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# Empowering Families in the Treatment of Autism

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## 1. Introduction

It is well known that autism is a complex, currently incurable disorder with an unclear etiology, and that individuals with autism typically have normal life expectancies which require parents, and later siblings, to provide varying levels of lifelong care. Because of the complexity of the disease, it is critically important to help families understand the disorder, manage stress, and sift through information that frequently includes erroneous media views and unsubstantiated claims of treatment efficacy. This chapter will help families and advising professionals by providing them with an overview of several topics: first, the common reactions and beliefs about autism and individuals with autism that are held by family members; second, the family-centered as well as complementary and alternative treatment approaches that are currently available; and finally, the best recommendations for helping families adapt to an autism diagnosis and maintain healthy functioning as caregivers—all while planning for, and addressing the lifelong needs of, individuals with autism.

## 2. Common reactions and beliefs held by family members

Families are faced with enormous challenges in caring for children with autism over a lifetime. The first challenge is obtaining the initial diagnosis, which can be difficult despite the fact that autism is better understood today than it was in the past. Indeed, it is common for families to consult a variety of professionals such as pediatricians and primary health care providers before receiving a conclusive diagnosis. Once the diagnosis is made, however, parents face a second, far greater challenge: mourning the loss of their “perfect child”—which can be a long and arduous process that involves coming to terms with the fact that their child, whose physical appearance is normal or even unusually attractive, has a complex, incurable, and frequently debilitating condition. After the family advances through stages of

grieving that can be characterized using Elizabeth Kübler-Ross's five stages of grief—Denial, Anger, Bargaining, Depression, and Acceptance (DABDA)—they eventually arrive at a “new normal” with family harmony reestablished [1].

The first stage of grieving, denial, is common in parents of children with autism, and can persist even after a child receives a diagnosis. Because fathers are typically less involved in day-to-day care than mothers, they may experience denial more intensely due to fewer opportunities to observe the symptoms. For example, a father may be more likely to say, “he doesn't have autism; he's just quiet,” which is supported by stories of other family members who were also “late to develop” yet still “turned out fine”. However, as the symptoms of autism become more conspicuous, caregivers notice differences between their child and other, typically developing children whom they encounter in playgrounds, preschools, and family gatherings. Frequently, it is extended family members who identify the autistic symptoms, share their concerns with the primary caregivers and try to convince the caretakers to seek further assessment and follow up as needed. This action is critical to accurate and timely diagnosis, early intervention (< age 3), and improved prognosis for overall quality of life.

The next stage, “anger”, may result in family members asking “Why us?” or “Why did this have to happen to him?” During this time, family tension is high and anger may also be expressed toward intervening professionals, especially if there has been a prior lack of, or slow responsiveness to, parental concerns. For example, one parent stated, “That pediatrician should have listened to me when I expressed concern about David not speaking at four years old; instead, he told me not to worry about it.” This failure to identify the signs sooner can lead to destructive self-blame, resulting in self-talk such as, “If only I had recognized the signs sooner” or “I knew we should have sought other opinions”—comments that may be responded to with active listening (e.g. “You sound as though you are experiencing a lot of regret”) and nonjudgmental advice (e.g. “Many parents struggle at this time. What is important is that you are seeking the necessary assistance now.”) In addition to self-blame related to behavior, it is also common in this stage for parents to evaluate their genealogy to determine who was genetically responsible for the disorder. Unfortunately, there is no conclusive genetic test for autism and while genetics likely plays a role, environmental factors may also contribute to its development.

The third stage, “bargaining”, can place families at great risk because it involves frantically seeking ways to reverse the diagnosis even if those ways are implausible. For example, it is common for parents to directly bargain with a higher power (e.g. “If you cure my child, I will be a better parent”) or indirectly, with a lesser power such as the health care profession (e.g. If I find the “right” doctor or medication, my child will be cured). As they desperately seek a “magic bullet”, parents may interrogate health care providers about the most useful medications despite the fact that no single medication is effective for all symptoms. In addition, parents may surf the Internet and read testimonials regarding treatments that are not empirically sound; consequently, well-informed professionals need to advise families against these treatments as some are risky and can lead to financial burden. (The most common treatment approaches will be described later in this chapter.)

The fourth stage, “depression”, can take many forms. Parents may at times feel overwhelmed and powerless in their ability to facilitate their child’s development or ameliorate difficult, disruptive behaviors such as severe tantrums or self-abuse. Indeed, negative behaviors may intensify to such a degree that families curtail their usual plans or avoid a desired activity all together, leading to feelings of hopelessness that is expressed in statements such as, “I can’t do anything right” or “why bother”. In addition, because many children with autism have sleep disturbances (e.g., difficulty falling asleep; waking up and becoming active in the middle of the night), parents must be vigilant at night, causing exhaustion and sometimes even deeper depression. At this point, it is important for caregivers to recognize that they may need professional help such as counseling or prescribed medications in order to optimally provide for their child and family.

Many families who advance to acceptance, the final stage, describe having gained spiritual strength, which helped them maintain “hope”—an essential ingredient to successful grieving. In this stage, families recognize that there is no instant cure for their child’s autism, but there are credible interventions that can help. Ultimately, families discover that they can be powerful advocates for their children, and after receiving proper education, can implement home interventions that positively affect the family unit and even improve their child’s condition. Once they gain confidence in these new approaches, they can serve other families struggling through the grieving process by contributing empathy and wisdom to local family support group meetings. Because grieving is rarely a linear process, these meetings can also help families as they revisit earlier stages by limiting the time they spend in previous ones, thus facilitating a more permanent acceptance.

### 3. Families as primary interveners

#### 3.1. Parent training

Historically, development of more family-focused interventions has resulted in a shift from didactic teaching and family therapy models to interactive approaches, in which parents are active participants in all levels of the training process [2, 3]. Although parents were once viewed as the cause of their child’s problems [4-6], they are now recognized for the key roles they can play in ongoing child training and skill generalization [7-9], which has led to better child prognosis and long-term quality of life.

Because there are now clearer linkages between core constructs such as *social reciprocity* (e.g. social turn-taking), *joint attention* (e.g. sharing interest in, and mutually commenting on, an object), and language acquisition, developing these skills can improve a child’s communicative capacity. In fact, researchers stress that teaching parents to target pivotal skills such as joint attention may produce positive, sustained effects on social and language development [10]. Similarly, evidence suggests that interventions that require parents to synchronize with the child’s attentional focus (i.e. become interested in what the child is interested in) may be more effective than parent-directed approaches (e.g., instructing the child to play with a toy in a certain way) for children who have difficulty responding to, or initiating, joint attention

[11]. However, there is a need to closely examine the individual parent-training intervention components thought to be linked with these core constructs to determine which components are most effective for a particular child. This would allow researchers to better identify the most convenient and efficient means of teaching these constructs and related intervention components.

### **3.2. Research development in parent training**

The author and co-investigators have been following a systematic sequence of research that began in the early 1980's with the development of a play-based, in-home intervention that was initially tested in-depth, over 8-12 weeks, with four mother-child dyads using intrasubject (single subject experimental) methodology [12]. In this initial study, Elder found that mothers figure prominently as recipients of training and other interventions and that even when the focus was on the dyad, mothers "took over" and fathers stayed in the "background," with inadequate diffusion of new learning through the mothers. This lack of father involvement piqued the interest of Elder's research team, who collaborated on new studies directed at fathers. Although a systematic review of the literature revealed only three intervention studies that included fathers, evidence indicated that fathers' interaction styles differed from mothers, possibly resulting in unique contributions to their child's social and language development [13].

Building on Lamb's (1987) seminal work related to fathers and their influence on child development, Elder et al. developed and tested a Father Directed In-Home Training (FDIT) intervention with a total of 36 father-child and mother-child dyads under controlled conditions in two NIH/NINR-funded studies [7, 8]. The study was designed so that data from individual training components could be analyzed rather than an entire intervention package. These training components were based on the theoretical constructs in social interaction theory and characterized by the broad concept of social "turn-taking". Because the team had previously observed many fathers sitting passively or aggressively directing interactions and not allowing their child time to respond, the research team created four intervention components: (a) following the child's lead (FCL), which involved allowing the child with autism to direct play, (b) imitating/animating (I/A), which entailed attending to and imitating the ADS child's sounds and/or actions in an animated manner, (c) expectant waiting (E/W), which required signaling the child and waiting for a response, and (d) commenting on the child (CC), which emphasized remarking on the child's actions at appropriate times during play [12]. Fathers were instructed to watch videotaped examples and read written directions about integrating these components into play sessions. After mastering the skills, fathers taught mothers the same techniques using the research team's educational approach, resulting in both parents reporting that training had helped them relax during the in-home play sessions.

After the intervention, fathers significantly increased their use of the skills taught and children with autism responded with greatly increased initiating rates as well as frequencies of child non-speech vocalizations. In follow-up interviews, fathers revealed that the training



had enhanced their paternal role and the quality of overall family functioning [14]. (Details of these studies can be found in published articles [7, 8]).

### 3.3. Including siblings

Most children with autism have difficulty with inconsistency as evidenced by their strong adherence to routines and rituals. Therefore, it may be difficult, perhaps even impossible, for these children to effectively modify their interactions if family members are not consistent in their approach. Furthermore, incongruence within the family can distress children with autism, who may express their feelings by engaging in a variety of aberrant behaviors such as tantrums, aggression, and other behavioral expressions of frustration. Present research indicates that training non-affected, typically developing siblings, or other individuals who have ongoing contact with the child with autism, could be beneficial. However, little is known about the effects of training siblings to use theoretically-derived strategies such as those Elder and others have implemented with parents. Also unknown is the effect that training typically developing siblings might have on their own behavior, anxiety, and overall quality of life. Although it seems likely that training would positively affect them, training effects on siblings should be addressed in clinical trials.

In a search of the literature related to non-affected, typically developing (TD) siblings of children with autism, few studies are found describing these children, their relationship with their sibling with autism, or what effect having a sibling with autism has on them [15]. Of the extant reports, the findings are inconsistent, making it difficult to characterize the siblings, identify those who are vulnerable to poor adjustment outcomes, or develop interventions that benefit both the sibling and the entire family [15]. It is clear, however, from both the literature and clinical experience, that TD siblings are often faced with unique challenges related to their affected sibling's autism. Also, because children with ADS rarely have physical disfigurement, it is often difficult for those who are not familiar with autism to understand why these children act the way they do; this, in turn, adds to the stress that TD siblings and the family experience [16-18]. Initial findings are promising because they show that when TD siblings care for their ADS siblings early in life, this can positively affect not only the child with autism but also the intervening sibling [19-22]. This clearly indicates that training and evaluating siblings is an area of research with enormous potential and clinical relevance.

Another important consideration that lends support for training siblings is evidence that children with autism learn best in naturalistic environments such as their homes. In a classic work, Baer, Wolf, and Risley (1968) state that skills taught to children in one setting cannot be expected to generalize to other settings without planned, systematic implementation. In fact, these researchers assert that no deliberate behavior changes, particularly related to language acquisition and socialization, should be made that are not reinforced regularly in the child's primary environment; otherwise, trainers must continue to intervene to maintain the behavior change [23]. If one ascribes to this view, clinic-taught interventions cannot be expected to generalize well to home settings unless: (a) the trainer is always present (an impractical and costly idea), (b) family members are taught to assist with generalization, or (c)

ideally, intervening family members and children with autism are trained in familiar home environments where naturally reinforcing (caregiving) activities are more likely to occur. Also, children with autism are more likely to exhibit abnormal language in unfamiliar settings than at home [11]. For these reasons, it is important that AD children acquire communication skills in naturalistic settings where they are most likely to encounter interactions and opportunities to utilize communication skills that are similar to the contexts of their daily routines [11].

#### **4. Using new technologies to train families**

The use of the Internet has grown substantially over the last few years, with an estimated 260 million people now online in North America [24]. In addition, between 2000 and 2010 the proportion of Internet users who are black or Latino has nearly doubled, causing the Internet population to closely resemble the racial composition of the nation as a whole. Health information is one of the most important subjects researched online, and this is reflected in the autism community, where many families are heavily dependent upon Internet services for education, updates on autism treatment, and peer support via parent chat rooms [15].

However, despite the great interest in using the Internet as a resource for learning about autism, online parent training interventions are rare. Recently, considerable evidence has become available demonstrating that web-based feedback systems may increasingly provide feasible and cost-effective patient education [25] because they are available 24 hours a day and can be used repeatedly to enhance learning. Further, with wide-spread internet technology, it may now be possible to provide much needed training to families living remotely and to those representing previously underserved minorities. Clearly, there is an urgent need for clinicians and researchers who have manualized training interventions to adapt them for online use and systematically evaluate their effectiveness through clinical trials.

#### **5. Managing family stress**

Until the 1980's, the diagnosis of autism was generally not well-known and most children diagnosed with autism were eventually institutionalized. Today, the majority of these children live with their families, who face enormous challenges in planning for and providing a lifetime of care. Families often experience significant financial burden [26], insecurity regarding long-term family planning, and stress related to the child's social impairments and adverse behaviors that often interfere with family functioning [27, 28]. Because additional care giving has been shown to predict parental distress [29] and parents of children with autism may experience greater stress than parents of children with other disabilities, interventions and techniques that can reduce stress are needed [30-34].

Although caring for a child with ASD can adversely affect quality of life for both parents [35], most research related to parental stress has focused on mothers [36] who have reported

higher stress levels than fathers [31, 37-40]. However, in two other studies comparing mothers' and fathers' stress levels, no differences were found [32, 41]. The author and team also found that both mothers and fathers scored very high, over the 90<sup>th</sup> percentile on the Parenting Stress Index pre-intervention with no statistical significance between the mothers' and fathers' scores [14].

In 2008, Davis and Carter provided more insight regarding how mothers and fathers may react to their child's autism. They noted that although mothers had a higher rate of stress and depression, fathers reported more difficulty interacting with the children. In addition, mothers were more involved with everyday activities and thus, more often affected by their child's inability to perform activities of daily living and self-regulate emotions. In contrast, fathers reacted more to overt behaviors such as tantrums, aggression, and/or loud/peculiar vocalizations, which are particularly difficult to manage and can be embarrassing in public settings. Because the core disability associated with autism is social, it can be stressful for parents to deal with a child who may not like to be held, will not respond to their affection, or even make eye contact.

Although only a few studies have explored effects of child intervention on changes in parental stress levels, [14, 28, 42, 43] results are promising. Parent involvement that results in improved child outcomes can empower parents and lower stress in both mothers and fathers. Also, it is important to consider that although fathers may not appear to be as overtly stressed as mothers, there is evidence that they also experience high levels of stress; therefore, interventions should include both mothers and fathers. Finally, although little is known about stress in siblings, it is likely that their stress is also high and that they could benefit from being included in an intervention.

## **6. Alternative and complementary therapies: Helping families**

### **6.1. Select credible treatment options**

A report from the American Academy of Pediatrics' Council on Children with Disabilities states that treatment goals for children with autism are to: (a) maximize the child's ultimate functional independence and quality of life by minimizing the core features, (b) facilitate development and learning, (c) promote socialization, (d) reduce maladaptive behaviors, and (e) educate and support families [44]. While standard treatments meet these goals and thus, are generally accepted by the autism research community, the variety of novel approaches are less accepted due to their lack of empirical support. As a result, families, who often become desperate to identify a ready cure for the disorder, must be equipped with the knowledge to avoid scams by fully evaluating the potential of new therapeutic approaches.

While it is not possible to cover the multitude of novel and complementary treatments for autism, the author will provide a critical review of some of the most popular strategies, ferreting out those that are empirically validated from those that are unsubstantiated. This section will include a discussion of findings from the author's previously



published, randomized clinical trial that evaluated the effects of the popular Gluten-Free, Casein-Free diet on individuals with autism, and subsequently recommend directions for future research.

## 6.2. Dietary intervention and nutritional supplements in autism

Increasingly, parents are using alternative treatments, such as dietary interventions or supplements, which they learn about from internet sites or anecdotal reports from other parents. Perhaps the most well-known dietary intervention is the gluten-free casein-free (GFCF) diet that restricts consumption of wheat and dairy products, and which adherents claim can “cure” autism [45]. This diet is so popular that a person can simply type, “GFCF” and “autism” into Google’s search engine, and hundreds of sites appear—from the “Gluten-Free Trading Co.” to “GFCF Diet Success Stories” with endorsements such as the following: “Three weeks ago, I decided to give it [GFCF diet] a try. After three days without dairy, Wow! Suddenly we had an alert child! He was talking more, making sense of the world, and engaging with us! When I phased out wheat and gluten, he got even better. He is happier; his behavior is better; his muscle tone seems to be improving; his eye contact is great; he is speaking like a normal 4 year old!” [46] Although testimonies like these abound on the Internet, there is limited empirical data to support the claims, resulting in a lack of data that health care providers can use to effectively guide parents in making informed decisions.

This dietary intervention, which has clearly “raced ahead of science,” poses health risks as well as financial and social drawbacks. While it is less costly than when it was originally introduced, the GFCF diet can still add financial strain to families and may even compromise nutritional health (e.g., insufficient calcium) in children with autism who already have restricted food repertoires. There are also social costs to the children, who cannot eat foods unless they are prepared at home, ruling out the possibility of eating cake, for example, at a birthday party. Similarly, families experience a social cost because they have to prepare dual meals plans that often consist of time-consuming recipes. Thus, unless families have additional financial or social assistance, the GFCF diet can represent a significant burden to a family already struggling with caring for a child with autism.

Despite the continuing popularity of this diet, only five controlled studies have been published since 1999. Three of these studies—Knivsberg [47], Whiteley [48], and Johnson[49]—were not double-blind. That is, parents not only knew when their children were receiving the GFCF diet but were also responsible for implementing it. Of these three single blind studies, Knivsberg [47] and Whiteley [48] reported positive findings but have been criticized for their reliance on reports from parents who were not blinded to the dietary intervention. However, it should be noted that Knivsberg [47] conducted a year-long study and some proponents of the GFCF diet suggest that the short duration of other clinical trials may have been responsible for the insignificant findings.

The other two studies were double blind randomized control trials. In the first study, Elder [50] partnered with researchers and staff at the University of Florida’s (UF) General Clinical Research Center [now part of UF’s Clinical Translational Science Institute Research (CTSI)] to conduct the first double-blind placebo controlled clinical trial of the GFCF diet that was

published in *The Journal of Autism and Developmental Disorders* (2006). The researchers evaluated the effects of the GFCF diet on: (a) autistic symptoms as measured by the Childhood Autism Rating Scale (CARS), Ecological Communication Orientation Scale (ECOS), and behavioral frequencies of child social and language behaviors, and (b) urinary peptide levels of gluten and casein. After videotaping the participating 13 children, aged 2 to 16 years, during in-home play sessions for 15 minutes before the diet's introduction, at the end of the first 6-week period, and at the completion of the 12-week protocol, Elder [50] found that group analysis showed no significant differences in any of the outcomes measured or urinary peptide levels of gluten and casein. Even when they were told that the findings were insignificant, parents of nine children kept the children on the diet, indicating that a strong "parent placebo effect" may exist and be responsible for perpetuating the diet's popularity.

In the second study by Hyman [51], children were given the GFCF diet and provided with food challenges; that is, snacks that contained gluten or casein, and which were disguised so that the participants could not identify if the snacks were GFCF. As in the other clinical trials, these investigators used a variety of well-established outcome measures but like Elder [50], found no significant differences or empirical support for the diet. Despite the insignificant findings, the GFCF diet continues to be popular with parents, leading to the author's published recommendations about how to properly advise families regarding diet: first, parents may use the GFCF diet as long as the child does not have a severely restricted food repertoire that could lead to a nutritional deficiency; and second, the family has the social and financial resources to continue the diet [7].

Similar to dietary interventions, nutritional supplements are frequently used by parents to treat their child's symptoms although there is little sound empirical evidence to support their efficacy in autism. Vitamins C, D, and the B vitamins are generally known to improve immunity, brain function, and overall nervous system activity [52-55]. As a result, they are often included in special autism supplements, which are specifically blended to treat autism-related symptoms. Other supplements that are frequently used include probiotics and digestive enzymes, which may help treat gastrointestinal problems such as acid reflux and constipation, and melatonin, a natural sleep aid that may help reduce nighttime sleep disturbances [56]. Finally, Omega-3 fatty acids, which have been shown to enhance neurological health in the general population, are currently being evaluated in several clinical trials for the treatment of autism [57]. Despite the lack of empirical support for these supplements, most are generally considered harmless if administered in age-appropriate doses.

### 6.3. Other approaches

Because of speculation that oxygen flow to the brain is reduced in children with autism, "hyperbaric treatments," in which individuals with autism are placed in a chamber and exposed to very high oxygen levels, have become popular. In 2009, the US ABC news network broadcast a story, "The Search for a Cure" describing preliminary results from a trial by Dr. Daniel A. Rossignol, himself a father of two children with autism. He and his colleagues evaluated hyperbaric treatment in 56 children with varying degrees of autism ranging in age from 2 to 7 years [58, 59]. Reports were positive, indicating that 30 percent of the children

who received the treatment had greatly increased functioning, while only 8 percent in the control group did. In response to this study, Paul Ott, a M.D., autism expert, and author of *Autism's False Prophets* commented on the questionable efficacy of the treatment and emphasize its potential to financially drain families [60]. For example, a one-hour treatment can cost \$100 to \$900, and generally at least 40 are recommended. Despite his warning, however, the ABC report concluded on an approving note by stating, "While its positive effects remain unclear, hyperbaric chamber therapy does not present the dangers that other therapies do," thus encouraging parents to consider using an unproven and expensive treatment.

Although hyperbaric treatments are one of the latest alternative therapies to become popular in the autism community, parents have long used other unsubstantiated, pharmaceutical approaches. For example, antibiotics have often been prescribed for children with autism who have frequent respiratory or gastrointestinal infections; similarly, antifungal agents, such as nystatin and fluconazole, have been prescribed for children who suffer from an overgrowth of gastrointestinal yeast (e.g. *Candida*) [61]. In both situations, the medications are prescribed due to the erroneous belief that an infection or "imbalance" is the root cause of the disorder. Other speculative treatments include the intravenous administration of secretin, a gastrointestinal hormone, and immunoglobulin-G, an immune system antibody, which are popular because of a few, uncontrolled studies that demonstrated improvement [62]. Despite their questionable efficacy—several gold standard clinical trials have invalidated the use of secretin—alternative treatments are high in demand, generating countless articles on the Internet, and sparking heated discussion on autism message boards [63]. This prevailing popularity, which shows no sign of slowing in the future, is a testament to the struggle many parents experience in caring for a child with autism.

Another popular, yet more controversial treatment is chelation therapy, which removes mercury—an alleged contributor to autism—from the body. When using this therapy, parents typically have a medical doctor treat their child for lead poisoning or they may also buy unregulated chelation agents from Internet sites. Unlike hyperbaric treatment and other interventions that are intended to complement evidence-based treatments, advocates of chelation therapy espouse it as a cure. Yet, to date, there is no proven link between mercury exposure and autism [64]. Joecker, a researcher from the Mayo Clinic warns that not only is chelation therapy's efficacy unproven, but also that it can be associated with serious side effects, including potentially deadly liver and kidney damage and as a result should be assiduously avoided [65].

## 7. Interventions with empirical validation

After the preceding discussion of popular yet largely unproven interventions, the author would be remiss not to provide at least a brief overview of interventions that are empirically sound. Because autism presentations can vary greatly among individuals, each intervention should be customized to meet the needs of the individual child, and be accompanied with the early speech/language and occupational therapy that are typically indicated.

In addition to the special education and pharmacological interventions that may be necessary, traditional treatment approaches include providing a child with speech, behavioral, occupational, and physical therapy as indicated in some cases. Although public schools in the United States are required by law to provide such services, the frequency, type, and quality of these services vary considerably. Consequently, parents need to actively participate in meetings where Individualized Educational Plans (IEP), or the equivalent, are developed to specifically address a child's behavioral or learning needs. Furthermore, parents should maintain close contact with educational personnel to help evaluate their children's progress and determine the future direction of treatment.

If the future direction includes medications, parents must carefully analyze the costs and benefits by questioning their health care provider regarding possible improvements and side effects. Although medications do not cure autism, sometimes they can alleviate behavioral symptoms that distress the child and interfere with therapeutic efforts such as intensive education and socialization [66-68]. These behavioral symptoms include hyperactivity, self-injury, aggression, compulsions (repetitive behaviors), mood lability, anxiety, and sleep disturbances [69].

In addition to medication, parents may consider using a behavioral intervention, which researchers have refined over time and developed into a highly successful treatment approach. In particular, two comprehensive behavioral early interventions—Lovaas' Model based on Applied Behavior Analysis (ABA) and the Early Start Denver Model—have been shown to be helpful in improving symptoms related to autism [70, 71]. Mounting evidence also supports the use of other commonly used therapies such as Floortime, Pivotal Response Therapy and Verbal Behavior Therapy [72-74]. For up-to-date information regarding behavioral interventions, visit the website for Autism Speaks, an internationally recognized organization within the autism community, at <http://www.autismspeaks.org/what-autism/treatment>. By visiting this site, parents will learn about the many valid treatments available that are safe, effective, and capable of producing a better quality of life for children with autism and their families.

## **8. Relationship of family training intervention research to NIH's priorities and NIMH's sponsored work-group recommendations**

Finding ways to improve quality of life for ADS children and their families is one of the top priorities of NIH and congressionally mandated research as noted in the Combating Autism Act of 2006 [75, 76]. A report from a NIMH-supported work group of well-known autism authorities addresses what has traditionally been problematic in the field of autism [77]; namely, that fragmented and isolated individual study approaches have not been effective in systematically advancing the most effective behavioral interventions [78]. In response, Smith et al. proposed a developmental process for designing and conducting studies on psychosocial interventions in autism, which provides a way to systematically validate and disseminate interventions; the process includes the following steps: (a) conduct initial efficacy

studies that may utilize intrasubject methodology to provide in-depth information about individual responses over time, (b) manualize the intervention and pilot-test it with larger numbers of participants, (c) conduct clinical trials to test the efficacy under controlled conditions, and (d) conduct effectiveness studies to evaluate outcomes in community settings.

The author and team have been following a developmental sequence that is consistent with that of the NIMH work group and especially part of the final step—evaluating outcomes in community settings. Delivering the training to all family members including siblings, and providing training interventions using state of the art internet technology would greatly expand our ability to deliver comprehensive family-centered training in the community, and produce significant gains that would improve the quality of life for individuals with autism and their families.

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