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Treatment Recommendations

[Adopted by the Autism New Jersey Board of Trustees on August 20, 2002; Revised on January 24, 2004]

Since its founding in 1965, Autism New Jersey’s primary mission has been to ensure that all people with autism receive appropriate, effective services. To attain this goal, Autism New Jersey provides information, education, and advocacy services. These services develop, improve, and expand programs for individuals with autism. Autism New Jersey is an organization whose members may espouse different philosophies and use various treatment modalities. Because of the diversity of methods that are considered and/or used in the treatment of autism, it is important to clarify Autism New Jersey’s position regarding the treatment of autism as it pertains to education and other clinical efforts. Autism New Jersey does so in order to inform its members, other organizations, government officials, and the greater public.

Those charged with improving the lives of individuals with autism have a complex task in terms of understanding, implementing, and evaluating treatments. While Autism New Jersey’s primary role is to educate parents and professionals so that they can make independent and informed decisions, Autism New Jersey also endorses the use of treatments that are individualized, positive, science-based, and shown to be effective.

Why use science as a guide when deciding upon treatments for children with autism?

Parents and professionals need a framework for decision-making that can provide 1) criteria to choose among interventions and 2) mechanisms to determine progress or lack thereof. Given that treatment should produce measurable skill gains, a system of accountability is essential. Such accountability is easily established when we use the structure and process that science offers.

What is behavioral science?

The scientific process includes testing hypotheses in a controlled manner to identify systematic relationships between an intervention and changes in a person’s behavior. Meanwhile, alternative explanations are systematically ruled out based on careful analysis of observational data. In other words, all likely explanations for a change in a person’s behavior are explored. It is likely that only one or a few interventions are the actual cause for the change in behavior. For example, if social interactions increase following behavioral treatment, other interventions such as dietary or medication changes also would have to be evaluated as the possible cause of change. Science relies on direct observation and objective measurement of a phenomenon, systematic arrangements of events, procedures to rule out alternative explanations for what is observed, and repeated demonstrations (called replications) by individuals working independently of one another. Good science is not determined by popularity, longevity, or unsubstantiated claims. While no method is guaranteed to predict success, the scientific method does have built-in checks and balances. The scientific method emphasizes objective data, independent replication, and critical peer review. These processes increase the likelihood that the results are valid.
What is the best course of treatment for an individual with autism?
Comprehensive assessment of the individual’s abilities and preferences is the cornerstone of designing an intervention package that is most likely to be successful. An assessment provides information that is crucial to determine baseline levels of performance, reasonable criteria for acquiring and mastering goals, and the number and type of objectives to address. One also must assess the range of treatment alternatives, the purported advantages and disadvantages for the individual and his/her support system, and the likelihood of benefit for all involved. Ongoing monitoring also provides valuable information when determining if and how much of a given treatment is reasonable. In summary, some elements of successful programming include assessment, individualization, a focus on building functional skills, an enhanced quality of life in developmentally and age-appropriate ways, frequent parent and professional collaboration, and a system of monitoring to evaluate progress. There are resources listed at the end of this position statement to assist in this effort.

What methods does Autism New Jersey endorse?
Autism New Jersey endorses those intervention packages that have been demonstrated to substantially improve an individual’s quality of life. Behavioral treatment offers a systematic and well-researched approach to teaching appropriate behaviors and decreasing inappropriate behaviors. This type of assessment and teaching is formally known as Applied Behavior Analysis (ABA) and is closely linked to Positive Behavior Supports (PBS). When this treatment is implemented in a positive, person-centered, and consistent manner, most individuals with autism spectrum disorders expand their repertoire of skills and experience an improved quality of life.

More specifically, research has demonstrated that individuals with autism make significant progress in learning new skills when teaching is highly structured, data-based, and clinically sound. Professionals who study and practice Applied Behavior Analysis have published hundreds of peer-reviewed studies demonstrating the effectiveness of ABA and PBS in teaching new skills and treating behavior problems. These successful outcomes have been replicated among numerous individuals with autism and independent investigators. Behavioral research employs sophisticated experimental methodology to clearly demonstrate how the change in behavior occurred, under what conditions, and the limitations of the procedure. ABA and PBS are grounded in the science of learning, a model of behavior that has been supported through laboratory and applied research.

The field of Applied Behavior Analysis includes structured and naturalistic methodologies for assessment and intervention. They include but are not limited to discrete trial training, incidental teaching, pivotal response training, natural environment training, mand (request-based) training, verbal behavior, fluency-based instruction, task analysis, descriptive assessment, functional analysis, and positive behavioral support. (For definitions and explanations of these topics, please see Autism New Jersey’s other publications on ABA.) As individuals’ learning styles vary, so should the educational package for each person with autism. Parents and professionals are encouraged to review the references at the end of this position statement for a more comprehensive description of ABA. Research information on these methods will be made available upon request.
Thus far, no other educational treatment approach has been subject to as much well-controlled research. Several studies have suggested little or no benefit from other treatments. This is not to say that other treatments do not have merit, simply that many treatments have not yet been systematically examined through research. As stated, Autism New Jersey promotes treatments that have been extensively studied in accordance with professional standards and determined reliable in improving the abilities of people with autism. Should other treatments yield demonstrated benefit, they would systematically be incorporated into the agency’s advocacy and clinical service efforts.

What methods are not recommended by Autism New Jersey?
Unfortunately, some methods that have been proposed to treat autism have not been proven effective for individuals with autism. A review of the available research on best practices leads Autism New Jersey to not recommend certain treatments: Psychoanalysis, Facilitated Communication, Auditory Integration Training/Therapy, and Secretin (American Speech-Language-Hearing Association, 2004; Smith, 1996; Green, 1996; Green & Shane, 1994; Sandler et al., 1999). While it is possible that an individual will benefit from these approaches, research evidence suggests that the majority of individuals will not benefit in a meaningful way, or at all. Research information on these methods will be made available upon request.

What is Autism New Jersey’s position on treatments not mentioned above?
This section applies to all other treatments except those that Autism New Jersey recommends (Applied Behavior Analysis and Positive Behavior Supports) and does not recommend (Auditory Integration Training/Therapy, Facilitated Communication, Psychoanalysis, and Secretin). Clearly, Autism New Jersey recommends treatment approaches that have been systematically evaluated and found to be beneficial; the more research conducted on a particular treatment, the more information available to the consumer to determine the best course of action. Without this information, Autism New Jersey suggests that consumers proceed with caution and utilize the resources listed below to evaluate these options.

Autism New Jersey recognizes that the autism community is comprised of individuals who respond differently to various interventions. For this reason, parents and professionals must work together to develop the most appropriate and effective plan. The great number of proposed treatments for autism often complicates this task. Some view these proposed treatments as opportunities while others view them as experimental endeavors. Autism New Jersey views these options as experimental because the term conveys caution. Caution is appropriate in these endeavors because such interventions could lead to improvement, no change, or harm. Autism New Jersey recommends that consumers also adopt a hopeful skepticism to navigate these options.
Does Autism New Jersey specifically endorse any agencies or service providers?

No, Autism New Jersey does not specifically endorse any agencies or service providers. Given the diversity of training experiences and clinical skills necessary for all methodologies, it is understandable that not all providers will adhere to best practices within a specific treatment. Treatment providers who are inadequately or poorly trained, do not stay abreast of the state-of-the-art techniques, or do not comply with standards of professional practice may place consumers in undesirable and harmful situations. These deficits in professionalism occur across all treatment methodologies. In order to determine the quality of both the methodology and the provider, consumers are encouraged to conduct thorough background checks to ensure that they are working with professionals who are practicing effectively and ethically.

What resources can be used to make informed decisions?

Given the great value that is placed on a caregiver’s right to choose among a variety of interventions, Autism New Jersey provides detailed information on how to make wise choices. As previously mentioned, collaboration among parents and professionals is crucial. Autism New Jersey provides information on a variety of topics and the tools to help the caregiver evaluate programming.

What is the prognosis for someone with autism and why is there hope?

There is considerable variation in the abilities of people with autism. Some individuals may need extensive, lifelong support to function in home, vocational, and community settings, while others may need intermittent support in fewer areas. While effective and early intervention can greatly improve an individual’s prognosis, as of now, there are no definitive markers to predict a person’s level of functioning decades ahead. Thus, early treatment must be sought to address current deficits and teach new skills; such skills are likely to have a substantial impact on the person’s ability to interact with others and his/her quality of life. Together, parents and professionals can provide effective treatment. The autism community continues to advocate for research to improve intervention strategies, identify methods of prevention, and possibly develop a cure. Autism New Jersey is committed to these goals on behalf of people affected by autism.

Footnote

1. Psychoanalysis is a specific type of psychotherapy and should not be confused with other types of therapy such as family, cognitive-behavioral, or behavior therapy. Some of these therapies can be helpful and effective in treating a variety of problems that can occur in all families.
Resources for making effective treatment decisions


References for practical information on Applied Behavior Analysis and Positive Behavior Support


**References for research on Applied Behavior Analysis and Positive Behavior Support**


Acknowledgement of diversity across treatment approaches
Autism New Jersey acknowledges the diverse range of treatments for individuals with autism. Requests for information on a wide variety of topics are met with a timely response, written materials, and referrals for additional resources. Autism New Jersey provides information to the community on a consistent basis via newsletters, our website, and the media. While Autism New Jersey does not promote the practices that it does not endorse,* the agency does provide information about such practices upon request.

Endorsement of scientifically-validated treatments
Applied Behavior Analysis (ABA) and Positive Behavior Support (PBS) are the only treatments that have been demonstrated to produce both short and long-term skill gains for individuals with autism.* Due to the research support of ABA and PBS, Autism New Jersey advocates for these treatments and provides such information to parents and professionals through presentations, consultations, and statewide advocacy efforts. Should another treatment demonstrate substantial benefit to people with autism through experimental investigation, Autism New Jersey would promptly incorporate it into its clinical services and advocacy efforts.

What can the autism community expect from Autism New Jersey?
Given the continuing advances in basic and applied research related to autism, Autism New Jersey strives to offer timely, consistent, and sound information to the autism community. Autism New Jersey will clearly label empirically validated findings, experimental hypotheses, and personal opinion. Together, the Autism New Jersey staff, Board of Trustees, and Professional Advisory Board will review and communicate significant developments related to the cause and treatment of autism.

* Please see Autism New Jersey’s Position Statement on Treatment Recommendations for further explanation.
Autism New Jersey Position Statement

Use of Restrictive Procedures Within Comprehensive Behavior Support Plans

Approved by the Board of Trustees on May 6, 2003

This statement outlines the agency’s position on the use of restrictive procedures within comprehensive behavior support plans. The agency recognizes the highly controversial nature of this complex issue. Fortunately, advances in behavioral teaching technology have significantly reduced the frequency of behavioral crises. Unfortunately, behavioral crises still occur. While these episodes are unusual for the majority of individuals with autism, others repeatedly exhibit dangerous behaviors that warrant treatment. When these behaviors are not effectively reduced with positive programming, alternatives to reduce the dangerous behavior are sought. These alternatives can carry great risk to the individual and must be considered in a cost-benefit analysis.

Autism New Jersey recognizes the potential for overuse and abuse of these procedures and thus emphasizes procedural safeguards. Autism New Jersey opposes the use of restrictive procedures when these conditions are not met.

All parents are perplexed by their children’s behavior from time to time. For parents of children with autism, it is even more difficult to understand their children’s behavior. Parents may ask, “Why doesn’t he play with toys like other children? Why won’t he ask for a cookie when I know he wants it?” In addition to deficits in communication and socialization, individuals with autism may also display aggressive and self-injurious behavior. “Why does he hit his sister for no apparent reason? Why does he bang his head on the floor?”

Safely and effectively treating and preventing these behaviors requires full knowledge of why and when they occur. Our understanding develops by systematically collecting information on the behavior’s frequency, intensity, and duration. We record 1) when these behaviors are likely and unlikely to happen, 2) if there are any triggers that seem to set them in motion (antecedents), and 3) how others respond to the behaviors when they are observed (consequences). Through comprehensive observations, data collection, and analysis, we analyze why the individual acts in a certain way. This process is formally known as a functional behavioral assessment. For example, a child may become frustrated during a work assignment. When he bites his hand, the teacher stops the instruction. Over time, this child may learn that biting results in escaping this difficult situation. Thus, intervention strategies that target the function of behavior (i.e., escape) rather than the form of the behavior (i.e., biting) can be developed and implemented. For example, the teacher might be taught how to modify demands, reinforce verbal behavior that replaces hitting (e.g., requesting a break or help), and more effectively reward progress so that the child can tolerate the instruction and behave appropriately.

Individuals with autism sometimes exhibit aggressive or self-injurious behavior as a way to communicate their needs,
desires, and dissatisfactions. It is the job of trained professionals, behavior analysts in this case, to work with parents, educators, and the individual to conduct the functional assessment procedures described above. The information that is collected is used to develop hypotheses regarding the function or motivation of the behavior. Professionals can then formulate a comprehensive plan to safely and effectively reduce the challenging behavior.

Best practice standards emphasize the identification, acquisition, and maintenance of more appropriate alternative behaviors so that the individual can express his/her needs, wants, and dissatisfactions (National Research Council, 2001). Teaching new adaptive skills is one component of what is known as a Positive Behavior Support (PBS) plan. These plans may also include environmental modifications in settings in which the individual participates, changes to instructional materials, and a high frequency of positive feedback. For the majority of individuals, these positive procedures are sufficient to decrease the dangerous behavior. Not only does the maladaptive behavior diminish, but also the person’s repertoire of appropriate skills is expanded, providing him or her with the skills necessary to engage in meaningful social interaction and other activities.

In some situations, however, the functional assessment and intervention may be insufficient to reduce some instances of problematic behavior. This is particularly troubling in the case of aggression or self-injury in which the individual remains in danger of severely harming him/herself or others. These behaviors unquestionably compromise health, safety, and quality of life. After exhausting all possible positive interventions designed to reduce the behavior and teach more appropriate replacement skills, other potentially more restrictive options may need to be considered.

The work does not end with the decision to use a restrictive procedure. Issues that must be continually addressed are: the effectiveness of the intervention, how best to fade and ultimately terminate the intervention, and to what extent has the individual’s quality of life benefited from the use of the intervention. Among the questions to be asked at this time include, but are not limited to: Has there been an increase, decrease, or no change in the frequency of the target behavior? Has the duration of target behavior decreased, increased or remained constant? Were there unintended side effects that impeded implementation and thus, effectiveness? When and under what conditions can the restrictive procedure be either faded or terminated? Despite the use of a potentially restrictive intervention, is the individual now able to participate in meaningful learning experiences, acquire new skills, become more socially involved, and spend more time in the community because he or she no longer engages in the harmful behavior? Is the individual’s health and safety secure?

Emergency situations also necessitate consideration and planning as these situations demand caregivers’ swift action to minimize and prevent harm to all individuals. Emergency situations may require the temporary use of restrictive procedures prior to a functional assessment and intervention plan. The use of any restrictive procedure should be documented and reviewed by the treatment team. Crisis episodes should serve as an impetus for team discussion to determine the necessity of a more detailed plan to best serve an individual’s needs and promote quality of life.
Clearly, this process is a long and difficult one. Yet, this process is essential to best meet the needs of individuals who exhibit serious recurring aggressive, destructive, or self-injurious behavior. As previously stated, the majority of individuals with challenging behavior respond well to positive behavior support plans. In few cases, a temporary restrictive component within a positive behavior support plan may be necessary to effectively reduce a behavior that could cause serious harm to the individual or others.

In summary, Autism New Jersey is committed to the dignity, welfare and progress of all individuals with autism. Autism New Jersey supports the controlled use of restrictive procedures as a last resort and as outlined below. Autism New Jersey encourages all parents and professionals to adhere to procedural safeguards such as those listed below when considering a restrictive component within a comprehensive behavior support plan. Autism New Jersey opposes the use of restrictive procedures when these conditions are not met.

**Essential Elements of Comprehensive Behavior Support Plans That Include a Restrictive Procedure**

Autism New Jersey believes that in rare situations restrictive procedures should be implemented only in accordance with the following conditions:

1. The individual's basic needs are met on a continuous basis. These include a nutritious diet, satisfactory living space and accommodations, frequent and positive social interaction, therapeutic services, preferred leisure activities, and opportunities to be a valued and productive member of society.
2. The target behavior has the potential to cause harm to the individual, others, or the physical surroundings.
3. The frequency, severity, and/or duration of the behavior has not been sufficiently reduced or eliminated by positive interventions. These positive interventions must be comprehensive, implemented by trained personnel, documented, and have failed to reduce or eliminate the behavior.
4. The individual, parent, or legal guardian provides informed consent following a clinician's thorough explanation of the objectives and limitations of the proposed option and alternative options. This explanation must be delivered in a developmentally appropriate and culturally sensitive manner. Any modifications to the plan also require consent prior to implementation.
5. Review and approval of all planning and oversight committees are provided.
   a. An interdisciplinary team, such as IEP, IHP, or interdisciplinary team
   b. A behavior management committee – appropriately credentialed master- and doctoral-level behavior analysts and psychologists, who review behavioral treatment plans for clinical appropriateness and technical accuracy.
   c. An independent human rights committee – a group of community members who also evaluate behavioral plans from an ethical standpoint. Individuals should be knowledgeable about autism and effective treatment.
6. The individual has no known physical or medical conditions that would contraindicate the procedure. Medical personnel document their assessment and approval for the procedure.
7. A qualified behavior analyst or psychologist, with expertise using functional behavioral assessment and in developing positive behavior support plans, creates and supervises the assessment and intervention in accordance with professional and ethical standards.
8. A clear and specific definition of the behavior for which the procedure is provided.
9. Pre-intervention data are collected on the frequency, severity, and/or duration of the behavior and determined to constitute a danger to self or others.
10. A functional assessment is conducted and documented to determine the environmental and/or biological factors that maintain the behavior.

11. The intervention chosen:
   a. Is based on the Principle of the Least Restrictive and Effective Alternative, that is, less aversive procedures must be considered and/or tried before more aversive procedures are considered and/or tried. Other untried procedures would result in unacceptable danger to the individual (e.g., the use of extinction for self-injurious behavior that could result in significant harm to the individual before it was effective). Deviations from this principle must be justified, documented, and guided by informed consent.
   b. Teaches the individual more adaptive, functionally-equivalent behaviors.
   c. Has empirical support from well-designed research studies.

12. All appropriate parties are provided with ongoing training regarding how and when to use the procedure and to recognize signs of distress that may warrant terminating the procedure.

13. Data are collected to monitor treatment fidelity to ensure that personnel are implementing the procedure as planned.

14. Data are collected to monitor changes in the target behavior and other relevant behaviors.

15. Procedures to facilitate maintenance and generalization of the behavior change are documented and implemented.

16. If continuous monitoring shows that the target behavior is not improving at the desired rate, the intervention must be reviewed and changed or terminated as necessary. Any change to the plan requires informed consent, medical clearance as appropriate, and committee approvals.

17. The procedure is effective and systematically faded or terminated as soon as the behavior is satisfactorily modified.

18. A primary focus in evaluating the success of the intervention must be the direction and extent to which the target behavior has changed as planned on and agreed to in the assessment process.

19. A secondary focus in evaluating the success must be an assessment of the other aspects of the individual’s functioning, that is, the extent to which the intervention has resulted in other positive changes.

20. An assessment of the individual or guardian’s satisfaction with the intervention must be undertaken.

21. All outcomes of the intervention must be thoroughly documented.

22. The restrictive procedure is one component of an individualized and comprehensive behavior support plan designed to increase adaptive behavior, independence, and participation in meaningful relationships and activities.

Autism New Jersey encourages all parents and professionals to adhere to procedural safeguards.

Some of the elements listed above have been adapted from the Guidelines for the Use of Aversive Procedures issued by The Australian Psychological Society.
Definitions

**Abuse** – any act or omission that deprives or has the potential to deprive an individual of his/herrights or that causes or has the potential to cause physical injury, emotional harm, or distress. The planned use of behavioral intervention techniques, which are a part of an approved behavior modification plan as outlined above, are not considered abuse or neglect.

**Aversive stimulus** – an item or activity that one avoids or escapes. From a behavior analytic perspective, it is technically defined by its effect on behavior, when a behavior increases by its contingent removal or when a behavior decreases by its contingent presentation. Aversive stimuli are subjective in nature, that is, what is aversive to one person may be preferred or neutral to another. (See examples of aversive stimuli under punishment.)

**Neglect** – the failure of a caregiver to provide for the care and safety of individuals under his or her supervision.

**Positive Behavior Support** – a dynamic and team-building process for designing individualized behavioral intervention plans based on understanding relationships between a individual’s behavior and aspects of his or her environment (i.e., functional behavioral assessment).

**Positive behavior support plan** – a written document created by all stakeholders (individual, parents, teachers, administrators, consultants, etc.). This document includes the following elements: 1) modifications to the environment, 2) teaching skills to replace problem behaviors, 3) effective management of consequences, and 4) promotion of lifestyle changes.

**Punishment** – From a behavior analytic perspective, the reduction of a behavior following the contingent presentation or removal of a stimulus. Defining punishment this way is helpful because it emphasizes that punishment is a two-part process. The first part is the environment: presentation or removal of a stimulus contingent upon behavior. The second part is the intervention’s effect on behavior: increase, decrease, or maintain. Too often in our society, more emphasis is given to the intervention than to the intended behavior change. Clearly, the goal is to safely and effectively reduce dangerous behavior using the least restrictive methods possible.

Here are some examples of punishment from a behavior analytic perspective. Please note that these examples are for illustration purposes only.

**Examples of Type I punishment – presentation of a stimulus**

— A child is running toward the street. The parent yells, “Stop!” The child’s running behavior stops as a result of the yelling.
— A student repeatedly calls out in class. One day, on the first time the student called out, the teacher moved his desk to the front of the room. The student called out less that day as a result of the teacher moving his desk.
A child with autism bites his own hand. Immediately following a bite, a teacher holds his hands in his lap for 5 seconds. As a result of holding his hands down, the child bites his hand less.

**Examples of Type II punishment – removal of a stimulus**

- A child pinches his sister while they are playing. The mother tells the child, “You know the rules. If you can’t play nicely, the toy goes away.” The mother removes the toy. As a result, the child pinches his sister less often.
- While playing on the computer with her classmates, a student becomes agitated, curses, and kicks the computer. The teacher removes playground privileges when she has these outbursts. This behavior happens less often when she is with the teacher who removes playground.
- When a child with autism hits his teacher, she provides a 4-minute time out. The hitting behavior decreases as a result of implementing the time out procedure.

**Restrictive procedure** – an intervention that limits an individual’s ability, freedom, or pleasure.

*The definitions of abuse and neglect were adapted from DDD circulars.*
Suggested Readings

The list of readings below provides resources for additional information on the topics relevant to this position statement. This list is by no means exhaustive and is intended as an initial resource.


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