



SECTION 7: **WORKING WITH CAREGIVERS AND OTHER PROFESSIONALS**

1 Family Members/Others as Important Contributors to Outcomes

Family members, including siblings, and other community caregivers should be included in various capacities and at different points during both Focused and Comprehensive ABA treatment programs. In addition to providing important historical and contextual information, caregivers must receive training and consultation throughout treatment, discharge, and follow-up.

The dynamics of a family and how they are impacted by ASD must be reflected in how treatment is implemented. In addition, the client's progress may be affected by the extent to which caregivers support treatment goals outside treatment hours. Their ability to do this will be partially determined by how well matched the treatment protocols are to the family's own values, needs, priorities, and resources.

The need for family involvement, training and support reflects the following:

- Caregivers frequently have unique insight and perspective about the client's functioning, information about preferences, and behavioral history.
- Caregivers may be responsible for provision of care, supervision, and dealing with challenging behaviors during all waking hours outside of school or a day treatment program. A sizeable percent-age of individuals with ASD present atypical sleeping patterns. Therefore, some caregivers may be responsible for ensuring the safety of their children and/or implementing procedures at night and may, themselves, be at risk for problems associated with sleep deprivation.
- Caring for an individual with ASD presents many challenges to caregivers and families. Studies have documented the fact that parents of children and adults with ASD experience higher levels of stress than those of parents with typically developing children or even parents of children with other kinds of special needs.

- The behavioral problems commonly encountered with persons diagnosed with ASD (for example, stereotypy, aggression, tantrums) secondary to the social and language deficits associated with ASD, often present particular challenges for caregivers as they attempt to manage their behavior problems. Typical parenting strategies are often insufficient to enable caregivers to improve or manage their child's behavior, which can impede the child's progress towards improved levels of functioning and independence.
- Note that while family training is supportive of the overall treatment plan, it is not a replacement for professionally directed and implemented treatment.

2 Parent and Caregiver Training

Training is part of both Focused and Comprehensive ABA treatment models. Although parent and caregiver training is sometimes delivered as a stand-alone treatment, there are relatively few clients for whom this would be recommended as the sole or primary form of treatment. This is due to the severity and complexity of behavior problems and skill deficits that can accompany a diagnosis of ASD.

Training of parents and other caregivers usually involves a systematic, individualized curriculum on the basics of ABA. It is common for treatment plans to include several objective and measurable goals for parents and other caregivers. Training emphasizes skills development and support so that caregivers become competent in implementing treatment protocols across critical environments. Training usually involves an individualized behavioral assessment, a case formulation, and then customized didactic presentations, modeling and demonstrations of the skill, and practice with in vivo support for each specific skill. Ongoing activities involve supervision and coaching during implementation, problem-solving as issues arise, and support for implementation of strategies in new environments to ensure optimal gains and promote generalization and maintenance of therapeutic changes. Please note that such training is not accomplished by simply having the caregiver or guardian present during treatment implemented by a Behavior Technician.

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The following are common areas for which caregivers often seek assistance. These are typically addressed in conjunction with a Focused or Comprehensive ABA treatment program.

- Generalization of skills acquired in treatment settings into home and community settings
- Treatment of co-occurring behavior disorders that risk the health and safety of the child or others in the home or community settings, including reduction of self-injurious or aggressive behaviors against siblings, caregivers, or others; establishment of replacement behaviors which are more effective, adaptive, and appropriate
- Adaptive skills training such as functional communication, participation in routines which help maintain good health (for example, participation in dental and medical exams, feeding, sleep) including target settings where it is critical that they occur
- Contingency management to reduce stereotypic, ritualistic, or perseverative behaviors and functional replacement behaviors as previously described
- Relationships with family members, such as developing appropriate play with siblings

3 Coordination with Other Professionals

Consultation with other professionals helps ensure client progress through efforts to coordinate care and ensure consistency including during transition periods and discharge.

Treatment goals are most likely to be achieved when there is a shared understanding and coordination among all healthcare providers and professionals. Examples include collaboration between the prescribing physician and the Behavior Analyst to determine the effects of medication on treatment targets. Another example involves a consistent approach across professionals from different disciplines in how behaviors are managed across environments and settings. Professional collaboration that leads to consistency will produce the best outcomes for the client and their families.

Differences in theoretical orientations or professional styles may sometimes make coordination difficult. If there are treatment protocols that dilute the effectiveness of ABA treatment, these differences must be resolved to deliver anticipated benefits to the client.

The BACB's ethical codes (the current *Guidelines for Responsible Conduct for Behavior Analysts* and the impending *Professional and Ethical Compliance Code for Behavior Analysts*) require the Behavior Analyst to recommend the **most** effective scientifically supported treatment for each client. The Behavior Analyst must also review and evaluate the likely effects of alternative treatments, including those provided by other disciplines as well as no treatment.

In addition, Behavior Analysts refer out to professionals from other disciplines when there are client conditions that are beyond the training and competence of the Behavior Analyst, or where coordination of care with such professionals is appropriate. Examples would include, but are not limited to, a suspected medical condition or psychological concerns related to an anxiety or mood disorder.

