-237-4874

e-mail: emcrae@sympatico.ca

Web site: www.asochapters.org/ottawa/

Ottawa Carlton Area French Chapter

Huguette Boisvert, President

Tel: Work 613-722-5608

Home: 613-722-2482

e-mail: boisvert@istar.ca

Web site: www.asochapters.org/ottawa-french/

Peel Region, including Mississauga

Peel Chapter

Kate Fisher, President

Tel: Home: 905-821-7046

Fax: 905-821-7217

Web site: www.asochapters.org/peel/

Peterborough and Area

Peterborough Chapter

Joyce Fee, President

Tel: 705-743-9315

e-mail: jfee@accel.net

Web site: www.asochapters.org/peterborough/

Renfrew and Area

Renfrew Chapter

Lending library, occasional meetings and special speakers

Susan Sullivan, President

Tel: 613-584-4207

e-mail: aa906@valleynet.om.ca

Web site: www.asochapters.org/renfrew/

Sarnia and Area

Sarnia Lambton Chapter

Lily Verhoeven, President

Tel: 519-786-4387

e-mail: verhoeve@xcelco.on.ca

Web site: www.asochapters.org/sarnia/

Sault Ste. Marie and Area

Sault Ste. Marie Chapter

Barbara Gjos, President

Tel: 705-782-6379

Fax: 705-785-3042

e-mail: gjosb@soonet.ca

Web site: www.asochapters.org/saultstemarie/

Simcoe and Area

Simcoe County Chapter

Sandy McFadden, President

Tel: 705-326-1421

Fax: 705-326-1617

e-mail: themcfaddens@home.com

Web site: www.asochapters.org/simcoe/

Sudbury and Area

Sudbury & District Chapter

Katrina O'Neill-Major, President

Tel: 705-688-9303

Web site: www.asochapters.org/sudbury/

Thunder Bay and Area

Thunder Bay Chapter

Sheila Waywanko, President

Tel: Work: 807-625-7609

Home: 807-473-4666

e-mail: waywanko@tbaytel.net

Web site: www.asochapters.org/thunderbay/

Upper Canada Chapter

Upper Canada Chapter serving the areas of: Stormont, Dundas & Glengary,

Prescott-Russell, Leeds-Lanary-Grenville

Heidi Kaack, President

Tel: 613-346-5745 e-mail: hkaack@glen-net.ca

Web site: www.asochapters.org/uppercanada/

Kitchener-Waterloo Area

Waterloo Chapter

Judy Kirkwood, President

Tel: 519-884-4676

Fax: 519-884-0426

e-mail: judy.kirkwood@home.com

Web site: www.asochapters.org/kitchener/

Guelph & Area

Wellington Chapter

Erica Gatten, President

Tel: Work: 519-843-1490

Home: 519-843-1163

Fax: 519-843-4112

e-mail: dr.jon.gatten@sympatico.ca

Web site: www.asochapters.org/guelph/

Sturgeon Falls & Area

West Nipissing Chapter

Anne Gingras, President

Tel: 705-753-5326

Fax: 705-753-5226

e-mail: bill.gingras@sympatico.ca/[ast13@hotmail](mailto:ast13@hotmail.com)

Web site: www.asochapters.org/sturgeonfalls/

Windsor, Essex County Area

Windsor/Essex Chapter

Jennifer Suzor, President

e-mail: jsuzor@kirwinpartners.com

Chapter Office: 519-250-1893

Web site: www.asochapters.org/windsor/

York Region Chapter

Cindi Buick, President

e-mail: cbuick@istar.ca

Chapter Office: 905-780-1590

Web site: www.asochapters.org/york/

Appendix 18

<http://www.ChristinaBurkABA.com/> (Christina is an experienced ABA therapist and consultant who also conducts VBA training and is exploring its application in play/social situations. I particularly want to direct you to two of the files on her website: Effective Teaching Procedures and Errorless Learning. They will give you a lot of the information that you need for running an effective ABA program.)

<http://cecp.air.org/fba/default.htm> (Functional Behavioral Analysis)

<http://www.coping.org/earlyin/content.htm> (Early identification, including developmental milestones and Greenspan's emotional and functional development scales.)

<http://www.wmich.edu/aba/publications.html> (Journals)

<http://www.gumnut.bc.ca/homeaba/> (Home ABA guide, etc.)

<http://www.behavior.org/> (Cambridge Center for Behavioral Studies.)

<http://members.tripod.com/~RSaffran/> (ABA Resources website)

<http://members.tripod.com/~Rsaffran/aba.html#evaluation> (More on ABA. A very rich site.)

<http://www.bbbautism.com/> (Part of the Autism Support Net Ring. It has many useful printable articles.)

<http://www.polyxo.com/> (Designing an educational program.)

<http://psych.athabascau.ca/html/387/OpenModules/Lindsley/> (Check out precision teaching.)

<http://www.tclc.com/research/index.html> (The Childhood Learning Center. Many useful articles.)

<http://autismabstracts.tripod.com/pdfpage.htm> (Articles.)

<http://melindasmith.home.mindspring.com> (Teaching play and social skills.)

<http://hunnybee.com/autism/autismsupport1.html> (Broad-based autism support site.)

<http://www.kessick.demon.co.uk/aia.htm> (Allergy induced autism.)

<http://www.isn.net/~jypsy/index.html> (Oops...wrong planet. Everything you wanted to know about autism but were afraid to ask :-)

http://www.cureautismnow.org/sciwatch/bib_index.cfm (Research literature.)

<http://www.iep4u.com/> (Writing Individual Educational Plans.)

<http://www.difflearn.com/> (A supplier of program materials.)

http://www.proedinc.com/store/index.php?mode=products_search (Another materials supplier.)

<http://policeandautism.cjb.net/> (Avoiding unfortunate encounters with the law.)

<http://www.isn.net/~jypsy/autilink.htm> (Millions of autism related links..)

<http://www.kathyandcalvin.com/> (Kathy's page -- very good.)

<http://trainland.tripod.com/> (Award winning parent's website.)

<http://members.tripod.com/~transmil/alp.htm> (Another autism links page.)

<http://www.makhomether.com/> (Home therapy resources.)

<http://www.bunt.com/~hageng/California%20Best%20Practices.htm> (California "Best practices.")

<http://www.vermontplace.com/iep.htm> (Individual education programs.)

<http://www.geocities.com/Athens/Troy/1807/guide.html#things> (Learning social skills.)

<http://www.wolfberg.com> (Another source of information about play and social skills; the "Integrative Peer Play" model.; books and videos.)

http://195.13.121.220/autism99/html/Papers/html/pmpapers/frames/fr_nav_mainpage.cfm (A paper on "Playing for Inclusion" from the Autism99 conference. This is the source of the paradox/conflict, noted by Tony Attwood, author of "Asperger's Syndrome, between language acquisition and social skills which is discussed below.)

http://www.ctfeat.org/ctfeat/recommended_reading.htm (CTFEAT recommended reading)

<http://www.cesa7.k12.wi.us/sped/autism/asper/asper11.html> (An extensive article by Susan Stokes on teaching children with Asperger's Syndrome, one of the Autistic Spectrum Disorders)

http://www.autism-society.org/packages/intervention_comparison.pdf (A comparison of various approaches to treating autism.)

<http://home.pacbell.net/cscomp/parent3.htm#danconf01> (DAN! 2001 papers)

Appendix 19

Teach Me Language is an excellent extension to any ABA program. I found most of the skills taught in the book require a child who has gained communications skills (that is not to limit to speech but may include signing etc). It is VERY parent friendly and not only teaches you how to teach a skill but WHY you teach it. There are excellent ideas throughout the book that we used actually very early on in our program eg. emotion scripts with picture of child on script feeling that way...you can gear it to your child's level. Most of all it covers areas of language not always covered by provider curriculums. I think it is an asset to any program and particularly for those on advanced curriculum and fine tuning. There is also a workbook that can be purchased with tear out worksheets for easy photocopying (some exercises you would do more then once). It will certainly give you all sorts of new directions to go in helping your child acquire more speech and better use of it. In well my humble opinion :)

Appendix 20

Strategies to Increase Social Initiation

Bridget Taylor, Ph.D

FEAT of Oregon

Innovative and Effective Interventions for Autism

January 29, 1998

I thought this was a very good presentation. Dr. Taylor used a lot of video examples to clarify what the teaching techniques were. I hope my handwritten notes are relatively clear in describing these.

I. Problems with social initiation in autism

A. social deficits

i. social avoidance

ii. reliance on others to communicate language (our kids are VERY used to adults verbally prompting them)

B. communicative deficits

i. Quantitative-preverbal or limited number of utterances

ii. Qualitative-articulation problems or the use of language is not communicative

II. Definition of initiation-SELF INITIATED communicative interaction that is DIRECTED TOWARD ANOTHER PERSON to begin or get going

III. Types of Initiation (Dr. Taylor used the phrase "topography of initiation"...sigh)

A. requests-"I want to go outside"

B. questions-"what's that?"

C. declaratives-"I went to the circus last night"

D. directives-"pick up the ball"

E. offers/shares-"here, this is for you"

F. comments-"look at the big tiger"

G. compliments-"I like your hat"

H. greetings-"good morning"

I. suggestions-"let's play ball"

J. show off-"look at my funny hat" (can be nonverbal-ie a child in dress up regalia presenting themselves to you)

K. We teach these types of initiations in order for the child to have a bank of initiations/utterances they can draw on which the social occasion arises

L. Learners have to be taught WHAT should occasion WHICH initiation and HOW to do it

IV. Strategies for Teaching Social Initiation

A. It is important to try to remove verbally prompting adults from the situation as soon as possible--we are so used to verbally prompting these children that this can be hard to do!

B. Techniques should concentrate on non-adult, non-verbal prompts

V. DTT techniques

A. DTT provides a reference for other strategies

B. DTT provides a foundation (a bank) of responses and initiations that are used in other techniques

C. Review of DTT-Establish attending, present SD, prompt target response, differentially reinforce. Child should attend to the SD and motivational system

VI. Shaping

A. differentially reinforce successive approximations to a target or terminal behavior

B. only reinforce responses that approximate the target behavior; other responses are placed on extinction.

C. Once the first approximation is met, only reinforce a better approximation--the shaping is moving the child towards the target.

VII. Time Delay Procedure for teaching Social Initiation

A. this is a form of errorless teaching

B. Prompt is given immediately upon presentation of the stimulus (ie when child begins to point to unknown picture; he is prompted to say "what's that?" BEFORE he starts to guess or zone out.

Another example would be to prompt the child to say "hi Mom" as soon as Mom enters the doorway (NOT after she has crossed the room to the child). This way...the unknown pic or Mom

becomes the stimuli...NOT what a therapist is saying/asking.)

C. After several trials of above, a systematic delay is introduced. The stimulus (the unknown pic or Mom in the doorway) is present for a few seconds before the prompt is given.

D. Continue to probe in this way for a correct response before the prompt is given.

E. This is frequently a two step forward--one step backwards type teaching method. If the child does not respond during the delay, you have to return to instant prompting and start again.

F. Dr. Taylor showed some examples on video of a child learning to ask "what's that?" when presented with novel toys. At first she prompted "what's that" as soon as she brought out the toy...then she progressed to playing with it a second or two to probe for acquisition.

VIII. Textual Prompts for teaching social initiation (ie written prompts...geez...the jargon around here)

A. The content of verbal information is written or preferably typed. The statements are velcroed in order on a board the student can hold.

B. The student reads the contextual prompt (but FIRST train the scripts in a separate context away from a social interaction to make sure the learner can read and say the words). The student waits for the response and goes to the next prompted statement.

C. The written prompt is faded backwards...ie "Do you want to play"....then "Do you want", then "Do you...." and so forth. They used little flaps to cover the end of the sentences progressively.

D. Dr. Taylor showed an example of two teenage girls reading a totally written out conversation to each other about going to play. Eventually the written prompts were faded and the girls engaged in the conversation without the script (they went to sing together with one playing a keyboard)

IX. Incidental teaching for teaching social initiation

A. This is performed by placing an enticing item in view of the learner but out of reach

B. The student INITIATES the onset of the learning trial by showing an interest in the item (grabbing for it or trying to reach it or staring at it)

C. Be sure and TAKE that opportunity for learning!

D. Model an elaboration on the student's interest (ie prompt...."I want a chip")

E. Prompt for the elaboration and provide access to the item contingent upon elaboration

F. These OPPORTUNITIES for teaching can't just wait to happen. You have to set them up. You have to plan for them and set out stimuli to create initiation in as many places/times as you can in a student's day.

G. SHAPE for more elaboration as you go along (at first..."please give me a cookie" may be all you go for...but then you begin to shape for " Those are my favorite cookies....please give me one..."

X. Video Modeling for teaching social initiation

A. the student observes the social interaction on video

B. the student is provided the same material or verbal stimuli he saw on tape and imitates the social interaction he saw on video

C. probes are conducted without the tape to assess acquisition

D. can use forward chaining to string together long series of social interactions

E. examples include videos of parents interacting with the child's siblings to demonstrate parent-child interactions, a play interaction, and an social interaction at work.

F. the learner has to be able to imitate from a video. Some do this very well and prefer to learn this way, others less so.

XI. Auditory prompts for teaching social initiation

A. prompts are recorded on Language Master cards or are audio taped. Language Masters are machines that will produce spoken sentences when you run a card through them that you have created with the words you want spoken by the machine.

B. student listens to prompt and imitates the prompt (coming from the Language Master machine)

C. The machine is used INSTEAD of a person so that it can be faded out consistently and to minimize the adult presence in the interaction

D. The auditory prompts (via the Language Master) are faded out back to front (like the written prompts above)

E. The adults are only present to run the prompting cards through--later the student will do this himself

F. Dr. Taylor showed a videotape. One autistic child wore headphones while listening to his Language Master. His tutor ran the cards through the language master for him, but did nothing else. When the first autistic child heard the prompts through his headphones, he spoke the

prompted instructions to another autistic child. The second autistic child's tutor prompted him to do the instruction and gave him reinforcement. (2 for 1 therapy!). Eventually the language master was totally faded out and the first autistic child was able to give instructions to the second without prompts.

G. the headphones were worn so as not to confuse the second child--otherwise he would hear the instructions both from the machine and from the other child

H. Dr. Taylor mentioned audiotape prompts but did not demonstrate. I think you could do a Language Master type auditory prompt with a small hand held dictaphone. The student or tutor could use the pause button between prompts. New recordings would have to be made every time the prompts were faded just as new Language Master cards are made each time those prompts are faded.

XII. Combining auditory prompts with incidental teaching for teaching social initiation

A. The goal is to move the learner from just making simple requests to a conversation about his request

B. You need to delay granting the request until the elaboration is done.

This method combines the use of auditory prompts (the language master) and incidental teaching (he wants something and can't get it until he does the elaboration)

C. Video example-learner has a board of various things he can do after earning tokens. The two he likes best are labeled on envelopes with the name of the preferred activity on them. Inside the envelopes is a stack of Language Master cards. When the student earns his tokens and then picks one of those two activities, he is prompted to run the stack of language cards through the machine, engaging in a totally prompted conversation with tutor about the activity he wants. He doesn't get the activity until he does this EXAMPLE: student picks music as the activity. He picks up the language master cards out of the MUSIC envelope and turns to the tutor who is standing by the machine. Student runs the card: " I like music" comes out of the language master. Student "I like music" Tutor " I like music too!"

Student runs next card "I like the Spice Girls Best" comes out of the language master

Student "I like the Spice girls best"

Tutor "Great, I really like Counting Crows!" and so forth

Eventually the language master cards are faded and the student engages in an unprompted

conversation with the tutor about the preferred activity before he gets the activity. The goal is for the student to come up with novel statements. In this example, the student said "I like to listen to the radio" as a NOVEL conversational statement after the language master had been totally faded away.

XIII. Tactile Prompts

A. These are vibrating beepers-at first time-activated ones were used, but they were inconvenient (what initiation occurs at precisely 60 second intervals?). The current generation of devices are manually activated devices that can be activated by remote. The tutor can sit in another room and 'beep' the child when an initiation should be started. This again, minimizes the verbal adult prompting problem.

B. Video example-this used a timed vibrating beeper set up

i. First, the child was trained with the device OUTSIDE of and PRIOR to a social interaction setting (ie...he was trained with an adult tutor first)

ii. Step one-the device is on the table and the child's hand is on the device. One tutor stands nearby and when the device goes off prompts the child to READ a script that is there on the table about what he is doing. The child reads script to another tutor who is doing something parallel next to him. Example-child is building an airplane with legos, device goes off, and first tutor physically prompts child to read from script to another tutor "I'm building an airplane". Tutor makes some sort of animated reply. This is repeated with several lines of script.

iii. Step two-device is in child's pocket and his hand is placed over it. Again, when it goes off he is prompted to read from script statements/questions about his activity to the parallel tutor. The adult prompting him to read the script is now faded out.

iv. Step three-hand is off device. Device is in pocket. Same as before but now script is faded. And the student will (hopefully) start to generate his own comments as well.

v. Step four-video of child in classroom at a table of kids. Device in pocket. Baseline (pre-device, the table of kids is silent). After device is in use, the learner begins to make comments and questions at intervals and the other (NT) kids begin to answer AND they begin to talk back to him and ask questions as well!!

THE GOAL IS FOR THE OTHER CHILDREN TO PERCEIVE THE LEARNER AS SOCIALLY COMPETENT. THEN THEY WILL START TALKING BACK TO HIM AND

ENGAGING HIM IN CONVERSATION.

IT IS IMPORTANT TO EXPOSE THE LEARNER TO A VARIETY OF THESE
TECHNIQUES TO SEE WHAT WORKS BEST FOR HIM/HER

Appendix 21

According to Ms. Littek:

"Children who are within the autism continuum may or may not have acquired speech, so as a special educator, is my focus primarily on communication skills or social skills necessary for inclusion? Can there in fact be any real social inclusion without effective communication abilities? To what degree do delays and difficulties in trying to communicate impair well-being, self-concept, and social status?"

The final section of Hill's (1989) literature review (strategies for promoting social competence which are appropriate for early childhood settings) considered if cooperative activities could lead to social interactions. The literature and studies Hill presents found that children who lack peer acceptance would not provide themselves with opportunities to improve their social skills, and were denied access to situations where social skills could be learned. Adult intervention was necessary but if too intrusive, would negate the purpose. Therefore time should be given within the early childhood setting to 'alternative contexts appropriate for the promotion of social competences (p.14)'. ...

In an assignment on group processes in the early childhood settings, the writer [C.L.] carried out running records and anecdotal observations of three children within the autism continuum to time the frequency and duration of social interactions within various types of groupings (Littek 1995a). Analysis of this study indicated that social inclusion was impaired by the peculiar behaviours or inappropriate language responses of each child according to the severity of the disorder [while research by Taylor et al. found that such challenging behaviours served an avoidance-of-social-interaction function for the autistic child and, hence, were behaviours to be circumvented through appropriate environmental manipulation and reinforcement].

...The second project [on group processes in the early childhood settings] was a collaborative

action research project focused on less structured cooperative activities and games with a boy who had pragmatic language problems and a boy who had autism. This project used play skills training in the homes of the boys prior to the intervention. The team members identified skills such as turn taking, watching others, and specific language phrases necessary for the success of the activities. The main finding from the research project (Littek, 1996b) was an increase in social inclusion for both children and a decrease in inappropriate behaviours. ..."

Appendix 22

The way one mother (Robyn Hawkins) did this for her school-age child was as follows:

"My son is six and this year we set up a token system for his peers and it has proven really worthwhile. At the start of the year I went in and talked to the class -- told them that while Ben was really smart and could read etc he had a little trouble with talking and listening and we'd appreciate any help they could give him in those areas. We set up a token board with about 30 velcro dots -- every time a child spoke to or interacted with Ben they received a star with their name on it for the token board. When the token board is full I bring in a treat (lollies or ice blocks) for the whole class and we also put all the stars in a box and have a few lucky dips where the children get a small prize.

At first all interactions were very stilted and his shadow really had to motivate the kids and Ben by prompting both sides of the interaction heavily but there are now 6 or seven kids who have really taken to it and are initiating independently quite frequently. I would definitely recommend looking into this as I believe Ben has gotten so much more out of his preschool experience as a result."

Appendix 23

Be Your Child's Most Important Toy

Children learn most through play;
By being free to create and manipulate and by finding out how things work.
We try to give our children toys that fit where they are,
Toys to learn cause and effect,
Toys to learn problem solving,
Toys, toys, toys!

Children can learn many things by playing with toys.
But if a child needs to learn to communicate,
If you want him to talk and be more of a people person
He does not need the kind of toys you can buy.

What does a child need to learn to communicate?
Cars, blocks, computers, books?
No! Learning to communicate calls for people
People are your child's best toys.
Rather than giving him toys that fit him,
Be the kind of person that "fits" and keeps him there.

A great many children know a lot about being with toys.
But very little about being with people.
We ordinarily judge children according to what they express, not what they know.
Mothers watching their children being tested often scream,
My child can do that!

Communicating may be your child's most important form of play.

When children do not play with people,

Those people may shortchange them on what they know.

Often it matters less what a child knows,

Than how he communicates and engages with others.

Haven't you seen the shy, smart child lose out

When the not-so-smart child who is charming and communicative gets much farther?

So, how can you become your child's favorite toy?

By being playful and making time an easy give-and-take,

By being more interesting than his distractions

So he stays with you to communicate;

By getting his attention and keeping him with you a little more than usual,

By acting in ways he can act and talking in ways he can talk,

And by teaching him he will get more from others as he gives more to them. When your child begins wanting to be more with people than with toys,

Then you will know he's coming closer to learning to communicate.

Begin by *being a toy* your child can control and move and enjoy.

Remember, people are the toys a child needs to learn to communicate.

Appendix 24

THE NIDS MEDICAL ADVISORY BOARD PRESENTS:

A DRAFT PROPOSAL OF ITS NEURO-IMMUNOLOGY HYPOTHESIS
STATEMENT CONCERNING AUTISM

Clinical Hypothesis - Immune "Dysfunction / Dysregulation"

- A Reason for Childhood Neuro-Cognitive Dysfunction:

Autism, as classically defined, is a devastating disorder that often robs children of their ability to communicate and thrive in society. It is characterized by primary alterations in social interactions and receptive/expressive language, and is often accompanied by symptoms including ritualistic behaviors and a lack of imaginative play. Additionally, many "autistic" children exhibit a craving for sensory (vestibular) stimulation that often manifests itself in self-stimulatory behaviors (e.g., spinning and hand-flapping).

By definition, autism has an early onset before 30 months of age (which has now been extended to 36 months under the DSM-IV guidelines), while disorders appearing later in life have been thought to be symptomatically and medically different from "autistic" conditions. However, publications over the last 13 years have cast some doubt on this assumption, and it has been noted in the literature that there is no firm evidence that similar or identical syndromes might not develop in older children.

From an epidemiological standpoint, autism has migrated from a rare disorder to one that is now ten (10) to twenty (20) times more likely to be

diagnosed. Ten years ago, "autism" occurred in 1-3 per 10,000 births. Now, current estimates suggest an incidence rate of 20 ñ 40 per 10,000 births. In fact, "cluster groups" throughout the world are currently being analyzed due to even higher incidence rates. It is also worth noting that other neuro-cognitive conditions such as "quiet" ADHD and "mixed" ADHD have received a renewed focus and attention among children and adolescents due to their perceived increase in incidence rates. Although a portion of these increases can likely be attributed to better and earlier recognition by the medical community and parents, the NIDS Board believes that this increase must prompt a change in how we approach these children. Specifically, we must begin to consider that these are not congenital, brain-damaged conditions but instead are medical disease processes acquired early in life.

In accordance with this premise, recent discussions have focused on the differentiation between "congenital autism" (including "classic" Kanner autism) and another form related to neurologic and medical disorders such as tuberous sclerosis, phenylketonuria, congenital rubella, and Downís syndrome. However, a third form has emerged which is being referred to as "acquired or regressive autism" (perhaps the largest sub-group of these children). For purposes of this hypothesis statement, "acquired autism" is a condition in which the child develops normally for the first 12 to 18 months of life and then regresses into the increasingly wide spectrum of "autistic" disorders.

These children challenge the previous belief that 70% to 80% of autistic children are mentally retarded. They crawl, sit up, walk, and usually attain "normal" motor milestones on schedule. Until the age of symptom onset, they are affectionate and appear to have above average intelligence. Children with acquired autism may begin to develop some speech but then, without

warning, cease to progress, and begin to regress. Suddenly, these children become withdrawn. They vacillate between being quiet and hyperactive. Often self-stimulatory behaviors (i.e. arm flapping, rocking, spinning, or head banging) may develop. Over time, some manifest symptoms that are both similar and atypical of children previously diagnosed as having congenital autism. The authors propose that many of these children with acquired autism fall into the medical category of N.I.D.S. (Neuro-Immune Dysfunction Syndromes), and need to be viewed as suffering from an auto-immune medical illness that is potentially treatable.

The Past:

Unfortunately, without the tools or the technology to accurately investigate the human brain, the label of "autism" evolved as a set of symptoms in a young, dysfunctional child. In its most severe form ("classic autism"), effective speech was absent and clinicians often saw symptoms of repetitive, highly unusual, aggressive and sometimes self-injurious behavior. Those afflicted had extremely abnormal ways of relating to people, objects, or events. Parents noticed that something was "not right," often within the first three to six months of life. These children typically did not smile and often resisted affection.

Most researchers and clinicians did not look for "medical" answers to autism because they believed it was a disorder that was medically untreatable. Without the technology to understand these children, pediatricians and pediatric psychologists accepted the concepts of poor parenting, childhood psychosis/schizophrenia and classified "autism" as a psychological and/or developmental disorder. Treatment was typically delivered by psychologists and psychiatrists.

Eventually, it became well documented that known medical disorders such as tuberous sclerosis, PKU, congenital rubella, and others could cause autism. However, to date, these remain rare disorders and a small sub-group of autism. Given that researchers are just now beginning to understand the medical origins and implications of the potential therapies for these children, autism is still treated primarily by psychologists and educators (with mixed results).

Past Medical Research:

A review of the existing medical literature relative to autism research reveals evidence of an emerging medical disease process in these children. For instance, research indicates that autism can follow infectious disorders affecting the central nervous system including encephalitis..., Multiple studies have focused on various anatomic locations of suspected dysfunction..., It is important to note that emphasis is often put on the medial temporal lobe. Pertinent to this new "model" of dysfunction, are the multiple published reports of autistic symptoms developing in association with encephalitis in children. (Ref: 1981 DeLong, 1986, Gillberg, 1989,) Most of these reports site injury to the temporal lobes as part of their findings. This is consistent with the areas of decreased function identified on NeuroSPECT scans initially by Dr. Ismael Mena from the NIDS Board and now by Dr. Bruce Miller and Dr. Fred Mishkin, both of who have clinical research in progress.

New research techniques are increasing the rates at which Herpes Simplex Virus (HSV) sequences are being identified in temporal lobe tissues, (i.e., locales likely to be substrates for various aspects of autism). In 1975, an article was published in *Cortex* describing a syndrome similar to autism in adult psychiatry. The condition involves the loss of emotional significance of objects, the inability to adapt in social settings, the loss of recognition of the

significance of persons, and the absence of sustained purposeful activity after temporal lobe damage.

The literature also comments on the cognitive and behavioral deficits caused by temporal lobe damage in Herpes encephalitis. There are many reports, particularly in the British literature, suggesting a connection to coxsackie/enteroviruses, while in the United States it has been suggested that many cases may be linked to the Herpes family of viruses (i.e., EBV, HHV6, HHV7, CMV, etc.),,,, Neither theory has been conclusively proven, nor has the evidence for a contagious disorder been conclusive (although some have inferred it based upon incidents related to epidemic outbreaks,) However, HSV in humans has long been known to prefer temporal lobe and limbic sites. One theory focuses on the olfactory nerves as a possible route for infection, but oral cavities may also provide entry. In 1996, O'Meara et al postulated that: "Inoculation of murine tooth pulp with HSV selectively infected the mandibular division of the trigeminal nerve and caused encephalitis predominantly affecting the temporal cortex and limbic system, a pattern of disease similar to human HSE [herpes simplex encephalitis]...."

While other studies have also implicated the temporal lobes in the pathogenesis of autism,, a direct association between temporal lobe pathology and autism has not yet been proven conclusively. In fact, research has found a variety of lesions in the "autistic" brain, particularly in the cerebellum. These variable findings may be due to the heterogeneity (differences) in the possible etiologies or time/duration effects within this syndrome.

Although Herpes virus has a predilection for the temporal lobes, the course of autism does not suggest an acute infection with traditional Herpes viruses. However, delayed temporal lobe development early in life may produce

different symptoms from those arising from deterioration or destruction of previously normal lobes.

In summary, although not conclusive, past research further strengthens the linkage of the temporal lobe and "autistic" symptoms. Boucher and Warrington noted similarities between behavioral deficits reported in animals with hippocampal lesions and autistic behavior. Medial temporal lobe damage on pneumoencephalograms was reported in a subset of autistic children. Damasio and Mauer proposed that "the syndrome results from dysfunction in a system of bilateral neural structures that includes the ring of mesolimbic cortex located in the mesial frontal and temporal lobes, the neostriatum, and the anterior and medial nuclear groups of the thalamus. At least two other studies have also implicated the temporal lobes in the pathogenesis of autism.,

The Present:

With new and more precise tools and technology available to us now, the medical anatomy of "autism" is gaining definition after years of conflicting findings. Currently, EEG abnormalities, immune markers, and NeuroSPECT findings support the concept of a medical disease process occurring in these children's brains. For example, it is generally recognized that an EEG finding of "slow" waves or "abnormal" brain wave activity is often consistent with the idea of an underlying and unknown "encephalopathy/encephalitis."

In addition, recent work with the NeuroSPECT strengthens the connection of blood flow abnormalities and neuro-dysfunctional states, particularly in situations in which patients appear to have immune and/or possible viral etiologies. NeuroSPECT scans capture blood flow through specific areas of the brain. Blood flow correlates with function/activity., As noted,

NeuroSPECT scans on children with autism have shown a decrease in blood flow in the temporal and parietal areas, which is consistent with past reports of temporal lobe dysfunction in such children. Neurological models of the brain correlate right temporal lobe areas with social skills and left temporal lobe areas with speech and auditory dysfunction, all of which are compromised in autistic children. It should also be noted that there is no good explanation for our finding of increased blood flow in the frontal lobes of a group of these children, which is more consistent with ADD and Hyperactivity. Further research is required relative to this finding.

Also, the Board has been monitoring the emerging body of evidence related to the immune system and its interactive messengers: interleukins and cytokines. It appears that a dysregulated immune system state, whether triggered by a virus, genetic disposition, intrauterine, prenatal, neonatal stress or trauma, may account for the cognitive processing and other deficits seen in some children with autism. This concept is supported by the lack of consistent neurological/anatomical abnormalities and metabolic abnormalities in these children. We now know that neuro-polypeptides called cytokines can and do restrict brain blood flow under certain conditions. In these children, we may be looking at an immune system continually sending out signals to restrict brain blood flow. Whether this continues as an "auto-immune" reaction (whereby the immune system continues this pathway with no active reason to do so) or is due to the presence of a retro-viral or other viral process is open to further research. However, the concept of an immune-related disease process in a large number of these children appears unquestionable at this point in time.

Futhermore, many autistic children have major allergies or intolerances to many chemicals and foods. While occasionally these reactions may turn into urticaria or asthma, the effect in the majority of these children is the

worsening of autistic-like behavior. Family history often reveals eczema, migraines (especially in mothers) hay fever, asthma, and histories of other disorders, which are often immune-mediated. These external symptoms may well prove to be signs of a "hyper-reactive" / stressed / dysfunctional immune system underlying the biochemistry of these children. Many anecdotal reports of successful therapies for autistic children (e.g., gammaglobulin, allergy-free diets) can most likely be explained through the concept of regulating a dysfunctional immune system and/or altering metabolic sensitivities and dysfunction.

Examples of autism's probable connection to immune dysfunctional states are:

Extensive clinical work over the last four to five years further supports the Board's hypothesis that we are facing an immune-mediated disease state affecting the central nervous system (CNS) in these children. The literature is replete with articles connecting immune system abnormalities to autism, ADD, ADHD, CFS and CFIDS. Among the main examples are:

1. Multiple researchers have found evidence that autoimmunity is a possible mechanism to explain autistic symptoms.,.,.,.
2. An increased incidence of two or more miscarriages and infertility as well as pre-eclampsia and bleeding during pregnancy have been shown to occur in mothers of autistic children. There are also multiple studies in the obstetrical literature connecting these events to immune autoantibody production.
3. Studies have been done comparing the maternal antibodies of mothers with their autistic children, suggesting an association of

abnormal maternal immunity with autism. Antibodies reactive with lymphocytes of fathers of autistic children have also been found.

4. Multiple researchers have shown an interaction of maternal antibodies with trophoblast or embryonic tissue antigens, and a cross-reaction with antigens found on lymphocytes.,,,

5. Researchers have also shown a significant depression of CD4+ T helper cells and their suppresser-inducer subset, with an increased frequency of the null allele at the complement C4B locus in children with autism. As similar changes have been known to occur in other autoimmune diseases,, these researchers have postulated that immune activation of a T-cell subpopulation may be important in the etiology of the disorder in some children with autism. (Note: Many of the autistic children evaluated by the Board have shown very high CD4 and CD8 counts, low natural killer (NK) cells, or other "markers" consistent with immune dysfunction/ dysregulation).

6. Abnormalities of Cell Adhesion Molecules (NCAM) have been reported.

7. Antibodies to neurofilament axonal proteins (NFAP) have been noted in autistic children 56a and have been reported in neurotropic slow virus diseases (Kuru and Creutzfeld-Jacob disease) in adults. Other studies, have suggested an association of an infectious agent (slow virus) in the etiology of these diseases. This is considered indirect evidence that some cases of autism may also be associated with the concept of a "slow virus."

8. Anti-central nervous system serum immunoglobulin reactivity has been

reported that was specifically directed against the cerebellum. 56a

9. A small percentage of autistic children with demonstrable immunologic abnormalities have normalized their autistic symptoms with intravenous immunoglobulin treatment. 59a 59b This result shows that immune abnormalities can cause autism in a subset of children and that "acquired autism" can be effectively treated.

10. Singh et al. hypothesized that autoimmunity secondary to a virus infection may best explain autism in some children. Congenital rubella virus and congenital cytomegalovirus have been indirectly involved as causative factors in autism.

Given this support from the medical research literature, the concept of immune dysregulation as a medical disease process in childhood neuro-cognitive dysfunction is an emerging reality. This concept could easily account for a portion of the increase of neuro-cognitive diagnoses over the last ten years. Whether the etiology of this dysfunction is related to environmental factors (e.g., ozone layer depletion, local toxins, etc.), new retro-viruses, stealth, spongiform or other viruses (or altered viral responses), we now have a medical hypothesis that can facilitate the definition of clinical sub-groups and lead to the treatment of these patients without first determining the origin or etiology.

If an infectious etiology indeed exists, it may be as ordinary as the common cold, or so rare that we have not yet developed the tools to either identify or study it. Whether an ongoing agent is present, or the body simply remains in a dysfunctional state, it seems likely we are confronted with a phenomenon/illness that has multiple etiologies, multiple origins, and various

clinical manifestations. At this point, they appear linked by an immune dysfunction or possible viral-mediated state. Genetic predisposition to this syndrome may have a great deal to do with why certain individuals suffer with these symptoms. However, we must begin to consider these apparently heterogeneous expressions as linked and potentially treatable through the common pathway of an immune dysfunctional/CNS dysregulated state. For example, in a recent study on Chronic Fatigue Syndrome (CFS), two NIDS Board members reported a significant diminution of blood flow in both the temporal and, to a lesser degree, the parietal lobes in children suffering from CFS and Chronic Fatigue Immune Dysfunction Syndrome (CFIDS). These findings are similar to those previously noted in children with acquired autism.

Based on the evidence presented herein, the NIDS Board believes that developing a focus on the inter-relationship of autism, ADD, ADHD, CFS, CFIDS and other immune-modulated conditions is a key to helping groups of these children in ways never before possible. If we can address the physiologic part of the dysfunction in these children (irrespective of its specific etiology), educational therapy, counseling, study techniques and most/all other current therapies have a far greater probability of success. In addition, research focused on developing and initiating new therapies for autism are likely to be useful in treating these other inter-related childhood disorders.

The Future:

As outlined, we have witnessed the evolution of what is now being recognized and accepted at the National Institutes of Health (NIH), the Centers for Disease Control (CDC), and academic institutions world-wide as a "neuro-immune" epiphenomena. Studies are now confirming the

concept of physiologic immune-mediated diseases underlying an abnormal physiologic state for these patients. This, in turn, creates both physical and neuro-cognitive deficits and dysfunction, usually of long-term duration.

The NIDS Board believes that many of the characteristics ascribed to autistic (and "quiet" ADHD) children overlap with the multiple complaints of adults afflicted with components of CFS/CFIDS and adult "ADHD". As previously noted, all of these groups have reports of various immune abnormalities including T-cell changes reflected, for example, by increased or decreased CD4/CD8 cells, increased / decreased NK and B cells, and altered viral titers. It is this common denominator of immune alterations that gives hope for potential new therapies in the near future for these children. However, while this hypothesis now has support in the literature, there are many important questions to be answered. How many "autistic" children have evidence of or are linked to an immune-dysfunctional state or a conclusive viral etiology? Can these children be viewed and treated differently than the "classic autistic" child of 20 to 30 years ago? Is their prognosis for recovery significantly better than the "classic autistic" children from the past?

It is time to recognize that these children are likely suffering from a medical disease process and need our clinical and research efforts now! Current treatments need to be modified and adjusted to account for this finding. The symptoms of the "quiet" ADD child (who is likely connected to this phenomenon) is not consistent with the past training or processes used to "explain" and address the "hyper" ADD child. It seems likely that the cognitive defects described in adults and children with CFIDS may be thought of as milder, later-onset form of "autism", as they are similar in symptomatology and possible etiologies. The continued exploration of an immune-dysfunctional epiphenomena, and the potential etiologies linked to

it, is a door we must walk through if we expect to change the future of this generation of children!

It is the proposed mission of this Board to accelerate the integration of the above clinical and research findings to facilitate the employment of new (and perhaps some older) immune-modulating therapies in the treatment of "acquired autism", ADD/ADHD and CFS/CFIDS. We believe that by helping to "regulate" or "normalize" the immune system, we can restore health to these children. Through our unique acceleration of clinical knowledge and academic research, there is a chance to recognize and treat this disease process while these children are still young and while there is still time to effectively help their cognitive development.

Appendix 25

Pediatrics & Young Adults
ADHD/ADD-Learning Disabilities,
Immune Dysfunction Autism

A New Definition of Autism

Autism as classically defined was and is a devastating disorder. It was a severely incapacitating disability that was relatively rare. It occurred in approximately 1-2 infants per 10,000 births.

In this severe form of "Classic Autism" effective speech was absent. It could include symptoms of repetitive, highly unusual, aggressive and self-injurious behavior. Those afflicted had extremely abnormal ways of relating to people, objects, or events. Parents noticed that something was "not right" generally within the first three to six months of life. These children did not coo or smile. They resisted affection and did not interact normally.

In the last decade, another type of autism has surfaced that is often referred to as "Autistic Syndrome." Children suffering from this disorder generally appear normal in the first 15-18 months of life. They do not present signs or symptoms pediatricians or neurologists would find atypical. These children create an inconsistency with previous held beliefs that 70-80% of autistic children are mentally retarded. They crawl, sit up, walk, and usually hit normal motor milestones on schedule. Up until the age of onset, they are affectionate and appear to have above average intelligence.

Children with this autistic syndrome may begin to develop some speech but then,

without warning, cease to progress, or begin to regress. Suddenly, these children become withdrawn. They are quiet sometimes and hyper at other times. Often self-stimulatory behaviors (i.e. arm flapping, rocking, spinning, or head banging) develop. In time, some manifest symptoms that are both similar and atypical to children previously diagnosed as "classically autistic. "

While training as a pediatrician, I was told if I saw one autistic child in a lifetime of practice it would be one too many. What I am seeing today is not the autism I learned about in medical school twenty years ago. What was once a relatively rare disorder is now twenty times more likely to occur. Before, "autism" was 1-2 per 10,000 births. Now, current statistics suggest a frequency of 20 per 10,000 births (rates of 40 per 10,000 or higher have been suggested).

In the past, autism was considered a "psychiatric" disorder. We now know that autism is a medical condition, not a mental disorder. Perhaps one of the reasons no one has come up with an answer for autism is the way we have thought of it (or rather did not think of it in medicine).

Most "MD" researchers did not look for the answers to autism because they felt this was a disorder that was untreatable medically. Treatment for this affliction was primarily left in the hands of psychologists and a few psychiatrists.

"Autistic syndrome," though still treated mainly by psychologists and psychiatrists, is also no longer considered a psychiatric disorder. It is a biological disorder that requires medical intervention. Physicians are now just beginning to understand the medical origins as well as the actual and potential treatments for autism.

Even though I believe children with classic autism might be helped medically as our knowledge of the brain's physiology expands, for now it might be helpful to separate children afflicted with autistic syndrome from those with classic autism. As children

with autistic syndrome increasingly become categorized as a "medical" problem, separating them from the many negative connotations and hopelessness associated with "classic" autism could be advantageous to promoting research and funding to help these children. The differences between the two groups may be summarized as follows:

Classic Autism

Generally "abnormal" early (i.e. 3 - 6 months of age)

"Classic" Autistic symptoms / presentation

Presumed "static," / unchangeable

Autistic Syndrome

An increasing population of children with "Autistic/ PDD" behavioral characteristics

Current estimate 20-40 children / 10,000 (incidence may be as high as 1-5% of Does

NOT have "objective" physical signs of neurologic damage / injury Majority (?? All) are

immune mediated, appropriately looked upon as a medical dysfunction - open to

potential medical therapy Generally "normal" early (usually until 15 - 18 months of age)

Atypical symptoms Asperger's Landau Kleffner's ADHD / ADD variants

A potentially progressive disorder (if not treated / corrected) May explain the origin of many cases of "Landau-Kleffner" syndrome.

Autism and the Immune System

I have been in clinical practice for the last twenty years. When my wife developed an "unknown" chronic illness in 1982, I began to explore and research neuro-cognitive dysfunction and immune dysfunction / dysregulation in an effort to help my wife.

Eventually she was diagnosed with Chronic Fatigue Syndrome, to what is now CFIDS (Chronic Fatigue Immune Dysfunction Syndrome).

The first suspicion I had that autism might be immune-related occurred in 1985. I was in the middle of exploring various alternative therapies in hopes of helping my wife and others afflicted with CFIDS. About the same time, some autistic children were referred to me for evaluation. These children had never had any blood work-ups because no one thought of their "problem" as a medical one. Much to my surprise, they had similar profiles on amino acid screens as the adults I was seeing with CFIDS. I couldn't help but wonder "What did Autism have to do with the immune system?"

The Causes of Autism

With the relatively new thinking that autism has medical origins have come several theories. Some doctors believe autism is a result of a metabolic, enzyme, or genetic defect. Although a few children may suffer a built-in genetic or functional defect present since early gestation, I do not believe this is the case for most children afflicted. In addition, the old theories do not fit or began to explain the large increase in the number of children diagnosed with autism today.

I believe "Autistic Syndrome" probably is a state of dysfunction induced in the brain by a dysregulated immune system. It could be possible that this dysfunction may occur in individuals that have a genetic predisposition. This predisposition is somehow triggered by various stresses placed on their immune systems. It's severity varies with the individual and age of onset. The triggers may be different (or similar) in each child.

If it is looked at in relation to the causes of blindness, it is easier to understand. There are many people who are blind but the cause of their blindness is very different. This is consistent with the idea of an immune dysfunction / dysregulation. For whatever the reasons (genetic, environmental, a combination of viruses, etc.), I believe what is occurring is an immune mediated, abnormal "shut down" of blood flow in the brain

and therefore central nervous system function. In adolescents and adults, this dysfunction manifests itself as CFIDS and various other atypical auto-immune disorders. In older children, it is seen as variants of ADD (Attention Deficit Disorder) / ADHD (Attention Deficit Hyperactive Disorder). And in younger children/infants, it appears as autism, autistic syndrome and PDD (Pervasive Development Disorder).

When these children are given a NeuroSPECT (a test to measure blood flow to various parts of the brain) and clinical blood work, this connection becomes more than reasonable, it is logical. The theory that much of autism / PDD is probably an immune-mediated auto-immune disorder is gaining rapid acceptance. It explains the progressive process of the autistic syndrome that occurs sometime between 15-24 months of age. The dysfunction / lack of blood flow eventually leads to injury of nerve cells, which explains the abnormal brain waves, and the large numbers of autistic children suddenly being labeled as "Landau-Kleffner."

The multiple metabolic, physiologic, and immune markers that are abnormal in these children, "make sense" when you think of the bigger picture and consider the primary cause of autism as immune dysfunction, creating multiple cellular / mitochondrial dysfunctions. A distinction often misunderstood is that dysfunction starts out of the immune system, not out of casein, gluten or other metabolic sensitivities. Children with autism have a lot of metabolic abnormalities, but that is a result of the problems with their immune systems.

If a metabolic dysfunction were the cause of a disorder, correcting it would eliminate the disease. If casein or gluten caused autism, eliminating them from the child's diet would cure them, but that does not work.

If metabolic dysfunction is a secondary factor of autism, you rarely, if ever, are going to have a patient recover, by treating the "secondary" rather than "primary" problem. Similarly, if it were true that adults with chronic fatigue have a metabolic defect, how come most of them were normal and generally high functioning for years?

In medical school I was taught to, get to the reason, and to get to what's underneath it. It's important not to just treat a symptom, or what appears to be on the "surface," but rather it is necessary to treat what is causing the problem.

Medical Treatments

Most of the children I see have healthy bodies with reactive and volatile immune systems. The first step, is to check functioning of various systems in the body. Unless another "medical" problem is found, the immune system is what is creating the misbalance / dysfunction in the brain.

Unfortunately, new, potentially safe immune modulators (steroids, IVGG, are old immune modulators, neither generally safe or effective with this type of immune disorder) are not yet available. Until these immune modulating drugs are scientifically tested in controlled studies, the way to help these children must focus on an overall approach using efforts / steps and medicines available now. By the time a child is referred to my office, their immune systems have not been functioning well for a very long time. This dysfunctional process did not occur overnight and it takes time to "cool" down / help "normalize" the body and the immune system.

The closer you can bring the body towards normal, the better the chance that the body may shut off this reactive and dysfunctional immune system. It is a difficult and complicated process to make the body heal itself especially after years of dysfunction. But if you remove some of the "offenders" that cause the immune system to fire when it shouldn't, you're making it easier for the body to normalize.

The Role of Allergens and Diet

I usually begin by testing the blood to determine allergies that could possibly trigger the immune system to react. Often autistic children come up allergic to a large number

of foods, not necessarily because they are actually allergic, but rather because their immune systems are so "revved-up," they react to everything.

This reaction may or may not occur as a traditional allergic reaction of asthma, a rash or hives. But what does occur is an immune mediated, abnormal "shut down" of blood flow in the brain that affect the language and social skills area of the brain and central nervous system function.

I generally start to improve the immune system by placing the patient on a diet free from dairy products, chocolate, and whole wheat. The reason for this is to help reduce the stress on the immune system. If dairy, chocolate and whole wheat are taken away, 96 - 98% of probable "food" allergies are alleviated. However, I do not believe that you can correct this condition by diet alone. If this were possible, parents (and physicians) by now, would have heard of multiple, "unbelievable" successes over the years. Reputable "institutions" would be conducting clinical trials to investigate the "successes."

Since nutritional therapies have not resulted in cures, or even published reports of significantly improved cognitive function, it is illogical, in fact potentially detrimental, to put these children on extreme diets. However, sometimes these children put themselves on extreme diets by only eating a limited number of foods. I don't think there are a lot of normal children who would be healthy on some of the diets these kids put themselves on.

For most of the children, all that is necessary is to eliminate the "main offenders" in their diets that will cause the immune system to react. It is not necessary to eliminate all wheat. Some doctors and homeopaths recommend the elimination of all gluten and wheat. I think these children show improvement because when they are put on a gluten / wheat free diet, they no longer eat whole wheat. Usually, all that is really needed is to eliminate whole wheat and other whole grains (due to allergenic

potential) from the diet.

I do not normally focus on casein beyond eliminating the primary milk products. Because even though they may, in theory, play a slight role in the background, if the allergies overall are lowered, it will decrease the immune system firing off.

It does not matter if "allowed" processed products are used, as long as they do not appear to be a "trigger." But, avoiding the "main" offenders is extremely important. Eliminating too many products from a child's diet, increases the risk of disturbing a child's metabolic balance, rather than helping to normalize it. (Note: Many supplements meant to compensate for the diet extremes, may in themselves have allergenic components, acting as negative triggers to the immune system and the child overall. They may fail to be properly absorbed or contain dangerous impurities. Children may be at far greater risk from diet and "supplements" than any perceived risk from properly used pharmaceuticals.)

The G.I. tract is loaded with lymphocytes (white blood cells that fight infection and disease). Those lymphocytes communicate with the brain. What has always made sense and is "logical" is if the body is sensitive to milk protein and whole wheat protein, coming into the G.I. tract it could cause the immune system to fire.

As research evolved, it was found that milk and dairy can actually cause a microscopic blood loss in the intestine by a "reactive" inflammation of the bowel. It is interesting to note that most of the world's populations get violently ill when given cow's milk. Apparently, it's not a normal human trait to digest the cow's milk proteins. Asian people have much healthier arteries than we do. One of the major assumptions for this is that they eat soy protein instead of dairy protein. Dairy is the number one source of cholesterol. The entire family can be helped indirectly if milk is eliminated from the meals. Parents often worry if their child is getting enough calcium. Soy and rice milk often have calcium and vitamins A and D added. However, if a child (girl or a

boy) is eating a normal diet, they will get enough calcium.

In the teenage years, girl's diets should be supplemented, if you're not giving them a lot of dairy. But usually, this is not necessary in these first three or four months. As time goes on a calcium supplement may need to be added. Often I will suggest Tums®. Tums® are a very safe source of calcium for a child and they taste good. Inter-related is the fact that many children and adults who are sensitive to milk but still continue to drink milk products, often have iron stores that are low. Their Hgb. / Hct. are chronically on the low side of normal, even if they were not truly "anemic." This is typically because of a microscopic blood loss occurring through this "inflamed" mucosa. If dairy and milk were eliminated from the diet, and then a biopsy of the intestine was done, the mucosa(the mucous membrane that lines a structure e.g. mouth and lips) would look normal. If milk and dairy were then reintroduced, the mucosa would look raw and inflamed. (Therefore, in approaching the idea of "leaky" gut, helping the body by removing negatives, is more important than "supplements" and nutritional "fixes.")

As a pediatrician it has been fairly routine for me to see a child do well on formula (even a cow's milk based one) for 12 months, but when the child is switched to real milk, the child experiences congestion, stuffiness, upset stomach, and a whole realm of symptoms not seen before. Whole protein, unprocessed food is much more allergenic and has a higher incidence of causing the immune system to react.

The truth is, there is not as bad an allergic reaction out of a processed product. When a food is processed, the protein structure is changed. So a child that might go berserk on milk... may not have a reaction to "processed" cheese. When the protein structure is changed, the food will not give as large an allergenic reaction.

Products from the health food stores are not necessarily the best for autistic children because they are less processed and more pure. They have a lot of whole wheat and

grains. For these kids, the cheapest white bread (without milk, whole wheat, or whey) is often the best choice.

To illustrate how peculiar the immune system is, when parents seen the results of the food test come back, a routine phone call is, "How come you did not say 'no eggs'?" You'll almost always see egg white and egg yolk with very high numbers, and yet I will usually say "ignore it." The reason being, unless a child has eczema where yolk or egg are triggering off a skin reaction, for some reason the immune pathway fired off by eggs doesn't seem to play a role in what we are talking about in the brain. I rarely have to worry about taking a child off of eggs, even though you may have this "huge reaction" on the food "screen." This illustrates how parents need to become aware of what doctors have known and "fought" about for years, there is no "perfect" food test / screen, results must always be interpreted in their clinical context. Too often, parents are being "guided" by interpretation of food and metabolic screens that do not have the capability to do what the parents wish. Many mistakes are potential being made, that may be "metabolically" and physiologically hurting these children.

Although processed food might give a lesser reaction, the importance of avoiding allergens cannot be stressed enough. In the beginning, it is especially important to avoid foods that might trigger the immune system. If the immune system is triggered, the body is affected for a minimum of a week to ten days (or longer). So it's necessary to be particularly strict at the start of the treatment, when the goal is to cool down the immune system.

If it comes down to choosing a food (cheat) with milk or sugar, choose the sugar. From the sugar the child may get hyper for a few hours, but it wears out of their body relatively quickly. From milk protein or other allergens, the immune system can be affected for up to two - three weeks. However since sugar feeds yeast, it is a good practice to minimize sugars in general.

It is also important to encourage the children to eat more protein. This will help balance out their own amino acids, which in turn will help alleviate some of their problems. All these children need protein. It is also necessary to restrict the starches. Healthy breakfasts, lunches and dinners should be served.

Sometimes this process of restoring the immune system to normal can be very deceptive. The child is doing extremely well, and appears almost well or "cured" to a parent, when everything suddenly falls apart.

A child may appear to be well, but unless the body has shut off this process, they still have a reactive, volatile immune system in the background. Even if a child is functioning at an extremely high level, a child should not be regarded as "cured", unless the immune system has truly returned to normal.

While a few rare children will actually outgrow this process, especially if you have taken steps to help normalize their bodies; realistically, it will probably take the advent and usage of new drugs that are immune modulators, to truly shut-off their dysregulated immune system.

This treatment needs to be thought of on a continuum. The closer the child gets to normal, the better the chance that the body may shut off this process. But unless you've gone that last little step, unless this process shuts off, it must be assumed that the immune system is still volatile and potentially reactive.

The only principle I have continued to find logical over the years, is the idea that I'm trying to just help a child "normalize" their body (and brain). Can I help them balance out their body? If I can change the diet, their own body can help balance itself. There continues to be no evidence in these children of any pre-existing, built-in enzyme or metabolic defect. Therefore, by focusing on the overall intake, encouraging more protein, less starch, a child's body will help balance out and replace needed amino acids (the building blocks of the body) and other nutrients.

With rare exceptions, I will never say don't do something if you truly see a child do better and it's safe, but in most cases I have found that you can get to the right point if you just think of it as cool down the body's immune system, help "safely" where medically and nutritionally possible, and extremely important, avoid offenders or triggers. If a child is doing better and their allergy test said they were not allergic to apple, but you give them a drink of apple juice and the child is bouncing off the walls, it doesn't matter what the test said, that child should not have apple juice. And this is the way parents have to work with their own child.

Until new immune modulators are tested and ready for use with patients, I regard each step of treatment as an attempt to help "cool-down" the immune system, and help the body "adjust" itself in a healthier manner. While the principles are becoming very consistent, each child (his/her body and brain) must be "individualized."

Candida or Yeast and Autism

While taking the risk of opening a medical controversy, this author certainly believes there is a logical connection between yeast and a dysfunctional immune system. However, this theory is not yet widely accepted by the medical community, but over the last few years has become easier to talk about and "discuss". Candida is a yeast-like fungus that is present in all our bodies. Presumably, yeast / Candida is in every normal G.I. tract. That is where the confusion begins.

Normally, a healthy immune system keeps the yeast in check. If the immune system is not working properly, the yeast have a chance to overgrow and become a problem. Yeast is one of the likely pathogens contributing to a metabolic imbalance that is a secondary result of a dysfunctional / dysregulated immune system. It is NOT the primary reason or cause for autism.

There is logic in saying that if an immune system is dysregulated, a secondary

problem potentially due to Candida needs to be treated. Some doctors hypothesize that autism is caused by a "leaky gut." With this theory comes the assumptions that withdrawing allergens and treating a yeast overgrowth, will help the GI tract to return toward normal. The problem with this thinking is that if yeast is not the cause of autism or PDD, then treating Candida is not going to end the autistic or PDD state. I believe it is only one of the many steps needed to help normalize the body.

Many children afflicted with autism have had frequent ear infections as young children and have taken excessive amounts of antibiotics. This has exasperated the yeast problem in these children. Other possible contributors to Candida overgrowth are hormonal treatments (i.e. steroids, BCP pills, ?? secondary exposure), immunosuppressant drug therapy, exposure to herpes, chicken pox, or other "chronic" viruses, or exposure to chemicals that might upset the immune system. There is an increased probability, that a "general" environmental factor affecting our immune systems (i.e. ozone layer depletion, "toxic" chemicals, etc.) may be operative, affecting many children and adults.

Because it is impossible and not practical to expect anyone to stay on a totally yeast-free diet, ongoing medication, anti-fungal supplements, and avoidance of dietary negatives are necessary to control Candida. Even with the use of anti-fungal drugs, it is still important to limit sugar when there is a yeast problem, because yeast grows 200 times faster in the presence of sugar.

If a potent anti-fungal such as Diflucan or Nizoral is used, it can be assumed that within 1 - 2 months most all of the yeast will die off. I do not use Nilstat or Nystatin. For most children Nystatin is ineffective. And yeast, like bacteria with antibiotics, have become resistant to Nilstat (and other antifungals).

Usually, I will use Nizoral or Diflucan for about four to six months while trying to alleviate other stresses on the immune system and "maximize" a child's function. In 7-

12 days some patients experience "die off." This is the only time, a "negative" reaction to a medication can be a good sign.

When the yeast is being killed one experiences either a "sensitization" reaction to "products" of the yeast being killed, or there is release of "formaldehyde" like products or other potentially toxic derivatives, that can contribute to negative symptoms in a patient, including bouncing off the walls, miserable, and irritated. I know it is ironic, because it actually is a good sign that the child has a yeast problem that can be corrected with medication.

It is important that the parents check in during "die-off" so I can be sure what is occurring is indeed die-off and not a reaction to the medication. Die-off usually lasts about 7-14 days and after that time the change in the child can be rather dramatic. If the die-off does not end in 14 - 17 days, it is generally a reason to change choice of anti-fungal.

If the treatment is successful, usually eye-contact improves. The children seem more tuned in and less "foggy." Parents report that after the yeast is under control the frequency of inappropriate noises, teeth grinding, biting, hitting, hyperness, and aggressive behavior decrease. The children no longer act almost drunk by being silly and laughing inappropriately.

While on Nizoral or Diflucan, I have the patient take monthly blood tests to monitor liver function before any damage might occur. I tend to be on the cautious side, "officially" testing is recommended every 2 - 3 months.

I change medication at six months, though in theory one could go longer. The reason I stop at six months is because Nizoral has a very mild effect on the adrenocortical axis. It's part of the internal steroid mechanism. While this may even be part of how "Nizoral" helps the body, it also limits how long one should be on Nizoral. Generally, I

will try to switch to Amphotericin B, which has recently been licensed as an oral liquid in this country, can now be legally compounded by certain pharmacies in the U.S.

If the antifungal therapy is stopped completely, and the body's immune system has not returned to normal, the yeast will return. Ultimately, the key is the body's own ability to keep in check an organism that it doesn't want to have there to start with.

Some doctors mistakenly give medication to control the yeast for only a few weeks or even a month. Then the treatment is stopped because the child is doing better. The problem with this kind of therapy is that if a child is helped for a short time and then the treatment is withdrawn, the yeast is going to come back, perhaps even as a stronger, more resistant strain. Whereas if the treatment took that child to normal, and their immune system became normal, it would be possible to withdraw all treatment and the child would remain healthy.

Antivirals

If the blood work suggests that a herpes related virus or "unidentified" retro-virus might be in the body, a therapeutic trial of the antiviral drug Zovirax is given. The only thing (in theory) treated with Zovirax is a herpes related virus. If a virus is present and it is gotten under control, it's one of many major steps necessary to help the body and the immune system.

On a few of the older children I am now starting to use Valtrex, which is an improved version of Zovirax. I never recommend something for a child unless I can say, "It is safe."

When herpes virus is discussed, we all think of cold sores, vaginal sores, but may not consider chickenpox, CMV (cytomegalovirus), or Epstein Barr. These are also herpes viruses. Being in the herpes family, they have the unique ability to sometimes stay

around even after the overt symptoms are long gone. They hang around the body and live in the nerves. Perhaps a "new" Herpes related virus or retro-virus may be playing a role in some of this epiphenomena. However, at this time we do not have the technology to explore and understand how all of this works.

Selective Serotonin Reuptake Inhibitors (SSRI's)

The only medical agent out there that's routinely available and directly seems to help the temporal lobe are called the SSRIs, Selective Serotonin Reuptake Inhibitors. The drugs that come under this category are Prozac, Paxil and Zoloft. What these drugs do is, for the first time, work on a specific pathway in the brain. They block the reuptake of the serotonin released.

If the serotonin released "stays around longer / more effectively," part of the brain works better. Prozac may also alter part of the "neuro-immune" axis, working to increase blood flow and function in the temporal lobe. This increased blood flow and improved function of the temporal lobes, helps many behavioral and processing problems in these "autistic" children. By helping restore and preserve temporal lobe function, one may be helping maintain a healthier brain.

Importantly, this is not an effort to control the children with medicine. A very small dose, usually 2-4 mg, is used with a four or five year old. If controlling a child's behavior was the goal, a dose of 10 - 20 mg would be used. Instead all that is needed to help function in the brain is a very small (but consistent) dose.

The purpose of using these drugs is an effort to get a child's brain to work better. In the past, if you talked about an antidepressant you were thinking Valium, Librium, Phenobarbital, that's how you "calmed" someone down. That's not what you're doing with Prozac, Paxil or Zoloft.

Pharmaceutical companies are trying to design drugs that will help the brain more physiologically than the agents out there did before. SSRI's represent the first of new "designer" drugs, with the capability of acting physiologically within the brain. These drugs can help a child medically to function better. They help transmitter effect and likely increase blood flow to the area of the brain that was not functioning properly before. And if the brain starts working, the results with these children can be phenomenal. These children are usually extremely bright. (Note: While capable of helping medically, this author believes strongly that one cannot judge their positive effects, avoiding negatives at low dosages, without controlling / combining diet and other steps at the same time.)

Immune Modulating Agents

There are agents that have already been tested and developed, and are now undergoing new usage's testing in adults that will let us adjust the immune system. Hopefully, they will have the ability to fine tune the body and put the immune system back on track. These drugs are already in existence, but are available only through appropriate research protocols. They could potentially correct all of the processing problems associated with autism (and possibly other childhood learning disorders) where "immune-mediated."

The trouble is, children are the last in line. Even though trials are now starting for adults, no agency wants to test children. The liability is too much. It is only after you've proven things extensively in adults that treatment for a child is even considered. If medicine follows its usual course of action, trials for children would be at least another four or five years away.

That is too long to wait. We must find a way to make this happen sooner. Even if the agents are identified that will "normalize" function or stop abnormalities from occurring in autistic children, these agents must be used before children pass

important functional and developmental steps that might not be regained if these agents are administered later in life. Funding for this research is of the utmost importance. We can not lose children to autism, who have the potential to lead a normal life.

Even in older children, it appears parts of the brain can be helped significantly. If cognitive function improves, the "equation" for the future changes. But, educators, therapists must start thinking "rehabilitation" rather than just "training." Often it is extremely slow and difficult to sort out compounding behavioral issues (perhaps after so many years of being bright but frustrated and dysfunctional secondary to the non-working parts of the brain).

Vitamins - Nutritional Supplements - Natural Therapies

I do believe the B Vitamin mechanism is off in children with autism (again, secondary to mitochondrial / immune dysfunction, not the primary reason or cause). Perhaps this is the reason that large amounts of Super Nu Thera have not seemed to cause any measurable damage.

Perhaps a lot of the Super Nu Thera is not being absorbed, and the small amount being absorbed may be helping some children. Some neurologists are worried that if some of these children are absorbing too much it is not healthy. There needs to be controlled trials to determine the correct dosage and real safety or dangers of this agent.

I believe in the product, but I don't believe in blindly giving it to a child. Any agent (nutritional, natural, medical) must be judged on effect (good or bad) and long term safety. It dangerous to push a child's body to any extreme with mega-dosages of supplements. Common sense does not mean "mega" dosages of anything. More is not necessarily better.

Since nutritional factors do not account for the cause of autism, as noted above, it is illogical, and in fact potentially detrimental, to push a child's body, to any extreme with mega-dosages of supplements.

Gamma Globulin

You don't in general cure someone afflicted with autism or CFIDS with IM gamma globulin, but it may play a helpful "supportive" role. Gamma globulin does have its place for various other acute autoimmune processes. Unfortunately, IV gamma globulin, is not the same as IM. With IV gamma globulin, a human product of blood goes directly into the veins, and must be prepared / processed differently than IM (Intramuscular). There is a danger of passing hepatitis and / or any number of unidentified retro-viruses with this type of therapy. Presently we have no reliable screens for hepatitis C (some screening becoming possible), D, E, F, G. etc. If there is an allergic reaction in a child with low IgA, the possibility of either getting very sick or even dying is very real.

This type of therapy has the potential to be very dangerous. Recently, in the Midwest (I believe Minnesota and/or Michigan), there were 12 cases of hepatitis C contracted from a bad batch of IV gamma globulin. This and other risks are not justifiable with such a low probability of "success" with this agent.

There are some people who will get a little better from IV gamma globulin, because once again a dysfunctional immune system is the culprit for these children's problems, and this product can help the immune system. But the trouble is that it is not a sustained gain. Until newer immune-modulators are available for these children, a combined plan of improving the immune system, the body, and the brain, has a much higher probability of success. If you help the immune system, the body will work to repair itself.

Therapy Focus - Goals - Issues

Even if we had that instantaneous answer to normalize the body, a child still needs to be caught up on what they missed and "re-educated." In the past, the focus for autistic children has been on trainability, cooperation, behavior, NOT on improving the cognitive processing. Hopefully, a shift to the idea of "rehabilitation" is already in motion, a full review of techniques and goals is urgently needed.

Sadly, medications or efforts to "calm" the brain and child down, may further shut down the areas we want to improve. What is necessary to ask about every medical treatment or medication is whether it results in a child who is brighter eyed, processes better, functions quicker? Are there negatives associated with what has been prescribed?

The hard part is often discriminating between what is behavioral and what is medical. If you get a change where a child is more tuned in, processing better and literally gives the parents, or the teacher / therapist a "bad" time, that needs to be dealt with behaviorally, not medically.

What I am continually seeing in these children is the better their brain works, the more they act out like a two or three year old kid that never had the "reins" put on them. If that's in the context of the brain working better, it's not a negative.

Clinically, my experience has been to literally watch a young child (below 4 or 5) "pick-up" where their brain development ceased to function normally. They need to go through the same developmental steps all children do, but they are doing it at an older age. They developmentally act like a 2 year old child, but have the body and skill of a 4 or 5 year old.

An older child, can be helped significantly if cognitive function improves, but as noted

above, it is a longer rehabilitation process and catch up effort. Often it is extremely slow and difficult to sort out the compounding behavioral issues (perhaps this is due so many years of being bright but frustrated with their inability to communicate).

It has now become common practice to hear a parent of a four or five year old tell me that their kid literally is doing things that they stopped doing at two. In these cases this is not regression. It as though you literally turn the brain back on where it stopped at 18 months or two years of age. This is what is expected and is fine as long as you get them through those stages and you help them catch up.

As a child is functioning better and even when they are dysfunctional, they like any normal child need praise, limits and consistency. The problem is that parents are dealing with a child with the physical ability to get into the trouble a five year old child would, but without the lines and limits parents would have set previously for a 2 or 3 year old child. (Note: All children go through normal testing phases, where they need to learn what is okay, what is not okay, etc.)

There is a critical time limit for helping these autistic children. If a child does not develop or use certain tracts in the brain, he may never do so. If the child has not used these tracts in the temporal lobe you may never get them to develop "fully." Usually, the younger the children are when you start to "normalize" the body and the immune system, the better the prognosis will be. These kids are young brains, the longer they don't get help, the worse off they're going to be. However, the discussion of "deadlines" must be taken in context by our past (and generally present) inability to adequately measure and evaluate areas of brain function objectively.

There are some physicians who will argue that the body is still "fixable" at eight or nine, but realistically there is a line. It has been this physicians experience to note children up to 5 or 6 will often "turn-on" and pick-up where they stopped, generally about 18 - 24 months old. On the other hand, as children approximately 6 - 10 or 11

improve, it is a slower process, often requiring more "help" to "learn" the basics, grow-up developmentally, and then move ahead successfully. All of these observations reinforce the fact that we can not wait the normal cycle of 10 to 20 years for medicine to find the answers for these children. If we're going to maximize the probability of success, we still must mobilize efforts to focus on "realistic"/ probable medical solutions available within 1 or 2 years, versus "genetic" therapies, perhaps available in 10 - 15 years.

We must never underestimate the unknown, and the power of the body when dealing with these children. An illustrative case is a physician's child who is now 10 years old. The child came to me literally wild, I mean the parents were that close to realizing they were going to have to institutionalize him. Currently, the boy is now up to a couple of sentences. He is in school and is starting to learn. Although I can't say to these parents that I have the same top hope for a patient who is 9 or 10 that I may have for a 4 or 5 year old, that doesn't mean there can't be a lot of improvement. This child NOW has a good opportunity to develop skills. He certainly is showing he's bright and can learn.

The Image of Autism and Its Implications

Unfortunately since doctors believed autism should be treated by psychologists and psychiatrists there has been an absence of pediatricians in this field. It was and still is believed by noted neurologists that nothing can be done medically to treat these children. Fortunately, as these children are changing with therapy, respected neurologists and other pediatric researchers, are beginning to feel it is time to "take a second look."

Psychologists and behavioralists, sometimes give parents advice based on the assumption that a child with autism is a retarded child who "doesn't know any better". While the advice given is meant to help, these are often bright children that are not

being expected to conform to or understand rules and limits. Because of these well-meaning professionals, these children often become a bigger problem behaviorally. Without proper discipline and expectations by teachers and parents, any child will be a problem, these children will be a disaster.

A overwhelming obstacle to changing the image for these children is the failure of tools available to date to "objectively" evaluate CNS (Central Nervous System) functioning, in turn perpetuating the subjective screening tests and procedures currently used. To this day, good researchers often take a position, if they can't measure it, it must not be real. Perhaps, it is far more appropriate to acknowledge there are areas of physiologic and metabolic function that we have not yet developed the tools or techniques to measure, but that does not mean they should be discounted clinically / medically.

As time goes on it becomes more evident by clinical confirmation and research that autism is an auto-immune disorder (see previous review article "Autism and the Immune Connection"). With this knowledge I have become extremely concerned that some of the previously used drug, metabolic, and psychological therapies that have had little or no history successfully treating this type of disorder in adults, are not likely to be successful in children. In fact, many may be potentially harmful.

It is one thing to try a potentially dangerous therapy or one with many unknown or undesirable side effects on a brain-damaged or retarded child. It is quite different to experiment or operate on children with dysfunctional, but potentially healthy, normal brains.

There is work being done by doctors with medicines and homeopathic therapies, that I am not sure is safe for children. They are prescribing extreme diets and mega-doses of supplements. In part these doctors are correct that metabolic processes in these children are not working properly. But I believe the evidence is mounting daily that they

are a secondary result of a stressed / dysfunctional immune system, NOT the cause of autism.

While some dietary restrictions and nutritional supplements may help to "cool down" the immune system, more is not necessarily better. Often these remedies are given because they will "do no harm." But harm is occurring by the failure to recognize and expedite potential new therapies with immune modulators that could possibly help normalize the immune systems of these kids. And harm is occurring when parents and physicians are using potentially dangerous therapies and even operating on these children's brains with little probability of success.

In contrast, the good news is that children afflicted with autism whose immune systems have been helped are showing they are bright thinking individuals that are not what the world expected. Children with the "label" of Autism / PDD are not retarded. They have normal or above normal intelligence. They are not throw away kids that cannot be helped. They are children who are suffering from auto immune dysfunction that can possibly recover.

But the label of autism still continues to carry old "negative ideas, negative implications," and in turn lowers the urgency and priority to help these children. It is time to change that label, that image, and the future for these children.

It is this physician's hope that 1997 is the year of that change. Through focusing and combining efforts, this can happen; for the children's sake . . . it must happen.

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Appendix 26

The Do's and Don'ts of the Diet

Avoid all dairy, chocolate, whole wheat and whole grains - limit sugars

All dairy means any product that has milk or bovine protein listed as a "major" ingredient. This includes cheese, yogurt, chips with cheese on them (Doritos's, Cheeto's etc.)

Don't deprive your child however. Substitutes are always available for almost any product. Children seem to really enjoy "Rice dreams" in place of milk available at most health food stores and more and more markets depending on where you live. Easier to find are soy milks and sometime goats milk. Mocha mix non-dairy milk substitute is available at most supermarkets, as well as Mocha mix ice cream.

Don't let them overdue this one because of sugar content. Fake cheeses are also readily available .. Tofurella comes in cheddar, Mozzarella and Jalepeno for the brave. These actually melt and make a reasonable fake pizza or fake grilled cheese sandwich. There are many other brands of Soy cheeses - make sure there is no added milk protein in them.

Chocolate is an offender because most chocolate is "milk chocolate." An occasional treat made with cocoa powder is permitted. Some of these children can tolerate Carob some cannot. With any "new" food watch for a reaction, if your child has a reaction, that product is not for them. Breakfast should consist of some "processed" (meaning not whole grain) cereals such as "Rice Krispies", Cheerio's, or Corn Flakes unsweetened served with one of the fake milks. Some children have a problem with the preservatives put in cereal especially BHT, if this is your child, then a preservative-free cereal like "puffed rice" from the health food

store is appropriate. (if necessary, you can add Nutrasweet or Sweet and Low for added sweetness or another approved sweetener as listed below (try to minimize or avoid, but whatever works.).

A lot of these children also have problems with Red and Yellow food dyes. Pay attention to your child if they consume these in cereal or fake candy. If there is a negative reaction it is not to be used for them. Eggs are also okay, French toast or pancakes (not buttermilk) in moderation with fake (not sugar sweetened) syrup. Vermont makes a great tasting one, also check the diabetic aisle of the supermarket as diabetics need to watch grams of sugar many products are made with sugar substitutes.

A "diet" soda is a great reward as long as your child does not react to Nutrasweet. Most sugarless candies can now be found sweetened with saccharin or Nutrasweet. Of the ones sweetened with Sorbital, be careful as this also works as a laxative so keep an eye out for loose stools.

Limit sugars. The average American consumes over 120 pounds of sugar a year. For example a hamburger bun has three teaspoons of sugar, a regular non-diet 12 ounce soda has nine teaspoons of sugar (regular Coke, Seven-up, Sprite etc.).

Other names for Sugar "NO NO's" are:

Brown Sugar, Corn Syrup, Dextrose, Fructose, Fruit Juice, Galactose, Glucose, Jam, Jelly, Lactose, Maltose, Maple Syrup.

Keep fruit consumption to two pieces of fruit per day, this includes juice. Avoid strawberry, cherry most "berries" as these can be very allergic. Water down juices, start with half water half juice and work down to ¼ juice the restwater. Be creative, if your child loves those juice boxes pour them out when the child is asleep, refill with diluted juice and put a piece of scotch tape over the top. You'll get

away with it. Kids love the new Crystal light drinks that come in sport bottles, while expensive buy them once then re-fill the bottles with the Crystal light you can mix-up at home.

Lunch is a good time for leftovers, we are trying to push extra protein into them.

Protein supplies necessary Amino Acids" the building blocks of the body". No supplement can do as well as the real thing. A sandwich is really okay as long as some protein is in the middle. Bread is really where the controversy begins. As long as your child is not gluten sensitive or has a positive titer to what is called gliadin antibodies "processed" white bread is okay. The word wheat is okay as long as the word "whole" is not in front of it. The reasoning is, most people are allergic to whole grains so a processed product is really okay and removes most of the allergy causing ingredients/properties. For this reason often the stores cheapest white bread is a good choice because when it cost's less it is less likely to have better (meaning less allergic) ingredients in it. While this may sound horrible for nutrition, the idea is not for a child to eat a loaf of bread, but to use it as a way to sneak in the protein (as part of a sandwich).

Dinner can be any meat, chicken, fish (if tolerated) with some vegetables and a little starch (small serving of rice, or potato, or pasta). Try to remember the body converts starch to sugar within 6-12 hours, so that is why we limit the consumption.

We know your child may be stubborn at first and only eat the starch on the plate.

ACT DUMB

Don't fight them, if they do not want to eat the rest do not force them. But do not let them fill-up on junk food / starches / sugar either. When they want more food present what they have not finished. Again "act dumb".

Believe it or not their pattern of eating will change. Too often we just "give in" afraid they will starve to death. As a Pediatrician I have really learned "No child offered food has ever starved to death". As parents we just feel too guilty and give in. We are not helping them to get the necessary nutrition they need. But, Do Not fight with them or they will go on a hunger strike You cannot make a child eat (or go to the bathroom), but "nature" will work for you if you let it.

Install a "good" water filter in your hme that removes metals and chlorine's. Many areas around the country have water with toxic levels but nobody wants to talk about it!!!

Recipes given to us from parents that seem to work:

Easy Rice Milk *

A good way to make rice milk is to use fresh rice that is still hot.

1 cup rice

4 cups hot water

1 tsp vanilla

Put all in blender, puree for about 5 minutes (until smooth) let sit for 1/2 hour pour into container being careful not to let the sediments at the bottom pour into the new container.

7 grams fat; 102 grams carbohydrates; 4 grams protein; 0.30 gram fiber.

Almond Milk *

This delicately flavored milk is a great addition to many foods. It's good on cereal and as a topping for waffles and pancakes. Made thickly, it can be used as a spread or thickener for soup. The ratio of almonds to water varies in our recipe to allow you to choose between a spread or milk-like consistency.

1 cup of almonds, freshly roasted

2 1/4 to 4 cups water.

Place the almonds and water (2 1/4 cups for topping or spread, 4 cups for drinking) in a tightly closed jar and store in the refrigerator for 1 to 2 days at the most. Pour into a blender and blend until the mixture is smooth. To use it as a drink, strain first. The remaining almond paste is delicious and can be tossed on cereal, vegetables or rice.

MEXICAN CHOCOLATE ICE *

3 (12-ounce) bottles nondairy rice milk (or equivalent)

1/2 cup cocoa

1 teaspoon vanilla extract

Combine 1 cup rice milk and cocoa in small saucepan. Heat and stir until cocoa is dissolved. Stir in remaining rice milk and vanilla. Let cool then freeze in ice cream maker according to manufacturer's directions.

Makes 8 servings.

Each serving contains about: 551 calories; 121 mg sodium; 0 cholesterol.

HYPOALLERGENIC COOKIES*

Preheat 325 degrees

1/8 cup canola oil

1 cup instant baby rice cereal (Beechnut or Earth's Best, not Gerber)

2 oz. (1/2 jar) strained baby fruit (pears)

1/4 cup sugar

1 tsp. GF baking powder

1/2 tsp. GF vanilla

Mix ingredients to blend, then squeeze into small balls (1"). Flatten with the oiled bottom of a drinking glass. They will not spread, so small and flat comes out the best. Bake on oiled cookie sheet for 15 minutes. These are much tastier than they look! Note: Bake on an Airbake cookie sheet for 20 minutes. Try not to over-bake!

Besides artificial sweeteners:

Stevia Powder -- From a South American plant called Stevia. It is 300 times sweeter than sugar so it is used in extremely small amounts. It is used by diabetics in many parts of the world.

You can purchase it from:

Cheryl's Herbs

836 Hanley Industrial Court

St. Louis, MO 63144

(314) 963-4449

(800) 231-5971

(314) 963-4454 (FAX)

Consumer Direct

640 South Perry Lane

Suite #2

Tempe, AZ 85281

(800) 899-9908

(602) 921-2160

Sells liquid concentrate of Stevia

from Paraguay.

Body Ecology Diet

1266 West Paces Ferry Road

Suite 505

Atlanta, GA 30327

(404) 266-1366

(800) 896-7838

Sells Stevia powder from China.

* With any recipe check for specific allergies in your child !

SUBSTITUTIONS IN RECIPES

Instead of 1 Cup Milk

substitute 1/2 cup Non-Dairy Beverage + 1/2 cup water or 1/2 cup juice + 1/2 water or 1 cup water

For baking:

Instead of 1 Cup Milk use 1 cup water + 2 tablespoons dairy-free margarine

Instead of 1 Cup Buttermilk use 1/2 Cup Non-Dairy Beverage + 1/2 cup water + 1 Tablespoon vinegar or lemon juice

Instead of 1 Cup Sour Milk = Same as Buttermilk substitute

Instead of Light Cream use Non-Dairy Beverage

Instead of Cream Cheese for baking use Mayonnaise

SUGARLESS TREATS

HEIDE GUMMI BEARS Sugar-free, Fat-free, Cholesterol-free.

INGREDIENTS: Hydrogenated starch hydro-lysate, gelatin, citric acid, natural and artificial flavors, artificial colors (including Red 40, Yellow 5 and Blue 1). Polished with vegetable oil and carnauba wax. Excess consumption may have a laxative effect. 1 lb for \$5.99

Fax orders to (407) 496-7017 - Not for those sensitive to dyes.

Estee Corporation

1-800-526-5051. 169 Lackawanna Ave, Parsippany, NJ 07054-1094. Hard candy, gumdrops, gummibears, cake mixes, preserves, syrups, gelatins, salad dressings.