Quality Indicator and Standards Review
In Autism Treatment

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Executive Summary

I have been contracted by the University of New Brunswick to provide a review of current Quality Assurance protocol, standards, and best practices applied in both the United States and Canadian jurisdictional settings. UNB is interested in establishing a protocol for the University to apply in its current Autism Intervention training programming, as well as to share with its provincial counterparts in the administration and support of programming across the province and across Atlantic Canada and elsewhere.

Although there are currently hundreds of treatments for autism, only a small handful have been scientifically validated. The Task Force findings discussed herein recognize the scientific support for ABA and have collectively determined that ABA is an “established” treatment. There are over 500 published articles demonstrating the efficacy of intervention derived from ABA. These research studies are published in a wide array of peer-reviewed journals and carried out by investigators affiliated with both academic and applied organizations. Funding sources should focus upon programs that provide applied behavior analysis competently and comprehensively, and they should exercise caution and greater diligence in reimbursing services for treatments that are not yet established.

As a framework, a reliance on “established” treatments represents “state of the art” treatment as it incorporates what has been demonstrated through published research in peer-reviewed journals. Therefore, providers and program administrators who choose to use treatments which are not yet established should be required to report and justify why they are bypassing “established treatments” and to then provide data and treatment summaries that document gain. Furthermore, when interacting with families, providers should describe other interventions as untested and/or under-researched and encourage families who are offered these interventions to consider them carefully.

Parents should be educated and fully informed about which aspect(s) of their child’s treatment is/are comprised of established treatments and which is/are not. Otherwise, the providers are negatively impacting the capacity for informed consent. In sum, a higher level of accountability should be demonstrated by those who use not yet established treatments, particularly when funded by public dollars.

Submitted by,

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Section I - Reviews of the available research:

In this section I share information about the finding of several task force reports that have evaluated the state of the published research related to autism treatment. One common theme across all these task force reports is the commitment to considering only research published in peer-reviewed journals. This is critically important at a time when less systematic “research” and glowing testimonials are abundant and easily accessible via internet searches. Moreover, many proponents of under-researched treatments often cite unpublished research or research that is underway.

The National Standards Report, a comprehensive report and analysis published by the National Autism Center, classified autism interventions into Established Treatments, Emerging Treatments, and Un-established Treatments.

- **Established Treatments** were determined to be known to be effective for individuals on the autism spectrum. It is important to be clear that the vast majority of these interventions were developed in the ABA literature.

- **Emerging Treatments** had some evidence of effectiveness, but not enough for the National Autism Center to be confident that they are truly effective treatments (e.g., Cognitive Behavior Therapy, AAC Devices, Developmental-Relationship based therapy, Social Skills Training, PECS).

- **Un-established Treatments** had no sound evidence of effectiveness (e.g., Auditory Integration Training, Facilitated Communication, GFCF Diets). In fact, the concern was raised that these treatments could, indeed, be ineffective or harmful.

- **Ineffective or Harmful Treatments** had several published, peer-reviewed studies in which either no beneficial treatment effects or adverse treatment effects were found. At the time that the Task Force was conducting their review of available published research, there were no treatments with sufficient evidence specific to the ASD population that met the criteria for Ineffective or Harmful Treatment.

- A major concern about this report is that several different interventions were lumped together and considered as one cohesive set under “Developmental Relationship-Based Treatment.” If these interventions were reviewed alone, they would not have met the criteria for “emerging.” Other limitations relate to the use of the term “emerging” as it may give providers and consumers the impression that research related to an “emerging treatment” would indeed be forthcoming. It would be beneficial if a subsequent iteration of the National Standards Report actually looked closely at the research activity associated with each “emerging” treatment to assess whether a trend towards more research support is present or absent.


The National Autism Center also published Evidence-based Practice and Autism in the Schools: A Guide to Providing Appropriate Interventions to Students with Autism Spectrum Disorders which can be found at [http://www.nationalautismcenter.org/pdf/NAC%20Ed%20Manual_FINAL.pdf](http://www.nationalautismcenter.org/pdf/NAC%20Ed%20Manual_FINAL.pdf). The 2nd chapter is devoted to description of 11 established treatments; however, there is tremendous overlap between the
established treatments and, again, it is important to note that all of these have a basis in applied behavior analysis:

1. Antecedent package (this includes proactive environmental procedures and modifications instituted before challenging behavior occurs).
2. Behavioral package (this involves an analysis of antecedents and consequences to develop interventions targeting specific behaviors—it is important to note that this includes antecedent strategies).
3. Comprehensive behavioral treatment for young children (this incorporates intensive and extensive service delivery at the early intervention level, including discrete trial instruction, among other behavior analytic teaching procedures).
4. Joint attention intervention (this encompasses interventions, again including discrete trial instruction, to help individuals with ASD learn to share attention on an activity or object).
5. Modeling (strategies targeting a broad array of skill domains to help individuals with autism observe and imitate a model of desired behavior so that these behaviors can be incorporated into their own repertoires).
6. Naturalistic teaching strategies (these incorporate strategies to promote the generalization of skills including the teaching of skills in natural settings).
7. Peer training package (this involves training peers to have positive and appropriate interactions with individuals with autism).
8. Pivotal response treatment (this overlaps substantially with many of the areas already listed, but one unique dimension is the underlying premise that certain key skills, once learned, can lead to acquisition of other untrained skills).
9. Schedules (this encompasses a wide array of methods to promote independence and to enable individuals with autism to carry out sequences of actions over an extended period of time).
10. Self-management (this approach may include schedule training, but largely involves teaching the individual with autism to choose reinforcing items, plan and monitor their performance carrying out desired tasks, and determine if performance warrants reinforcement).
11. Story-based intervention package (this may include written scripts or social stories).

There are other useful chapters in *Evidence-based Practice and Autism in the Schools: A Guide to Providing Appropriate Interventions to Students with Autism Spectrum Disorders*. I will discuss these further in the section related to quality assurance indicators.

Another task force report comes from the state of Maine. The Report of the Children’s Service Evidence-Based Practice Advisory Board (Collaboration of the Maine Department of Health and Human Services and the Maine Department of Education) was published in October 2009. This report was precipitated, in part, by the 276% increase in the number of students receiving services for autism spectrum disorders in Maine from 2000 to 2008. Prior to delineating their findings, I want to share the final 2 sentences of the Executive Summary on page 11: “The first step toward evidence-based practice is creating awareness of what the best practice research says. It is no longer enough to use what we believe works we must consider what we know works in order to close the gap between science and practice, utilize limited resources wisely, and best serve Maine children with ASD.”
Here interventions were classified based on six levels of evidence:

**Established Evidence:** Multiple strong or adequately rated group and/or single-subject studies. Findings indicated ABA for challenging behavior, communication, Early Intensive Behavioral Intervention (EIBI), PECS, and a small number of pharmacological agents including Halperidol (Haldol) for aggression, Methylphenidate (Ritalin) for hyperactivity, and Risperidone (Risperidol) for irritability, social withdrawal, hyperactivity, and stereotypy.

**Promising Evidence:** Shown effective in more than two group-design studies or three single-subject studies. Findings indicated ABA for adaptive living skills, Cognitive-Behavioral Treatment for anxiety, and Voice Output Communication Aid (VOCA).

**Preliminary Evidence:** The intervention has been shown effective in at least one group or single-subject design study. Findings indicated ABA for academics and vocational skills, Cognitive-Behavioral Treatment for anger management, Sign Language for communication, Vitamin C for sensorimotor symptoms (modest effect), a small number of pharmacological agents including Atomoxetine (Strattera) for attention deficit and hyperactivity, Clomipramine (Anafranil) for stereotypy, ritualistic behavior, and social behavior, Clonidine (Catapres) for hyperactivity, irritability, and stereotypy, as well as Touch Therapy/Massage, and Hyperbaric Oxygen Treatment.

**Studied and No Evidence of Effect:** Numerous studies show no positive effect on the desired outcomes. Findings indicated Dimethylglycine (DMG) and Secretin.

**Insufficient Evidence:** Conclusions cannot be drawn due to a lack of quality research and/or mixed outcomes across several studies. Findings indicated Facilitated Communication, Gluten-Casein Free Diets, Omega-3 Fatty Acid Supplements, Vitamin B6/Magnesium Supplements, DIR/Floortime, RDI, SCERTS, Solomon’s PLAY model, Social Skills Training, Social Stories™, Auditory Integration Training, Sensory Integration Therapy, TEACCH, and a large number of pharmacological agents including Guanfacine (Tenex), Intravenous Immunoglobulin, Melatonin, Naltrexone (Revia), SSRIs, and Valproic Acid (Depakote).

**Evidence of Harm:** Studies indicate that the intervention involves significant harm or risk of harm, including injury and death. Findings indicated intravenous chelation using Edetate Disodium.

- The “Findings” section of this report describes the research that was used to render a decision about the level of evidence published in peer-reviewed journals. It is important to share that the inclusion criteria for this analysis was quite strict in that studies which included participants who did not have an ASD diagnosis were excluded altogether.
- Information about the 2009 Maine State document can be found at http://www.maine.gov/dhhs/ocfs/cbhs/ebpac/asd-report.doc
Albeit over 10 years old at this time, I included information about the New York State 1999 Department of Health Report. Applied behavior analysis was the only treatment substantiated to be effective based on the scope and quality of research. Again, this does not mean that ABA is the only intervention which is effective for students with ASDs, just the only one demonstrated to be effective at that time.

- This finding is important as it demonstrates that applied behavior analysis enjoyed a respectable body of scientific support and was scientifically investigated by a wide array of researchers.
- ABA has been known to be effective for a number of years now (in contrast to newer approaches that have no such track record of documented success).

I also included information about the 2004 New Jersey Department of Education report. The 2004 New Jersey State document can be found at http://www.special-ed-law.com/docs/autism%20program%20indicators.pdf

- Appendix B lists unsupported treatments; however, some of these are unsupported because they do not fall under the responsibility of school districts (e.g., medications). From an educational system standpoint, it is important to differentiate between educational approaches and those which are more bio-medical in nature and would not be carried out by educational staff.
- Appendix A includes a more elaborate description of ABA and DIR (Floortime). It is puzzling that DIR would be given such attention in the Appendix when the intervention itself was classified by this same Task Force as possessing “insufficient evidence.”

Recommendations related to the above findings:

1. Applied behavior analysis is the only treatment that has been determined to be effective by multiple task forces. Because ABA currently possesses more scientific support than any other behavioral or educational intervention for children with ASD, I strongly recommend that providers first use ABA and consider other approaches cautiously.
2. It should be considered that some providers might implement an ABA intervention inconsistently or otherwise poorly and use those data to justify a switch to an under-researched alternative intervention.
3. The task forces highlighted above may reconvene periodically to update their findings; however, this may not be the case. Fortunately, their criteria can be used to assess the additive value of newly published research to determine if any particular intervention enjoys heightened scientific support.
Section II - Considerations when using an eclectic model of intervention:

1. From a research standpoint, there are no scientifically-validated eclectic models, with one exception. One study has provided some interesting data related to positive outcomes of a blended model combining developmental and ABA approaches (see citation below). The results of this study warrant replication by independent investigators. The nature of the control groups included in this study precludes any definitive statement about which components of the intervention accounted for the outcomes. Further research would be needed to tease out the additive and unique benefit of developmental approaches.


2. In fact, there is a growing body of research that suggests that children receiving eclectic treatment do not achieve the same outcomes as those whom receive more homogenous ABA intervention.


3. Researchers arguing for the superiority of an eclectic model should be able to demonstrate that A + B is better than either A or B alone. As stated above, comparisons that do not look at treatment components rigorously and systematically can lead to faulty conclusions and overgeneralizations. I anticipate that in the next few years we will witness many researchers of not yet established treatments overreaching in their claims.

4. There are no direct comparisons between ABA and another treatment which demonstrate the superiority of that other treatment.

5. From a clinical standpoint, eclectic programs can lead to diluted treatment delivery and a failure to achieve necessary intensity. Eclectic providers may lack the necessary training to carry out the various interventions adequately, as well as the clinical judgment to determine which treatments should target which deficits. As a result, treatment delivery may lead to poorer outcomes.
Section IIIa- Aspects of ABA that have implications for measuring and evaluating non-ABA interventions:

There are a number of assessment and evaluation procedures within ABA that bear tremendous relevance to other interventions:

- **Identify targets for change:** Many providers fail to identify specific behaviors being targeted by their intervention. Every proposed treatment for autism is hypothesized to improve specific areas of functioning or other observable behaviors. It is important to establish these a priori (i.e., prior to intervention). This would be a litmus test through which treatment outcome should be measured.

- **Operationalize targets (specific, observable):** Although some providers have identified targets, it is often the case that the behaviors targeted for change are not measurable or observable. In order to adequately assess outcomes, targets must be explicitly determined so that they can be reliably measured over time and measured consistently across multiple members of the intervention team.

- **Obtain adequate baseline data:** Many providers initiate intervention in the absence of any baseline data, preventing adequate comparisons with levels of the treatment. Prior to beginning an intervention, it is important to collect data reflecting present levels. These data would be used to compare with data collected over the course of the intervention.

- **Repeated measurements by collecting data on an ongoing basis:** Often times, interventions are carried out in the absence of data, rendering determinations about benefit challenging and likely invalid. Data should be collected continuously to assess trends and to prompt timely troubleshooting.

- **Collect Inter-Observer Agreement data (IOA):** Not all data are collected accurately. The collection of IOA data related to the treatment targets enables the team to assess the reliability of the data being collected at a given point in time. Poor IOA data would suggest that one or more individuals have deviated from the operational definition of the treatment target(s).

- **Change treatments one at a time to maximize accuracy of decisions evaluating those changes:** A common mistake is to make multiple changes at the same time (e.g., add or remove an intervention, reduce or increase the intensity or dose of an intervention). This tactic makes it challenging to determine which changes culminated in behavior change. Systematic modifications to an intervention enable providers to assess if changes in the rate of target behaviors can be attributed to the change in intervention.

- **Employ a variety of single-case research designs:** This enables providers to test hypotheses, to identify functional relationships between the independent variable (the intervention) and the dependent variable (targets), and to ultimately assess outcome. Commonly-employed designs: AB designs, ABA reversal designs, ABAB repeated reversal designs, Multiple baseline designs, Simultaneous or alternating treatments designs, and Changing criterion designs.
• **Visual Inspection of Data**: Far too often, providers collect data but do not utilize the data they collect. When reviewing data, providers should look at the latency for change to be observed, the heterogeneity of data, trends and levels, overlapping data across conditions, and similarity in data display across conditions.

**Section IIIb- Aspects of ABA that have implications for the implementation of non-ABA interventions:**

There are some additional procedures routinely used with applied behavior analysis that can lead to better outcomes.

• **Operationally define the intervention**: Many of the current proposed treatments for autism lack explicit standardization, such that implementation varies widely. This is a concern both within and across intervention teams. Unfortunately, many providers operate under the belief that interventions need to be individually tailored, which may lead to poor treatment fidelity. Providers should be explicit.

• **Evaluate treatment fidelity**: This relates to multiple members of the team carrying out intervention in similar ways, as well as consistently over time. This applies to both skill-acquisition and behavior-reduction interventions. Ensuring such levels of consistency must be a theme that runs throughout training and supervision. Treatment fidelity is measured through direct observation of implementation, review of video footage, as well as the incorporation of self-monitoring checklists. The latter would be predicated on the respondent understanding the self-monitoring checklist and being willing and able to complete it reliably.

• **Maintain, alter, or discontinue intervention based upon objective information**: These decisions must be made at the team level, by qualified supervisors, and based on the data that are collected.

• **Explicit efforts to promote generalization and maintenance**: It is widely accepted that outcomes achieved in one setting may not readily carry over into others. Furthermore, the skills of children with autism do not automatically generalize across instructional materials, formats, and people. Robust treatment gains are generally associated with more evidence of generalization; however, all treatment providers, regardless of discipline, should assess and promote carryover.

• **Family training**: One of the hallmark features of applied behavior analysis is its long term commitment to the education and training of parents, caregivers, and other key family members. Any autism intervention should include these essential stakeholders, given their significant roles in the lives of children with autism.
Section IV: Existing Quality Assurance models

The New York State Department of Education published The Autism Program Quality Indicators, a self-review and quality-improvement guide for schools and programs servicing those with autism spectrum disorders. Information about the 2001 New York State document can be found at: http://www.p12.nysed.gov/specialed/autism/apqi.htm. The Autism Program Quality Indicators (APQI) are a compilation of the best practices in educating students with autism, which were developed to serve as a means of guiding quality-improvement activities. A checklist format is used and the APQI are organized into the following 14 areas with seven categories referring more broadly to program characteristics and supports and seven categories relating to the specific aspects of the educational process for students. Guidelines are offered with respect to program characteristics and supports (in italics I have provided language directly from the New York APQI):

- **Family Involvement and Support** (*Parents are recognized and valued as full partners in the development and implementation of their children's IEPs*)
- **Inclusion** (*Opportunities for interaction with nondisabled peers are incorporated into the program*)
- **Planning the Move from One Setting to Another** (*Parents and professionals work collaboratively in planning transitions from one classroom, program, or service-delivery system to another*)
- **Challenging Behavior** (*Positive behavior supports, based on a functional behavioral assessment (FBA), are used to address challenging behavior*)
- **Community Collaboration** (*The program links with community agencies to assist families in accessing supports and services needed by students with autism*)
- **Personnel** (*Teachers, teacher aides and assistants, related service providers, school psychologists, administrators, and support staff are knowledgeable and skilled about that which is related to the education of students with autism*)
- **Program Evaluation** (*Systematic examination of program implementation and impact is conducted, including the aggregation of individual student outcomes and consumer satisfaction*)
Guidelines are offered with respect to specific aspects of the educational process:

- **Individual Evaluation** *(Thorough diagnostic, developmental, and educational assessments using a comprehensive, multidisciplinary approach are used to identify students’ strengths and needs)*
- **Development of an Individualized Education Program** *(The Committee on Preschool Special Education (CPSE) and the Committee on Special Education (CSE) use evaluation results, parent and family concerns, and present levels of performance in developing individualized education programs (IEPs) to meet students’ needs)*
- **Curriculum** *(The program uses a curriculum which addresses the significant skill deficits of students with autism, and relates it to the New York State Learning Standards)*
- **Instructional Activities** *(The program provides a variety of developmentally and functionally-appropriate activities, experiences, and materials which engage students in meaningful learning)*
- **Instructional Methods** *(Teaching methods reflect the unique needs of students with autism, and are varied depending upon developmental appropriateness and individual strengths and needs)*
- **Instructional Environments** *(Educational environments provide a structure that builds on a student’s strengths while minimizing those factors which most interfere with learning)*
- **Review and Monitoring of Progress and Outcomes** *(The program uses a collaborative, ongoing, systematic process for assessing student progress)*

NYS APQI scoring involves the following scales:

- **NA:** Program not responsible.
- **0:** There is no evidence of this indicator.
- **1:** There is minimal evidence of this indicator, but clear evidence exists that the program is in the process of planning for implementation and/or staff development.
- **2:** There is some evidence of this indicator or there is clear evidence of the indicator for only a portion of students with autism.
- **3:** This quality indicator is clearly evident for all students with autism.

In the fall of 2004, the New Jersey Department of Education, Office of Special Education published Autism Program Quality Indicators. Please see [http://www.special-ed-law.com/docs/autism%20program%20indicators.pdf](http://www.special-ed-law.com/docs/autism%20program%20indicators.pdf). This document is very similar to the NYS APQI with some slight alteration in wording. Guidelines are offered with respect to Program Considerations:

- Program characteristics
- Personnel
- Curriculum
- Effective Instructional Methods

As is the case with the NYS APQI, guidelines are offered with respect to Student Considerations:

- Individual Student Assessment
- Developing an Individualized Education Program
- Challenging Behaviors
- Family Involvement and Support
- Community Collaboration
- Program Evaluation
- Program Options
- Transition
- Individual Progress and Monitoring
Please be advised that researchers in Ontario have developed a few instruments that bear relevance to quality assurance. One instrument specifically focuses on teaching interactions whereas the other is broader in scope. For further information about these two instruments, please contact perrylab@yorku.ca

York Measure of Quality of IBI (YMQI)


York System of Quality Assurance (YSQA)

Recommendations related to the use of Program Quality Indicators:

1. It would be advantageous for a small task force to convene to select and/or adapt existing tools, garnering permission to use or adapt when necessary.

2. As stated above, program quality indicators delineate the array of best practices in educating students with autism (as determined by a particular group). Although they can serve as a means of guiding quality-improvement efforts, they can also be used for program selection and evaluation purposes.

3. It may be best to start off small and expand the scope of the instrument over time. Alternatively, both brief and comprehensive instruments can be developed to be implemented at different times for different purposes.

4. Ratings related to program quality indicators can be collected in a variety of ways:
   a. Providers/program administrators can self-assess using the program quality indicators and submit their ratings.
   b. Providers/program administrators can share permanent products such as video footage of teaching interactions, staff training materials, protocols, written behavior reduction plans, etc. These can be used by an outside evaluator to rate the program using the quality indicators.
   c. Providers/program administrators can respond to a structured written assessment tool that would provide the information needed for an outside evaluator to rate the program using the quality indicators.
   d. Onsite visits by an outside evaluator using established criteria can be used for the purposes of rating. Alternatively, interviews can be used to collect some of this information.

5. Please note that relying heavily on self-report data can be problematic as many providers may deliberately or inadvertently exaggerate the overall quality or consistency of their efforts. Nonetheless, self-report data may still be useful as part of a multimethod program evaluation.

6. The actual rating scale of the New York State Autism Program Quality Indicators is excellent; however, the distinction between 1 and 2 may be nebulous. A rating of “1” may indicate that the program is attempting to implement that standard program-wide. This may be better, in some cases, than a rating of “2” based on a few providers carrying out that standard on their own apart from any broader programmatic expectation.
Section V: An additional resource that may be of interest


Albeit brief in length, this resource does highlight where administrators can turn for information about best practices and urges them to take staff training very seriously with respect to the special education of students with autism. Several staff training topics were delineated in this booklet: Overview of autism, ABA, and learning theory; Instruction strategies; Curricular modifications, Challenging behavior, Facilitation of peer interactions, and social skills, Functional curricula and life skills instruction, Data collection and analysis, Generalization and maintenance strategies, Parent collaboration, Interdepartmental collaboration, and Relationship building with the students. I would add a few other important staff training topics: Paraprofessional staff training, Supported inclusion, Shadowing, Promoting Independence, and Transition planning.
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