

The INCLUSION NOTEBOOK

Problem solving in the classroom and community

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This issue and the next of The Inclusion Notebook provide educators with essential information about students with autism spectrum differences (ASDs) from preschool through high school. ASDs include classic autism, Asperger syndrome, pervasive developmental disorder-not otherwise specified (PDD-NOS), and several genetic conditions in which the student appears to have autism. Whereas Volume VI, Number 1 of TIN provided an overview of traditional service models used to educate students with ASDs, this edition (Part 1) and the next (Part 2) contain a variety of cutting edge research-to-practice information. This 2-part series will shatter myths about autism spectrum differences; provide readers with actual situations in which, by applying the MACS Model described in the first article, students with even the most severe autistic behaviors have been successfully included in general education class without requiring substantially separate instruction; and address common questions educators across the country have been asking. Unlike previous editions of TIN, neither Part 1 nor Part 2 will contain a pull-out section because these two editions are handy "keeper" references for all educators.



Labels on the Autism Spectrum: A New View

by Linda H. Rammler, M.Ed., Ph.D.



Introduction to the MACS Model

There is considerable disagreement among “autism experts” today as to whether autism spectrum disorders (or “differences”) do or do not involve intellectual disability. The thinking about autism has, in many professional circles, changed significantly over the past several years. (See, for examples, the professional literature by such researchers/authors as Don Cardinal, Anne Donnellan, Morton Gernsbacher, Temple Grandin, Martha Leary, Doug Biklen, Margaret Bauman, Donna Williams, and Herb Lovett.) No longer do these experts view autism as a variant of mental retardation. Rather, it is becoming better understood as a complex brain condition that reflects structural and functional differences in the movement, anxiety, communication, and sensory (MACS) systems of the brain as well as the interconnectivity between those systems and, in some situations, other parts of the brain. Certainly many individuals who have labels of autism spectrum differences (ASDs), in discussing their own experiences, have described their own movement differences, heightened levels of anxiety, communication challenges, and sensory sensitivities in powerful terms. The Autism Spectrum Differences Institute of New England (ASDI/NE) shares this view because we have found it to be more helpful in providing an appropriate education program to individuals carrying this diagnostic label.

How DSM-IVR Diagnostic Criteria and the MACS Model Overlap

It is because of these issues with movement, anxiety, communication, and sensory systems that some individuals also meet the traditional criteria for ASDs – i.e., language delays, persistence in engaging in odd repetitive behaviors, and poor social interactions. For example, a person could be expected to have difficulties with language and communication if he could not coordinate his oral musculature to form words easily, or his perception of other people’s faces is so distorted (see writings by Donna Williams) that the intent to communicate is overshadowed. As another example, a person could be expected to engage in self-stimulatory or other odd, repetitive behaviors if she either could not control the movement or the movement helped soothe the brain from an onslaught of sensory input that other people’s brains handle easily. Difficulty with motor planning and sensory dysfunction (including a tendency to attend to the wrong stimuli) prevents these individuals from developing “automaticity” in their actions. Anxiety compounds these challenges.

What are the Long-Term Outcomes of ASDs?

People who experience some autism spectrum differences (e.g., Asperger syndrome) can function reasonably independently in some arenas of life, but may have difficulties with, for example, maintaining employment or developing social connections without support. Other individuals with severe motor dysfunction and severe sensory integration issues will probably require lifelong and intensive supports in all areas of life, including assistance with basic life skills such as managing personal hygiene and maintaining a daily schedule.

ASDs are NOT Intellectual Disabilities

When most of the available standardized tests used to evaluate such constructs as “intelligence” depend on factors such as movement and language, it is not possible to obtain an accurate measure of ability for someone with autism (particularly if they experience significant movement, anxiety, communication, and sensory differences), any more than it would be accurate to test the great physicist, Stephen Hawking, if he were not allowed to use his Liberator communication device. However, as movement, anxiety, communication, and sensory differences are systematically addressed, many of us have learned that individuals with labels of autism previously thought to be “intellectually disabled” are not necessarily “cognitively impaired” regardless of the severity of their autistic symptoms. It is very important to recognize, then, that each individual with autism is one individual with autism—the types of services or supports required by that person depends entirely on his/her movement, anxiety, communication, and sensory challenges; the supports already available to that person, his/her family, his/her school and/or community; and the interaction between the individual and those supports.

In fact, many, if not most, individuals with labels of ASDs not only have special areas of superior functioning (a la Kim Peek a/k/a Rainman), but overall appear to have higher cortical capacity, not just in terms of concrete skills such as solving complex mathematical equations, being a precocious reader without necessarily being able to comprehend the inferential meaning of what is read, having superior abilities in creating music or art, etc. As Antonio DeMasio, Oliver Sacks, and others have pointed out, higher order thinking can still develop circuitously when other brain functions (in the case of ASDs, those dealing with movement, anxiety, communication, and sensory systems) are operating atypically. Thus, despite the challenges of autism, many individuals with autism spectrum differences are being recognized not “just” as occasional savants but rather as intelligent human beings whose bodies are, at best, inefficient in a neurotypical world.

As movement, anxiety, communication, and sensory issues are systematically addressed, it is also clear that individuals with autism have language abilities previously not recognized. They often do NOT avoid social contact but rather, like anyone else, have shown themselves to be both desirous of and willing to work hard at interpersonal connections, even if the results are not always satisfactory. Engagement in “odd, repetitive, and stereotypical behavior” typically serves a clear function for the individual that relates directly back to how they, as individuals, need to accommodate their own movement, anxiety, communication, and sensory challenges.

Why Some Interventions Work

It is also this need for accommodations that explains why many people with ASDs often are most successful with predictable routines and familiar environments. These types of accommodations allow them to respond to familiar stimuli, thereby increasing their independence and reducing anxiety. Accommodations allow them to automatize more of their responses (both to activities of daily living, and their social-communicative interactions with others), so they can perform them without re-planning every time. Accommodations allow people with ASDs to use compensatory strategies that they have developed themselves to protect, as well as they can, from being sensorily overwhelmed. Other strategies such as visual supports, augmentative and assistive communication options, and advanced notice of transitions serve a similar function.

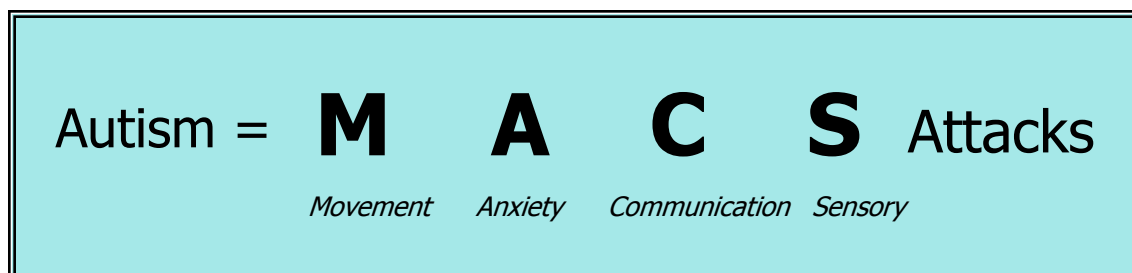
Why Some Interventions Work, cont.

Note that autism spectrum differences often co-exist with other disabilities and dysfunctions. For example, a number of people with autism have learning disabilities because they do not perceive the world in the same manner due to their movement and sensory issues. Some may have seizures, exhibit challenging behaviors that may be either aggressive or self-injurious, or have dietary sensitivities.

Summary of a New View of ASDs

Most of the students, with whom we have worked, who have labels on the autism spectrum “fit” this definition of ASDs in terms of MACS systems differences, based on our personal experience working with them, interviews with their staffs and parents, and reviews of their records. It is also why such a concerted effort needs to be made to enable persons with ASDs to have others accommodate movement differences, minimize anxiety, and access and use augmentative and assistive communication strategies, so that they can communicate what they really know and understand, and/or access and use sensory diets. Until then, people with the full range of ASDs are truly “untestable,” because their motor planning difficulties preclude optimal performance on standardized tests, anxiety makes performance sub-optimal, and their oral language deficits prevent them from being able to convey effectively what they think, feel, or know. As such, labels of “intellectual disability/mental retardation” should be avoided and prognostications about what their true abilities are should be taken with a grain of salt.

As Lucy Harrison humorously noted (and Jacob Pratt, Tom Page, Hope Block, Sharisa Kochmeister, and numerous others with ASD labels have confirmed this model is a helpful way to view their daily experiences):



Applying the MACS Model in Practice: Fully Including Students with Autism

Meet Mary Alice (age 11)

Mary Alice is now in 5th grade. She has been a full member of her class at each grade level in her neighborhood since she was in kindergarten and attended her district's inclusive preschool program. Mary Alice's test scores are low enough so that she meets the federal and state definition of "intellectual disability," but her primary diagnosis is "classic autism" because everyone agrees that she meets the DSM-IVR criteria for that categorical diagnosis.



Each year, Mary Alice has had a different 1:1 para-educator to make sure that she doesn't become dependent on any one person. The para-educators (including their substitutes) receive autism- and Mary Alice-specific training along with other members of Mary Alice's team. (See "Labels on the Autism Spectrum: A New View" in this issue for an overview of autism-specific content. Note that this training focuses on how Mary Alice's movement, anxiety, communication, and sensory systems affect her classroom participation and what the team can do to individualize her educational program to address resulting needs. Currently, training is being done by the inclusion facilitator who was extensively trained, using a "train the trainer" model over several years by an autism-inclusion consultant with specific expertise on how to include students with ASDs most effectively.)

Each year, Mary Alice's team includes her parents, general education teacher(s), special education teacher/case manager, and any new related services providers. The staff of Mary Alice's program know that Mary Alice is capable of accessing the general education curriculum with the following additional goals, instructional modifications, and individualized accommodations and supports as specified in her individualized education program (IEP). (Note that specific components of her IEP have changed to reflect grade level curriculum, chronologically age-appropriate social and instructional opportunities, and Mary Alice's own growth and maturation.)

Mary Alice's Individualized Education Program (IEP)

It is the responsibility of EVERYONE on her team to make sure Mary Alice's IEP is followed; and, if there are issues in interpretation, fidelity, monitoring, etc., to bring those issues back to the collaborative team (including Mary Alice's parents) that meets bi-weekly for resolution. In addition to the collaborative team meeting, Mary Alice's classroom teacher and special educator/case manager meet formally for 10 minutes every other day and "on the fly" as needed. Formal supervision of Mary Alice's para-educator is the primary responsibility of the case manager who conducts randomly scheduled observations on a bi-weekly basis and relies on collected data as well as transdisciplinary input from the parents and all professional members of the team.

Mary Alice's Goals and Objectives

Goal 1: Across the curriculum, Mary Alice will earn a grade of B or higher as measured by modified assessment processes.

Objective 1: Mary Alice will demonstrate grade-level literacy and numeracy skills given untimed and compacted assignments, quizzes, and tests.

Objective 2: Mary Alice will demonstrate grade-level mastery of grade-level science and computer technology curricula given untimed and compacted assignments, quizzes, and tests.

Objective 3: Mary Alice will demonstrate mastery of the essential understandings and core concepts of grade-level content in social studies, music, PE, and art given modified and untimed assignments.

Objective 4: Mary Alice will participate with her peers in Block X as well as all health and world languages class activities.

Goal 2: Mary Alice will use speech, written language, and her voice output communication aid (VOCA) to communicate effectively throughout the school day by meeting the following objectives.

Objective 1: Given advance notice by her teacher that she will be called on, Mary Alice will answer a teacher-directed question at least once per class period using the communication modality of her choice.

Objective 2: During both Block X and a weekly Circle of Friends meeting, Mary Alice will increase the number of on-topic conversational exchanges with her peers using the VOCA from baseline to a minimum of 4 exchanges including questions and comments.

Objective 3: Given natural opportunities (e.g., during quizzes and tests, unstructured time such as lunch and recess, Circle of Friends, and individual work time in class), Mary Alice will use her VOCA in free-ranging conversations with staff or peers, demonstrating increasing length and complexity of her contributions/content.

Goal 3: Mary Alice will increase self-advocacy skills across the school day by meeting the following objectives.

Objective 1: Mary Alice will take an appropriate sensory break using appropriate sensory materials to return her body to "just right."

Objective 2: Mary Alice will finish handwritten starter phrases in writing to describe "what's wrong" and "what can we do about it" with increasing detail.

Objective 3: Given wallet cards describing her needs, Mary Alice will politely present one to new staff or students, or in new situations, with increasing independence.

Mary Alice's Accommodations and Modifications

Mary Alice's accommodations and modifications are listed on page 8 of her IEP (CT's IEP form is available for download at <http://www.sde.ct.gov/sde/lib/sde/PDF/DEPS/Special/ED620.pdf> or <http://www.sde.ct.gov/sde/lib/sde/PDF/DEPS/Special/ED620.pdf>) and on the next page.

Materials/Books/Equipment:

Same texts, lab, and other classroom materials/equipment as all other students. Dynavox VI with back-up Dynavox V as VOCA. Sensory Diet materials in attached Sensory Diet approved by PPT; new materials may be added/old ones removed per core team with OT sign-off.

Tests/Quizzes/Assignments:

Core team to select representative samples of work related to Objectives 1.1 and 1.2. Certified teachers to identify core curriculum concepts/essential understandings collaboratively for Objective 1.3. Case manager to assure exemption from all tests/quizzes/assignments related to Objective 1.4. Any modified assignments may be completed by Mary Alice herself or dictated to staff using the VOCA. Questions to be on same page(s) as space for answers.

Grading:

Reflects only modified assignments. Any individual grade less than B may be retaken if it affects overall grade average and cannot be dropped from inclusion in average. Core team may override grades inadvertently entered into system by classroom teachers based on portfolio of work.

Organization:

Waive from district's planner format. Individualized written schedules/task lists, social stories, Power Cards. Color coded book covers, loose leaf and spiral bound notebooks, assignment folders, and posted daily schedule on desk/over cubby. Post class schedule with "oops" for planned/unplanned changes.

Environment:

Sit with preferred peers away from bright light and blowers/fans. Provide room for para to move in/move out as needed for extra support. Para needs separate desk/place to be as "co-teacher" to prevent "hovering."

Behavioral Interventions/Support:

See behavioral support/intervention plan (BS/IP) approved by PPT (not actually included in this issue). Minor changes to target behaviors according to established hierarchy, staff responses from menu of options, and specific reinforcers may be made by the collaborative team. Other changes require a new FBA.

Instructional Strategies:

Wait/extended response time with advance notice when possible; post-it note/index card followed by light upper arm touch to "jump start movement" (e.g., get out of seat/get in line); give time to self-correct; social stories/Power Cards TBD as needed (review only as needed) using age-appropriate language; faded physical prompts for new motor activities; plan extra time needed for VOCA; explain all idioms/figures of speech/intended interpretation when alternative meanings are possible to the whole class; coach peers to model, include, wait, etc.

Other:

Summary of Sensory Diet and BS/IP: Do not demand eye contact! Use anti-anxiety and sensory strategies as needed. Ignore refusals. Clear classroom if tantrum occurs. Use restitution to restore relationships as needed. Para OR teacher to "stay behind" to implement BS/IP. Use checklists to record data for Goals 2 and 3. Rides regular bus with monitor to facilitate friendships.

Summary of Mary Alice's IEP

Typical for a student with classic autism? *Probably not.* Controversial? *Perhaps among those who buy into a particular "programmatically approach" to ASD.* Individualized for Mary Alice? *Definitely.* Scientifically based strategies? *Yes, of course, although each is drawn from a wide range of sources from occupational therapy to pediatrics to psychology to education, etc.* Further, it is at the discretion of certified staff whether a given situation best requires an applied behavior analytic, developmental, integrated play group, or other approach ... just as it would be for teaching any other child regardless of whether that child was neurodiverse or neurotypical!

What's remarkable is that, at her last birthday party, several neurotypical girls were arguing over which of them was Mary Alice's best friend; Mary Alice continues to keep pace with the general education curriculum; and she astounded everyone in a grade level trivia contest that referred back to facts to which she and all her peers had been exposed to since first grade by coming in third!

Meet Vijay (Age 16)

Mary Alice happens to go to the same school that Vijay attended from kindergarten through grade 5, but Vijay is now in the 11th grade. When Vijay was in elementary school, he was considered "learning disabled" because his math scores were significantly lower than his gifted scores on all tests of verbal and language ability. Much of his core academic instruction from third grade on occurred in the resource room with other students who had learning disabilities, but he was mainstreamed without support in specials and, depending on the year, for social studies and science.



Toward the end of sixth grade in the district's middle school, Vijay had been flunking most of his courses and the PPT decided to transfer him to a district-wide, self-contained class in another school for children with severe emotional challenges. They felt, despite Mr. and Mrs. Guha's objections, that this was a preferred placement because he was unable to make friends and persisted in engaging in behaviors (rocking in his chair, refusing to come out from under his desk, and running away when frustrated) that staff perceived to be dangerous to himself as well as disruptive to the learning of other children. The "emotional disorder classroom" also turned out to be a poor match for Vijay, and his parents pursued a series of outside evaluations to try to pinpoint why school was so agonizing for their son.

Interestingly, Vijay's full scale IQ (despite lowered performance scores) was 117 and he scored at grade level even in math. General knowledge, vocabulary, and written language were all in the superior range when untimed. These results had remained static since the first time he was referred to special education in third grade. Other types of evaluations that had never been done by the district showed that Vijay had sensory differences (i.e., his hearing was hyperacute, his proprioceptive system required nearly constant input to be regulated, and he could not integrate auditory and visual input simultaneously), difficulties with expressive and receptive language prosody, and poor motor planning skills. A psychiatrist found that he was extremely anxious and borderline for clinical depression.

Finally, a neurologist specializing in autism spectrum diagnoses summed up Vijay's challenges in a single diagnosis: **Asperger syndrome.**

The Guhas made a strong case at the PPT meeting at which these evaluations were reviewed that the district had failed to accurately identify what was going on with their son and, therefore, had failed to provide him with an appropriate program. They requested, and were granted, ongoing consultation to the team by both an adult with Asperger syndrome who was successfully employed and an inclusion expert familiar with college-bound secondary education.

These professionals worked with district staff to understand Vijay's particular manifestation of Asperger syndrome and how to program best for him. They have since faded their services completely as district staff, including the new high school inclusion facilitator and a guidance counselor who received specific training in all forms of autism spectrum Differences, serve as in-house consultants. After two successful years in general education high school classes with support, Vijay is currently in his junior year.

Vijay's IEP

As with Mary Alice's IEP, EVERYONE on Vijay's team (including each general education teacher in whose class he is enrolled) is responsible for following his IEP and, if there are issues in interpretation, fidelity, monitoring, etc., to address these issues as they arise. Vijay benefits from a "floating para-educator" who checks in with him and his teachers regularly to see if support is needed for a particular class, to help work on a particular IEP objective, or to collect data.

Because of high school culture, Vijay's collaborative team consists of his case manager, the secondary level inclusion facilitator, and the specially trained guidance counselor. His parents are welcome to attend (but seldom do any more, because they are scheduled during a study hall and Vijay himself has begun to attend). Vijay is primarily in heterogeneous but not co-taught classes. Because the district has not entirely eliminated tracking, he is in advanced placement English and History courses with the accommodations and modifications applied as equally as they are in all other courses (including elective).

Vijay's Current Goals and Objectives

Goal 1: Across the curriculum, Vijay will earn a grade of B or higher as measured by modified assessment processes.

Objective 1: Vijay will be able to identify when modifications, accommodations, and other supports identified in his IEP are not being implemented and will approach responsible parties politely to advocate for what he needs.

Objective 2: With increasing independence, Vijay will approach general education teachers with ideas for how to approach his schoolwork or suggest alternatives for a grade.

Objective 3: Vijay will read Cliff Notes or similar interpretive guides for English Literature 10, Music Appreciation, and individual assignments in other courses.

Objective 4: Given permission from any teacher, Vijay will research course content using valid and reliable internet resources with increasing independence.

Goal 2: Vijay will apply strategies to interact appropriately with peers in structured classroom settings, during unstructured times at school, while participating in extracurricular activities, and in the community.

Objective 1: By the end of semester 1, Vijay will identify several friends and invite them to participate in an age appropriate activity outside of school approved by his parents (e.g. home to do homework or play video games, extra- or intra-mural sporting events).

Objective 2: Given scripts and in vivo instruction, Vijay will respond to mistakes made by others in a constructive manner and end or redirect conversations politely.

Objective 3: When he feels himself becoming overwhelmed or anxious, Vijay will use relaxation strategies and/or request a sensory break with increasing independence.

Objective 4: With increasing independence, Vijay will make alternative transportation arrangements if he can't take his regular bus for any reason and will politely decline the activity if alternative arrangements cannot be met.

Vijay's Accommodations and Modifications

Vijay's accommodations and modifications are listed on page 8 of his IEP (CT's IEP form is available for download at <http://www.sde.ct.gov/sde/lib/sde/PDF/DEPS/Special/ED620.pdf> or <http://www.sde.ct.gov/sde/lib/sde/PDF/DEPS/Special/ED620.pdf>). They are as follows:

Materials/Books/Equipment:

Same texts, lab, and other classroom materials/equipment as all other students. Cliff Notes/ other interpretive materials for Eng 10, Music App, and other inferential content. Computer access in all classes with age-appropriate, content-specific software as possible (e.g., universal design software accompanying district texts); online access in the library with a classmate during work times. Calculator/algorithms for work in any class incorporating math.

Tests/Quizzes/Assignments:

Same as other students. Vijay may choose to take quizzes orally within 48 hours or open book in the classroom. Vijay may choose to take extended time for tests and may either write, use the Alphasmart, or dictate answers. Tests with grades less than a B- should be retaken or grade replaced by internet research report to class.

Grading:

Missing assignments are not counted in grade averaging. See Tests/Quizzes/Assignments. Attendance does not count toward class grade due to anxiety/sensory breaks.

Organization:

Use individual system carried over from grades 9 and 10 (Vijay can explain).

Environment:

Identify positive role models/friends and assign to Vijay for all groupwork. Allow Vijay to choose and change seat as needed.

Behavioral Interventions/Support:

Breaks as requested. Be non-confrontational to address misbehavior if needed and avoid "yelling" at class or changing schedule (e.g., keeping class late or after school).

Instructional Strategies:

Models, extra discussion, and re-teaching as needed of appropriate referencing methods given various sources. Provide explicit explanations for inferential content regarding why a particular interpretation is preferred; nonverbal cues for social behaviors (e.g., pre-taught gestures, how-to articles about age-appropriate behaviors, reminders to the whole class written on the board).

Other:

“Pocket version” of IEP for reference. List of pre-approved alternate assignments for all teachers. “Pocket version” of how to judge website information for reference. Participation in after-school Animé and debate clubs.

Summary of Vijay’s IEP

Typical for a student with Asperger syndrome? *Probably not.* Controversial? *Perhaps among those who buy into a particular “programmatically approach” to this form of ASD.* Individualized for Vijay? *Definitely.* Scientifically based strategies? *Yes, of course, although each is drawn from a wide range of sources from occupational therapy to pediatrics to psychology to education, etc.* Further, it is at the discretion of certified staff whether a given situation best requires an applied behavior analytic, developmental, integrated play group, or other approach ... just as it would be for teaching any other child regardless of whether that child was neurodiverse or neurotypical!

What’s remarkable is that Vijay already met Objectives 2.1 and 2.4 and is well on his way toward meeting 2.2 and 2.3; individualized data records show that he has increased his independence from a baseline of “total reminders from staff” to independence for more than 70% of the natural opportunities he encounters during his school day. General education teachers report no difficulties and that “Vijay is a great student and a joy to have in class.”

Selected References

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Common Questions Educators (and Parents) Have About ASDs

Question: Isn't Applied Behavior Analysis (ABA) the only scientifically proven intervention/teaching strategy for ASDs?

Short answer: No. There are a number of evidence-based practices that are quite effective in teaching people with ASDs and ABA has been called into question by some groups such as the American Academy of Pediatrics.

Sample Article: Spreckley, M., & Boyd, R. (2009). Efficacy of applied behavioral intervention in preschool children with autism for improving cognitive, language, and adaptive behavior: A systematic review and meta-analysis. *The Journal of Pediatrics*, 154, 338-344.

Abstract: Objective: To review the effectiveness of applied behavior intervention (ABI) programs for preschool children with autism spectrum disorder (ASD) in their cognitive, adaptive behavior, and language development.

Study Design: Systematic reviews, randomized or quasi-randomized controlled trials (RCT) of applied behavioral intervention (ABI) delivered to preschool children with ASD were reviewed. Quantitative data on cognitive, language, and behavior outcomes were extracted and pooled for meta-analysis (RevMan 4.2).

Results: Thirteen studies met the inclusion criteria. Six of these were randomized comparison trials with adequate methodologic quality (PEDro ≥ 6). Meta-analysis of 4 studies concluded that, compared with standard care, ABI programs did not significantly improve the cognitive outcomes of children in the experimental group who scored a standardized mean difference (SMD) of 0.38 (95% CI -0.09 to 0.84; $p = .1$). There was no additional benefit over standard care for expressive language; SMD of 0.37 (95% CI -0.09 to 0.84; $p = .11$), for receptive language; SMD of 0.29 (95% CI -0.17 to 0.74; $p = .22$) or adaptive behavior; SMD of 0.30 (95% CI -0.16 to 0.77; $p = .20$).

Retrieved from [http://www.jpeds.com/article/S0022-3476\(08\)00777-4/abstract](http://www.jpeds.com/article/S0022-3476(08)00777-4/abstract)

CONCLUSION: Currently there is inadequate evidence that applied behavioral intervention has better outcomes than standard care for children with autism. Appropriately powered clinical trials with broader outcomes are required.

Question: Facilitated communication has been disproven as a hoax, right?

Short answer: No, quite the contrary. Facilitated communication may be thought of as a specific type of prompt.

Sample Article: After a thorough review of the literature, the Board of the Autism National Committee, with input from a number of facilitated communication users both independent and still relying on some form of support, promulgated its Policy and Principles Regarding Facilitated Communication (<http://www.autcom.org/articles/PPFC.pdf>).

Summary: Key points in this document concerning facilitated communication (FC) are as follows:

- Those who are not yet using FC and who are not speaking fluently have a right to be exposed to, and to receive, competent facilitated communication training (FCT) in addition to being exposed to and receiving training in other specific (Augmentative and Alternative Communication or AAC) processes and methods.
- The benefit of FCT as an acceptable and valid form of AAC has been established: (1) the number of individuals on the spectrum who are typing independently today; (2) the studies in which at least some messages were passed correctly; and (3) practical applications when individuals' messages about pain, discomfort, choices, and other personal information have been successfully addressed.
- The primary goal of FCT is always for individuals to achieve independent typing. However, given the complexity of challenges faced by individuals, total independence in typing and in demonstrating literacy may not be possible at all times and for every single person.
- Literacy is essential (and no one, regardless of the apparent severity of their ASDs, should be denied literacy instruction).
- The existing body of research points to essential cautions in using AAC (including FC) with anyone who does not fluently or independently speak, sign, or write to communicate. FC standards must be followed, including independent verification of any potentially life-altering communications. "Facilitator influence is not an insurmountable obstacle (though)."
- FC requires multiple levels of support, just as any instruction for any new skill does. One size of instruction/support does not fit all.

CONCLUSION: Facilitated communication works for some non-speaking people with ASDs at least some of the time under some circumstances. It is but one of several "accepted and valid way(s) in which individuals with autism can exercise their right to say what they have to say."

Some videos or DVDs to watch

Jamie Burke in *Inside the Edge: A Journey to Using Speech Through Typing*

Sharisa Kochmeister in *Sharissa: My Life as a Pioneer*

Sue Rubin in *Autism is a World*

Larry Bissonette in *My Classic Life as an Artist*



Question: Are mercury and vaccines (thimerosal) causal factors in ASDs?

Short answer: Probably not—and the risk of ANY relationship is much smaller than the risk of the widespread and devastating effects of these diseases if preventative vaccines were not given. However, on a case-by-case basis, we have no way of knowing for sure.

Facts: “...report of the Immunization Safety Review Committee (of the Institute of Medicine of the National Academies) examines the hypothesis that vaccines, specifically the measles-mumps-rubella (MMR) vaccine and thimerosal-containing vaccines, are causally associated with autism. The committee reviewed the extant published and unpublished epidemiological studies regarding causality and studies of potential biologic mechanisms by which these immunizations might cause autism.”

“The committee concludes that the body of epidemiological evidence favors rejection of a causal relationship between the MMR vaccine and autism. The committee also concludes that the body of epidemiological evidence favors rejection of a causal relationship between thimerosal-containing vaccines and autism. The committee further finds that potential biological mechanisms for vaccine-induced autism that have been generated to date are theoretical only.”

Retrieved 9/29/09 from <http://www.iom.edu/CMS/3793/4705/20155.aspx>

According to the Centers for Disease Control, “Thimerosal is a mercury-containing preservative used in some vaccines and other products since the 1930s. There is no convincing scientific evidence of harm caused by the low doses of thimerosal in vaccines, except for minor reactions like redness and swelling at the injection site. However, in July 1999, the Public Health Service agencies, the American Academy of Pediatrics, and vaccine manufacturers agreed that thimerosal should be reduced or eliminated in vaccines as a precautionary measure.”

Retrieved 9/29/09 from <http://www.cdc.gov/vaccinesafety/updates/thimerosal.htm>

CONCLUSION: There is substantial evidence that the public health risk of contracting diseases prevented by early childhood vaccinations outweighs the risk to individuals. This is not particularly comforting if you are an individual or family for whom such risk may be, unbeknownst to you and others, a reality. Clearly, there is no current evidence of a direct or indirect reason to believe that any particular individual receiving vaccines will develop ASD. However, the role of past vaccines, particularly those using thimerosal, is unknown and may indeed have been a causal or correlative factor in some individuals only. If there were such a relationship, it is most likely limited only to a small percentage of those who have a biological predisposition toward developing autism that MAY be triggered by thimerosal, other vaccines, or other environmental conditions alone or in conjunction with a vaccine or vaccines.

Question: Is there biological evidence that people with ASDs lack “theory of mind”?

Short answer: No. People with ASDs often show remarkable empathy and other indicators that they are very capable of “putting themselves into others’ shoes,” but they may not be able to express this or may have a different “theory of mind” because of their autistic experiences.



Sample Article: Gernsbacher, M. A., & Frymiare, J. L. (2005). Does the autistic brain lack core modules? *The Journal of Developmental and Learning Disorders*, 9, 3-16.

Abstract: Researchers have hypothesized that autistics are missing core modules of the brain, critical neural tissue necessary for accomplishing various processes. In this article, we critically review the evidence supporting two such hypothesized deficits. We ask whether autistic brains lack a module for understanding the behavior of others (i.e., theory of mind) and whether they lack a module for processing faces. We illustrate that successful performance on theory of mind tasks depends on linguistic ability; therefore, it is not surprising that autistics are more likely to fail theory of mind tasks because a qualitative impairment in communication is one of the primary diagnostic criteria for autism. Similarly, we illustrate that autistics are less likely to fixate the eye region of facial photographs and that the amount of time spent fixating the eye region correlates with activation in the face processing “module”; therefore, it is not surprising that autistics are less likely to activate the putative face processing area. These illustrations cast doubt on the arguments that the autistic brain is missing the core modules responsible for understanding theory of mind and for processing faces.

Retrieved 9/30/09 from http://psych.wisc.edu/lang/pdf/Gernsbacher_autistic_modules.pdf

You may enjoy reading Daniel Tammet's first person account, *Born on a Blue Day: Inside the Extraordinary Mind of an Autistic Savant* (Free Press, 2006).

CONCLUSION: Every individual with autism is different and while some, like Temple Grandin, may truly have difficulty understanding others' thoughts and feelings, others may be perfectly able from a cognitive perspective but be missing valuable sensory information leading to possible inaccuracies in their interpretations. Still others, like Daniel Tammet, may simply have different communication experiences because of their sensory differences.

An Adult Perspective on MACS (reprinted with permission)

Jacob Pratt, one of the original named plaintiffs in the P.J. Case¹, analyzes his MACS differences and what to do about them. This information was taken from a PowerPoint presentation, *Teaching Your Support Staff How to Understand Your Autism Using the MACS Approach*, by Jacob Pratt, 2005, rev. 2008. **REMEMBER:** Children with ASDs grow up to be adults with ASDs.

MY MOVEMENT DIFFERENCES: I have severe apraxia which means my body does not always do what I want it to do. It's almost as though there are two parts of me – the conscious part I control and the part that does its own thing. Here are things I have trouble with and what you can do to help me:

Starting. I take a really long time to get going. Sometimes it may seem like I am ignoring you when I'm really just trying to organize myself to get going.

What to do. Once you ask me a question or give me a suggestion, just wait for me to respond. If I'm really taking too long, it's okay to ask me through facilitation if I need more time or if there's something else I want to say. Respect what I tell you.

Stopping. I can't help some of the things my body does even though I try really hard to stop doing them. These things include yelling and getting too close to people.

What to do. Apply the THREE QUESTION RULE in ignoring me. Please ignore my yelling. It embarrasses me and I am already trying to control it myself. Please ignore me when I appear to bite you or lunge at you. Just get out of my way because that makes it easier for me to control myself and not hurt you!

Please ignore me when I invade your personal space. I know what a good distance is between people but sometimes I get too close by mistake. Redirect me by walking away from me and getting a letterboard so we can talk.

Combining. Actually, this is an area of strength for me. Some people with autism can't concentrate on two things at once. I am able to separate the part of my brain that does meaningful things from the part that does inappropriate things.

What to do. N/A (Editor's note: Although Jacob perceives this as an area of strength, this strength can be problematic when he is typing words of wisdom during a presentation while at the same time emitting unusual vocalizations. Although he is not distracted by this [almost because parts of his brain operate independently of one another], it can be extremely distracting to his audience!)

Continuing. I can get stuck in the middle of doing something.

What to do. Be patient. If I take too long, use facilitation to ask me if I need more time or if there's something else I want to say. Respect what I tell you.

¹ See CT State Department of Education <http://www.sde.ct.gov/sde/cwp/view.asp?a=2626&q=320792> for details.

MOVEMENT, cont.

Executing. I often have difficulty doing a task from start to finish without adding some extra movements, appearing to forget a step, or messing up because I don't have full control over my hands.

What to do. I am more of a perfectionist and harder on myself than anyone else. Please just let me self-correct or, if I'm way off base, give me a gentle reminder like "Here, Jacob, do it this way." That can help me refocus. If I yell when you do this, it's only because I am frustrated with myself. Use facilitation if you're not sure what's going on.

Switching. This is another area where my autism does not get in the way. I don't have trouble changing activities or transitioning like some other people do. I hate change because it makes me anxious.

What to do. N/A

MY ANXIETY: Anxiety is HUGE for me. I am naturally more anxious, but I get overanxious when I don't get what I need and people keep doing things that don't work for me. When I am overly anxious, I can behave in ways that are challenging to both of us. There is a separate section of this book that addresses those behaviors so you know what to look for. Here's how to minimize my anxiety:

LET ME DO THINGS I LIKE/AM GOOD AT

- Watching sports
- Playing sports (bowling, basketball)
- Advocating for myself/telling people what I need through facilitated communication
- Learning things quickly
- Academics
- Going to church ("Everyone needs God")
- Music

AVOID THINGS THAT DO NOT WORK FOR ME/THINGS I DO NOT LIKE

- Change
- Unpredictable noises
- Unpredictable situations
- Having decisions made about me without my input
- Disrespect
- Insensitivity to my autism (i.e., MACS differences and challenges)
- Lengthy periods of unstructured time/boredom
- Not filling my medications on time
- Having no choice but to live with my family

ANXIETY, cont.**MAKE SURE I HAVE THE THINGS I NEED**

- Predictability through a regular daily schedule
- Feeling safe and secure in my home
- To be treated as a 32-year-old man who is at least as intelligent as the people who work for me
- Daily physical activity and exercise
- Gainful employment
- Friends and being around people who like me
- Some time alone to regroup (WARNING: Too much time alone can make me depressed)
- To be treated in an age-appropriate way
- To converse with people daily through facilitated communication
- Higher education
- Things I can fidget with like my box of marbles or a squeeze ball
- Healthy foods

MY COMMUNICATION DIFFERENCES: Communication is also a big thing for me. There are times when I am able to answer yes/no or other short answer questions with my voice. However, it is still a good idea to check with me to see if I really mean whatever it is I said because sometimes what comes out of my mouth is a movement difference, not true communication.

USING FACILITATED COMMUNICATION

I need to use facilitated communication to let people know what I'm really thinking. I am patient and look forward to using this form of communication with you on my letterboard or on my computer. I also like to use other peoples' computers. Facilitated communication works best for me because it is easier for me to type what I want to say than it is for me to get my mouth to work right.

I am an excellent speller, although I may misspell words I don't see very often or have only heard and never seen. The reason for this is that no one ever taught me how to decode or encode while reading or writing. Instead, I taught myself to read so if you have any doubts about how smart I really am you can forget them now!

HOW TO DEAL WITH MY UNUSUAL VOCALIZATIONS (echolalia)

The "THREE QUESTION (OR STATEMENT) RULE" is a guideline I ask all who work with me to follow to the best of their ability. What I need is for you NOT to respond to me when I ask a question or make a statement several times in a row, because most of the time repeating these questions/phrases are not things I want to do.

COMMUNICATION, cont.

Here is how the rule works:

- Ignore the first question or comment completely if it is out of context and not something someone without autism would say at that time.
- Ignore the second time I ask the question or make a comment, too.
- If I ask the question a third time, use facilitation to verify whether I really want an answer or not. Do the same if I repeat the statement a third time. For example, ask me, "Do you need me to answer this question, Jacob?" Help me use FC to answer, because my voice is unreliable and my mouth may say yes when my brain means no.

WARNING: While the "THREE QUESTION RULE" usually works; it doesn't always, especially when I am upset or bothered by something like background noises. I will try to be patient with you if you work hard to apply this rule.

Some things I am likely to say but don't want to say are:

- "Hi, (your name)" when I've already spent time with you and saying "hi" is not necessary.
- "Tomorrow's (day of the week)" when I actually know exactly what day of the week tomorrow is!
- "Mommy coming" (I can read and am perfectly capable of checking the schedule myself to see when I'm getting together with my mom)
- Any time I ask to sing a song, especially a childish one. There are some people with whom I like to sing such songs occasionally, because we are being goofy. Even those people need to ask me if I'm just saying the name of the song or if I really want them to sing it to me or with me. Use facilitation to find out for sure.
- Any time I ask to do anything I've done with you before like "Go to McDonald's?" "Meds at 8:00?"

MY SENSORY CHALLENGES: Did you know there are actually more than 5 senses? Let me tell you how each sense affects me:

Vision. I wear special prism glasses. I'm not exactly sure how my vision is different from yours but I know it is. You can tell by the way I hold my head to examine some things. It is also too hard for me to focus my eyes when I'm reading something that's lengthy.

Hearing. My hearing is much more sensitive than yours. That's why I don't like babies or dogs (their crying/barking hurts my ears) and sudden loud noises. I hate it when people make some noises like popping their gum because I can't block out the sound.

SENSORY, cont.

Taste and Smell. I'm actually pretty tolerant of different tastes and smells unless your breath is really bad. I prefer peppermint to coffee breath.

Touch. Some people with autism can't stand light touch. I'm actually okay with light touch and enjoy being tickled because it is calming. I'm not too fussy about my clothes like other people are, but I do need the tags cut out of new clothes and I hate being barefoot. Brushing can help me stay calm, as can sifting the marbles that I keep in my bedroom.

Proprioception. This is the sense of knowing where your body parts are in space. I have a lot of trouble with proprioception, because there are times when I actually can't feel parts of my body or they seem like they have fallen asleep. This is why, if you are typing with me for an extended period of time, I may slam my hand on the table so I can continue to type. I may catch myself so I don't accidentally hurt you, but my problems stopping may get in the way. Know that I don't mean to hurt you. If I do this, massaging my hands and putting deep pressure on my joints can help.

Vestibular. This is the sense of balance – another sensory area where I don't have too much difficulty any more. When I was younger, though, I used to love swinging and spinning. I could do these much longer than other kids without getting sick!

by Jacob Pratt

COMING SOON! - The Spring 2010 issue of The Inclusion Notebook

IN THE NEXT ISSUE:

- ◆ **Formal Assessment of Children with ASDs: If the Scores Don't Mean What We Think They Mean, Then What?**
- ◆ **Adapting Ecological Assessments to Students with ASDs**
- ◆ **Including Children with Autism in Inclusive Preschools: Strategies that Work (by Ilene S. Schwartz, Felix F. Billingsley, and Bonnie M. McBride; reprinted with permission)**
- ◆ **Abstract of Research Literature Supporting the MACS Model**
- ◆ **Look What These Kids Can Do! Teaching Music to Children with Autism (by Sherri James Buxton; reprinted with permission)**
- ◆ **How Camp Counselors and 1:1s can Include Kids with Autism in a Typical Summer Camp Setting: It's NEVER Too Early to Start Planning!**

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