

# **Assessing 'Alternative' Therapies for Communication Disorders in Children with Autistic Spectrum Disorders: Facilitated Communication and Auditory Integration Training**

## **Évaluation des thérapies alternatives pour traiter les troubles de la communication chez les enfants souffrant de troubles du spectre autiste : communication facilitée et formation en intégration auditive**

by • par

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### **ABSTRACT**

This report will review and critique the existing literature on two techniques for improving the communication skills of children with autism. The two techniques that will be reviewed are facilitated communication (F/C) and auditory integration training (AIT). The purpose of this review is to help speech-language clinicians and audiologists assess the validity and utility of these methods based on research that has been conducted with each method. Another, and over-arching purpose of this report is to aid clinicians in using sound principles of scientific thinking about research methodologies as the need arises to assess future new techniques.

### **ABRÉGÉ**

Ce rapport étudiera et critiquera la littérature actuelle sur les techniques visant à améliorer les habiletés de communication des enfants porteurs d'autisme. Les deux techniques examinées sont la communication facilitée et l'éducation en intégration auditive. Le but de cette étude est d'aider les orthophonistes et les audiologues à évaluer la validité et l'utilité de ces méthodes à partir de travaux de recherche entrepris à l'égard de chacune de ces méthodes. Un autre objectif, plus large encore, serait d'aider les cliniciens à avoir recours à des principes scientifiques rigoureux vis-à-vis des méthodes de recherche à employer pour évaluer les techniques futures.

### **KEY WORDS**

**autistic disorder • pervasive developmental disorders • auditory integration training • facilitated communication**

**F**acilitated Communication(F/C) and Auditory Integration Training (AIT) were both designed to aid in the development of communication skills. F/C was designed primarily for moderate to severely cognitively impaired individuals who were nonverbal, and who had met with limited success in mastering nonverbal augmentative forms of communication such as picture boards or sign language. AIT was aimed at the individual with some expressive communication skills, but who evidenced auditory processing problems that could impair phonological discrimination and/or receptive language development-resulting in a cascade of problems in expressive function.

### **Auditory Integration Training (AIT): A Critical Review of the Research and Research Hypersensitivity in autistic children**

Various abnormalities in response to sounds have been reported in children with autistic spectrum disorders (Condon, 1975; Hayes & Gordon A.G., 1977; Hutt, Hutt, Lee, & Ounsted, 1964). These include apparent "deafness" (inattention to sounds), hypersensitivity to specific sounds (i.e., vacuum cleaners, sirens), and altered auditory event-related potential. Hypersensitivity to sounds has long been described as one of the more common and sometimes debilitating features of the autistic spectrum disorders. Although this is not explicitly included in the diagnostic criteria for Autistic Disorder in the DSM-IV (American Psychiatric Association, 1994),

this is noted to be a frequently associated feature in this population.

**History of Auditory Integration Training.** Auditory Integration Training (AIT) was developed by two French otolaryngologists, Guy Berard and Alfred Tomatis, for people with a variety of disabilities involving the auditory system. Many of the patients they worked with had learning and language difficulties. Most attention in the United States has been on the work of Guy Berard. In his book *Hearing Equals Behavior*, Berard described his work with approximately 8,000 patients using AIT (Berard, 1993). Although most of these patients had learning disabilities, 48 were described as autistic. Most of these patients were regarded as improved, but only one patient was thought to have recovered from autism.

In the Berard method of AIT, the patient first has an air conduction test to identify frequencies that the patient hears hyperacutely (these are regarded as "peaks", defined as frequencies whose thresholds differ from those of adjacent frequencies by 5 dB or more). Berard believed that these peaks represented audiologic abnormalities that resulted in learning, behaviour, or emotional problems. He believed that the auditory system could be retrained, which would then lead to a flattened audiogram (Berard, 1993). The equipment used for the treatment is the Ears Education and Retraining System (EERS) or the Audiokineton. The patient wears a set of headphones and listens to music that is altered in two ways. First, filters (.75 Hz to 8k Hz) are applied to the music to dampen these "peak" frequencies. Next, there is a modulation of the high and low frequencies from 250 milliseconds to 2 seconds on a near random basis. The Audiokineton functions between frequencies of 30 and 15,000 Hz. This music is often described as garbled by those that hear it. The patient listens to this altered music through a set of headphones for 30 minutes twice daily for a period of 10 days. The patient has a repeat audiogram midway through the treatment, in order to make any necessary adjustments in the filtering of the frequencies. The patient usually has the treatment for two weeks, while having the weekend off in between.

**Case reports.** Several case reports have described significant improvement in children with autistic spectrum disorders following AIT. In her book *Sound of a Miracle* (Stehli, 1991; excerpted in *Reader's Digest*), Stehli reported significant emotional and cognitive improvement in her daughter, who she described as being autistic, after receiving 10 hours of AIT from Guy Berard's clinic in France. Many

parents and professionals have wanted to pursue this treatment for their children, based on this and other such case reports, despite the lack of efficacy demonstrated by controlled clinical trials, as will be described next.

**Clinical trials.** When one looks at the widespread use of this treatment, it is surprising to find that there are only a handful of clinical trials, which have shown mixed results. One of the first clinical trials of AIT was conducted by Rimland and Edelson (1995). In this double blind study, 17 patients with autism were paired as closely as possible in terms of age, sex, hearing sensitivity, and history of ear infections, and assigned to the treatment group or control group. Hearing sensitivity was measured by pure tone discomfort. The participants were presented with 16 different pure tones at a level of 85 dB and observed for any negative reactions, and the Hearing Sensitivity Questionnaire (HSQ), a scale that was developed for this study, in which parents rate their child's discomfort to various sounds was administered. Hearing sensitivity ranged from none to severe in the participants. Prior to treatment, both groups were assessed using the Aberrant Behavior Checklist (ABC) and the Fisher's Auditory Problem Checklist (FAPC), as cited in Rimland and Edelson (1995). The treatment group received AIT for two half-hour sessions for 10 days, using the Berard EERS device. The control group listened to music that was not filtered or modulated. The treatment group was noted to have improvement in behaviors such as irritability, stereotypies, hyperactivity, and excessive speech (as measured by the ABC) and hearing sensitivity (as measured by the FAPC). There were also improvements noted in auditory memory and comprehension (as measured by the FAPC). There were no statistically significant changes in these measures in the control group. However, there was no improvement in either group in auditory discomfort, as measured by pure tone discomfort or the HSQ, nor was there a difference noted in hearing acuity, as measured by air and bone conduction tests. This latter finding is quite notable, given that advocates attribute the improvements in these children to improvements in their auditory functioning.

Rimland and Edelson concluded that AIT is potentially beneficial for patients with autism, based on the changes in ABC and the FAPC. However, there are notable methodological flaws with this study. First, the participants in the above study were not adequately matched. There were signifi-

cant differences in the baseline scores on the ABC and the FAPC between the control group and the treatment group. Because of this, the authors chose to analyze changes in the scores on the ABC and the FAPC, rather than the absolute scores. One must view this interpretation of data with caution, given that the results of the study could also be attributed to the initial differences in the characteristics of the two groups, rather than to the treatment itself. Additionally, as noted by Patricia Howlin, the difference in the average score between the two groups on the ABC was only 0.4, which is quite small in a scale with 58 items (Howlin, 1997). Mean differences in the FAPC were larger (12 points on a scale which contains 93 items). Given the small number of patients and the significant flaws in this study, it is of concern to note that many proponents of AIT use this study to support its use.

Bettison conducted a placebo-controlled study on the effectiveness of AIT in children with Autistic Disorder, significant autistic symptoms, or Asperger's Syndrome who had histories of hypersensitivity to sounds (Bettison, 1996). The study consisted of 80 children ages 3-17 years. In this double blind study, the children were randomly assigned to the control or treatment group. All patients were evaluated using the Autism Behavior Checklist (Krug, Arick, & Almond, 1988), the Developmental Behavior Checklist (Einfeld & Tonge, 1995), a Sound Sensitivity Questionnaire (Rimland, 1991b), and the Sensory Problems Questionnaire (Edelson, 1992), both before and after the intervention. Scores on all of these questionnaires improved equally in both groups one month after treatment. Improvements were also noted in the mean audiogram scores 6 and 12 months after the intervention, with no differences between the two groups. Improvements were also noted in verbal and performance IQ for both groups (forms L and M of the Peabody Picture Vocabulary Test - Revised) (Dunn & Dunn, 1981), which measures receptive language, and the Lieter International Performance Scales (Lieter, 1980). There were no outcome data on expressive language. Again, there were no significant differences between the two groups. Although this study does not lend support to AIT as a treatment method, the results of this study suggest that some element of listening to the music, (either 'modulated' as described by Berard or 'unmodulated'), produce comparable improvements in children with autistic spectrum disorders who have hypersensitivity to sound. The author suggests that some aspect of listening to the music may

have led to improvement in these participants. However, the results may also be attributed to a placebo effect in the behavioral reporting (parents were expecting improvements with treatment, which may have falsely raised expectations in their reporting on the behavioral scales), and retest phenomena (improvements in test scores with repeat testing) may have also contributed to observed 'improvements' in both groups.

A recent open nonblind pilot study of the benefit of AIT in children with autistic disorder was described by Gillberg and colleagues (1997). This study consisted of nine children aged 3-16 years. All children were administered the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1988) and the Autism Behavior Checklist (ABC; Krug et al., 1988). All children received half-hour sessions daily for 10 days, although it was unclear whether the children received one or two sessions daily. After the treatment, there were no significant changes on the CARS or the ABC, with the exception of the ABC sensory subscale, which improved nonsignificantly. (Interestingly, it should be noted that auditory sensory threshold was measured quite extensively in the Rimland and Edelson, 1995, study but showed no improvement in that sample.) The results of this study, like those of the earlier studies, do not support the efficacy of AIT.

The above three studies provide inconsistent results, statistically nonsignificant results, and for some measures no results. The most positive reports on AIT come from anecdotal evidence based on single cases. No consistent theme appears as to domains of functioning that may be positively influenced. Empirical support for the efficacy of AIT, then, has yet to be developed (if indeed it can be), and so results of case reports and controlled studies should be viewed with caution. Overall, no well-controlled studies have shown differential benefits of AIT in children with autism.

**Advocacy groups.** Various advocacy groups have been founded to support parents of children with autistic spectrum disorders who desire information about AIT, such as the Society for Auditory Integration Training and the Georgianna Organization. The Society for Auditory Integration Training provides information for parents and professionals, and maintains a website ([www.teleport.com/~sait](http://www.teleport.com/~sait)). However, one must view the information supplied by these agencies with caution, as there is usually a bias in how the information is presented. For example, the web site for SAIT provides a review of the literature, noting problems with studies that do not support

AIT, but not critically evaluating studies showing presumed benefit of AIT. Websites and other grassroots means that disseminate incomplete and inaccurate information, can present pitfalls to parents in need of coming to realistic terms with their child's disability and the treatments that will benefit them. Such web sites may exacerbate difficulties some parents have in selecting appropriate treatments, as will be discussed in the final sections of this paper.

**Conclusions.** Auditory Integration Training has been reported to show potential promise in the treatment of hearing hypersensitivity in children with autistic spectrum disorders. The promise has been bolstered by broad hypotheses that remediation of auditory processing deficits might translate into remediation of deficits in other language based skills and perhaps remediation of other nonspecific difficulties encountered by children with autism. Despite the lack of data to support the use of AIT, it has been widely used for treatment of this population of children, likely fueled by parents' often desperate attempt to find a "cure" for their children. Additionally, as noted by the American Speech-Language-Hearing Association (ASHA, 1994), concerns have been raised about the training of practitioners administering AIT, selection of patients, and calibration of the instruments (pp. 55-58). These questions, it can be argued, remain moot until there is more reason to endorse any form of AIT as a treatment. One must be cautious in advocating the use of AIT until there is further proof of its efficacy.

#### **Facilitated Communication (F/C): A Critical Review of the Research and Research Methods**

**Suppositions about F/C.** The study and controversy around F/C started in 1990 with the publication of Biklen's first description of this procedure in an article entitled 'Communication unbound: Autism and praxis' which was published in the prestigious *Harvard Educational Review* (Biklen, 1990). Not only did this article serve to introduce North American clinicians to this new treatment for autism, there was a certain rapid acceptance. F/C methods had been developed in Australia and reported by Crossley and McDonald (1980) in their work with children with cerebral palsy and then extended by Biklen to include work with individuals with autism and significant degrees of mental retardation. The claims about F/C based on Biklen's observations and many anecdotal reports that followed (including a Sunday New York Times Magazine story) promoted workshops

for facilitators, and the treatment method was disseminated quickly.

It was claimed that virtually 100% of nonverbal children could learn to communicate with F/C, even if they did not have well-established skills in using other nonverbal augmentative forms of communication such as sign language or communication boards. F/C was accomplished by a facilitator supporting or actually holding the child's hand, wrist, arm, or elbow in a certain manner that allowed the child free and independent movement of fingers, but did not (reportedly) involve any pressure or other positioning of the hand or fingers by the facilitator as the child chose keyboard keys or touched letter icons on a paper keyboard array. This type of support by the facilitator was hypothesized to be both physical and emotional. The child, it was postulated, had to feel safe with and trust the facilitator or the child might choose not to be expressive.

The hand support was hypothesized to also play a more mechanical role in helping the individual control involuntary hand movements (an idea presumably borrowed from the original work on cerebral palsy patients). Facilitation was said to work equally well in individuals with or without prior typing or hand-writing experience, and with or without frank fine-motor coordination difficulties. The physical support was hypothesized to serve some unknown function whereby individuals would be encouraged to be more confidently expressive.

Reporting on the clinical findings of Crossley, Biklen suggested that participants would be most likely to express more complex ideas with the help of a facilitator who treated them with respect, did not talk about the participant in the participant's presence, and in other respects did not act in ways congruent with an expectation of a developmental age for the participant that might be significantly lower than chronological age (Biklen, 1990). The support of the facilitator was said to be able to be faded over time (although the logical inconsistency that a form of prompting was necessary to execute an apparently established competency appears not to have been specifically addressed). The success of facilitation for an individual did not seem related to measured intellectual level or experience over time with F/C, but rather seemed to be the expression of completely hitherto praxis-bound abilities to read, spell, and write. F/C was hypothesized to remove the limitations in expression imposed by the praxis. Therefore, subsequently exhibited skills would appear to have been acquired without any

conventional practice or skill acquisition curve that might otherwise have been expected to be evident (or measurable). Because of this formulation, an F/C participant was often described as a cognitively typical individual who had been functioning with typical receptive abilities, but, until exposure to F/C, had not had appropriate augmentative methods to implement corresponding expressive functions.

A final piece of the theoretical underpinnings for F/C was the notion that F/C could probably not be tested experimentally because the participants would not be trusting, as trust was hypothesized to be a significant factor in the augmentation process. An experimenter then, by the fact of conducting an experiment on F/C, was expressing some degree of skepticism (or at least could be said to be trying to confirm the null hypothesis). Practitioners of F/C also discouraged empiricists with the caveat that F/C worked in a way that was not presently explicable via any previous theory about communication disorders, neuro-linguistics, neuro-psychology, or neurology (Biklen, 1990).

**Empirical research addressing assumptions about how F/C worked.** A few years after the publication of Biklen's report on F/C (Biklen, 1990), empirical studies questioning the validity of several aspects of F/C began to appear in peer-reviewed journals. In the interim, information about F/C had become well disseminated through many unpublished case reports of its success and a few published reports (Duchan, 1993). Initially, the Autism Society of America (ASA) provided advocacy material on F/C but also including cautionary analyses of the extant methodological shortcomings of reported cases (Rimland, 1991a).

By July of 1996, the ASA had reversed its advocacy of F/C. When the sponsoring local chapter of the ASA's annual national conference in Milwaukee, Wisconsin invited Douglas Biklen as their keynote speaker, the national ASA office responded by organizing a panel of experts and parents to respond to his presentation. Other organizations felt pressed to take a position as well. The American Academy of Child and Adolescent Psychiatry issued a November 3, 1993 paper strongly cautioning against its use, and later, the American Academy of Pediatrics followed suit. Also, on October 19, 1993, WGBH TV in Boston produced a Frontline program entitled 'Prisoners of Silence' which traced the history of F/C, presented its claims, and concluded by debunking its methods. This program also included

some case histories of parents who were accused of prolonged and recurrent abuse of their developmentally disabled children that had been allegedly revealed through F/C, but not supported by physical evidence in courts of law. In 1995, ASHA also issued a position paper which claimed F/C had no established validity and stated that SLPs must inform potential clients of this fact.

Beginning in 1993, a series of research studies began to appear that very consistently invalidated various assumptions underlying F/C by empirically testing various extant suppositions. The first type of methodology used was designed to rule out the possibility that the facilitator was 'passing information' to the participant. This method typically consisted of: (a) establishing the participant's receptive language by having the participant identify pictures using F/C with the facilitator's assistance; (b) not using the facilitator's assistance at the keyboard; and, finally (c) showing the participant and the facilitator different stimuli. Studies such as those by Wheeler, Jacobson, Paglieri, and Schwartz ( $N = 23$ ; 1993), or Smith, Haas, and Belcher ( $N = 8$ ; 1994) consistently found that, in the 'a' condition the participant could accurately type the name of objects whereas in the 'b' condition, the participant would fail, and in the 'c' condition the participant would generally type what the facilitator saw. Other methodological variations were tried. For example, Szempruch and Jacobson ( $N = 23$ ; 1993) found that performance did not change as a function of use of familiar setting, familiar stimuli, or familiar facilitators. Another study looked at whether participants ( $N = 21$ ) became more competent at typing via facilitation after 20 hours of training, and found this did not make a difference (Eberlin, McConnachie, Ibel, & Volpe, 1993). One interesting study investigated socio-demographic characteristics of the facilitators themselves, and found that the heaviest users of F/C as a treatment technique were those with less education, a stronger belief that autistic individuals had higher IQs than were evident, and a lack of belief in science as having explanatory power for understanding human behavior (Dillon, Fenlason, & Vogel, 1994).

Myers (1994) noted a willingness of the legal system to take F/C reports as valid evidence, showing that it was not just the less educated or the more mystically inclined who found F/C plausible. A major area of fallout from F/C was the emergence of allegations of sexual molestation of developmentally disabled individuals, virtually always by parents.

Siegel (1995) showed that two teens, one male and one female, contradicted their own alleged molestation accusations when facilitated by a facilitator unfamiliar with the charges, and that structured interviews were more similar in academic abilities (i.e., spelling and grammar) when the transcripts of individual facilitators were compared, as opposed to the transcripts of individual children being interviewed. Howlin and Jones (1996) similarly debunked abuse allegations 'revealed' through F/C.

Over time, questions were asked about just what was happening in the F/C process. Vasquez (1995) examined whether participants might have a visual agnosia that prevented them from naming objects as they touched them (as per some communication board systems). This was ruled out by showing that participants could touch pictures or spell words in an experimental condition that involved a facilitator's assistance, but could neither receptively (touch) or expressively (spell) identify pictured objects without a facilitator. Bomba, O'Donnell, Markowitz, and Holmes (1996) showed that F/C, unlike any other skill, did not seem to show a learning curve. Students were as competent when first introduced to the method as after a posttest weeks later. Bebko, Perry, and Bryson (1996) conducted a study that suggested that students became more passive when being facilitated by having their hand guided. It could be hypothesized that passivity was a way of being 'left alone' while the facilitator concentrated on the participant's hand movements. A more explicit study by Kezuka (1997) used strain gauge measurements and showed the presence of small (guiding) movements on the part of facilitators as they provided arm/wrist support (although facilitators consistently denied providing intentional assistance).

After this first rather unequivocally negative round of research led many away from F/C, the height of the phenomena seemed over. However, some research reflected an apparent blind spot on the part of some investigators. Eliasoph and Donnellan (1995), for example, provided what they called strong support for F/C, having conducted a support group with five autistic participants and their facilitators, when they reported that the content of discussion was similar to groups where individuals communicated with one another orally. In general, then, after 1994 or 1995 the strongest wave of enthusiasm for F/C seemed to have passed, and only a smaller number of stalwarts remained in its camp.

With the arrival of many corroborating negative

studies most trends involving F/C were reversed. Concerns about misspent educational dollars dissipated as educational administrators decided not to include resources for F/C in speech-language pathology services. There were fewer reports of new law suits and some families who had been caught up in abuse charges made through F/C filed civil suits against facilitators and/or their agencies for pain, suffering, and needless legal fees. In most parts of North America, at this date, remaining supporters of F/C have, in a sense, gone underground, as parent-based publications such as the ASA's *Advocate* report no lack of efficacy.

### **Summary and Synthesis of the AIT and F/C Research Reviews**

What remains after exploring the empirical literature on AIT and F/C is an intriguing question: 'What attracted some people to the claims of treatments such as AIT and F/C in the first place?' It would be easy to answer this question simply by saying 'hope', but we propose that there may be systematic ways of predicting which parents and practitioners may be most susceptible to claims that are eventually disproved using conventional scientific methods.

AIT and F/C can be seen on a continuum. AIT seems to many to have face validity couched in quasi-scientific hypotheses. There seem to be possible reasons that mechanisms governing auditory processing might be rehabilitated, with subsequent benefits to a range of skills that are intertwined with communicative competence. However, as the review has shown, there is very little support for the efficacy of AIT for individuals with autism as a group, or even for auditorily hypersensitive individuals with autism. Perhaps well-designed single case studies will someday show robust pre- to postbenefits of AIT that cannot be attributable to placebo effects. However, given that no empirical or replicable benefits have yet been identified for AIT, it is difficult to plan how further research might proceed.

The pursuit of F/C continued in the presence of what, for many, was perceived from the start as a lack of logical or empirical support. Unlike AIT, it is less clear from a standpoint of basic scientific research principles why so many individuals found the F/C hypothesis intuitively correct. The Dillon, Fenlason, and Vogel (1994) study suggested such facilitators did not necessarily subscribe to 'seeing is believing' or face validity with respect to appraising

the existence of developmental disabilities.

**Methodological issues.** Apparently, there is a need for standards for evaluating treatments, starting with one for face validity: If it seems too good to be true, it probably is. Studies that compare groups of treated and untreated matched subjects (placebo-control studies) or use a participant as his own control (single case, repeated measures designs) are designed to detect positive (or negative) outcomes. If 'X' apparently changes as a result of a treatment, change in 'X' may be regarded as suspicious and spurious if: *a priori* 'X' was not hypothesized to change; 'X' was not measured or controlled; or there is no reasonable post-hoc explanation for change in 'X'. There is greatest reason for concern when later follow-up research that specifically hypothesizes that treatment will change 'X', and measures it pre- and posttreatment, can not substantiate the earlier patterns of improvements in 'X' with independent samples or independent measures of the variable.

Also, a clear distinction needs to be made between clinical significance (e.g., being able to enumerate new skills) and statistical significance (these new skills helping the child perform better on a test of the treatment's effectiveness). The two do not always correspond. Improvements from a treatment may not be frequent enough or consistent enough in quality or quantity to translate into statistical significance on empirical outcome measures. Clinically significant findings should encourage a clinician to better understand how a new treatment may benefit certain patients in certain ways, but should not serve as a basis for broad endorsement of a treatment.

Methodological difficulties alone or the lack of timely confirmatory studies, however, do not fully account for why phenomena like AIT and, especially, F/C proliferate.

**Parental coping with a child's disability.** Some families express awareness that the nonmainstream treatments they are seeking on behalf of their children with autism are 'long-shots' but they feel nonetheless compelled to pursue such treatments. Parents of children with disabilities are a very vulnerable population, susceptible to almost any enticement of dramatic improvement or cure, irrespective of professional advice they may receive to the contrary. Long-experienced professionals are repositories of a chronology of many of these nonmainstream treatments, some of which are a 'flash in the pan', others of which recur on an irregular but seemingly predictable basis with each new cohort of children

with disabilities. Parents of children with autism may be particularly vulnerable because their children are most often without the physical stigma that would promote more ready acceptance of an immutable biological impairment.

Clinicians who provide intervention to developmentally disabled children are familiar with the fact that it takes time for parents to adapt to coping with their child's disorder, and that some parents come to terms with their child's difficulties more readily than others. While developmental disorders are often recognized as major stressors for caregivers, and a class of very negative life event, there has been less attention paid to how to cope with this type of life event, successfully or unsuccessfully. We suggest that selection of treatments for children with autism are both influenced by, and subsequently influence, parental coping. A parent's style of coping may lend itself to the selection of either more unproved interventions or more conventional interventions.

A case can be made for various clinicians, including speech, language, and hearing professionals, taking on the role of psychological counselor to enable parents to think about their style of coping, and their expectations for their child. This will help parents choose interventions based on what, realistically, can be expected, demarcated from what they wish, hope, or have faith that an intervention will be able to accomplish. Arguably, it is important for parents to have realistic expectations of therapies and therapists they select, because if expected results are not achieved, parents may be likely to blame themselves. Alternatively, parents may blame the clinician for a job inadequately executed. If the parents feel that much-anticipated improvements have not materialized, their sense of helplessness and despair about the child's condition may increase (Siegel, 1996b).

**Stages of parental coping with a child's disability.** Parental adjustment to a disabled child can be characterized in terms of stages of grief. This grieving process can be described as paralleling stages of bereavement from death of a loved one. Just as in the death of a family member, the loss of the hoped for developmentally normal child proceeds through the stages of: outcry that this could have happened, denial that the child is not 'normal', intrusive and emotional flooding with the reality of the loss, a working through of what has happened and what it will mean, and finally, some sort of stasis (Siegel, 1996a). As in the bereavement literature for adults, it may be hypothesized that there is both healthy

coping with loss as well as dysfunctional maladaptive, or more pathological coping with loss. The Appendix shows a postulated set of structures for more normal versus more dysfunctional grief responses in parents of children with autism, based on grief responses to a death.

In autism, maladaptive coping is hypothesized to focus around a failure to reschematize the child as autistic, which results from prolonged and unresolved denial and affects all subsequent stages of grieving. Thus a persistent focus on ways to find or release the hoped for child is evident, rather than re-schematizing the child as an individual with disabilities. We hypothesize that parents who adhere to beliefs in therapies that have no firm basis in data are viewing the unreschematized child (who is a reassuring but unrealistic fantasy), and reporting that this fantasized child is an improvement over the actual child who has shown no significant improvement or cure in response to treatment.

### Conclusion

The popularity and widespread use of both AIT and F/C seem to support the proposition that some individuals tend to hold a homunculus theory of autism - that there is an undamaged child residing inside the normal-looking child. In the case of AIT, the treated child may be perceived as patently better as a result of treatment, although others simply may not be sure they can see what is in the eye of the beholder of AIT's stated improvements. Empirical studies to date have not been able to clearly quantify such effects for AIT. In the eye of the beholder, however, the individual is perhaps seen as more 'whole' than before AIT, and perhaps as more nearly, the hoped for child. In F/C, by contrast, (which deals with a more severely disabled population, and claims an even more fantastic change), the critical difference is that all those who can share the fantasy of normality by believing F/C messages originate with the F/C participant will behold the true child, and by doing so, have personal resolution of the grief around loss of the hoped for child.

It is a terribly sad reality that there is no evidence of an autistic homunculus or any sort of a 'boy inside'. Nonetheless, there are important reasons for speech and language clinicians to take care of parents and to identify the qualities of their grieving and help them through the grief process, (even if it involves giving up the hoped for typical child). In so doing, they may enable parents to make more well-reasoned choices in the care of their children.

It is one thing for research to prove the null hypothesis—that treatment is no different than no treatment. It is another thing to allow the 'no treatment' treatment to take the place of interventions that are supported by sound research even if proven interventions are simply palliative and unlike the miracles promised by unsupported interventions like AIT and F/C.

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### Editor's Note

This article was invited. A peer commentary follows, and further commentaries are anticipated in the future.

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## APPENDIX

### Normal versus Dysfunctional Responses to the Diagnosis of Autism.

<b>Stage</b>	<b>Normal Responses</b>	<b>Dysfunctional/ Maladaptive Responses</b>
<b>Outcry/Shock</b>	<ul style="list-style-type: none"> <li>* Crying; intense feelings of loss.</li> <li>* Protective action toward child in response to diagnostic 'threat'.</li> <li>* "Why me?"; questioning of etiology and bad odds.</li> </ul>	<ul style="list-style-type: none"> <li>* Numbing/ shutdown in response to news</li> <li>* "Kill the messenger"; invalidate credibility of diagnostician.</li> <li>* Abandon spouse and child emotionally and/or physically.</li> </ul>
<b>Denial</b>	<ul style="list-style-type: none"> <li>* Continue to seek further diagnostic opinions.</li> <li>* Avoid situations where child may look 'different'.</li> <li>* Compare child to others who started slow too, and later were fine.</li> <li>* Don't talk about it to siblings unless they ask.</li> </ul>	<ul style="list-style-type: none"> <li>* Avoid contact with helping professionals.</li> <li>* Resist recommended special education as not needed.</li> <li>* Persist in belief that child will outgrow autism.</li> <li>* Resist/refuse a 'label', even if dealing with professionals.</li> </ul>
<b>Intrusion</b>	<ul style="list-style-type: none"> <li>* Fear of the child getting injured or becoming self-injurious.</li> <li>* Fear for the child's future if something happens to the parents.</li> <li>* Vividly imagined re-enactment of possible 'casual' events.</li> <li>* Wishing child were dead.</li> <li>* Re-experiencing the moment when it was realized the child really was autistic.</li> <li>* Dreams of the child as healthy</li> </ul>	<ul style="list-style-type: none"> <li>* Uncontrollable intense shame and guilt as negative thoughts about child.</li> <li>* Real fear of harming child and/ or self (uncontrollable rage).</li> <li>* Uncontrollable, and unfounded diffuse anxiety about the child.</li> <li>* Anger at success of sibs/ relatives children.</li> <li>* Recurrent nightmares about fate of child.</li> </ul>
<b>Realization/ Working Through</b>	<ul style="list-style-type: none"> <li>* Realization that child can change but that hard work is needed.</li> <li>* Realization that intrusive fears can be handled and learned from.</li> <li>* Recognition of situations that may trigger renewed sadness about child.</li> <li>* Ability to seek and accept support from family, friends and system.</li> </ul>	<ul style="list-style-type: none"> <li>* Continued hope for a 'cure'; pursuit of illogical, long-shot 'miracles'.</li> <li>* Child becomes 'feral' becomes of lack of help, confirms worst fears.</li> <li>* Feels 'No one knows what will be.'</li> <li>* Feeling that no one is helping; system is out to thwart parents.</li> </ul>
<b>Chronic Sorrow/ Stabilization</b>	<ul style="list-style-type: none"> <li>* Acceptance of autism as part of child's 'personality'.</li> <li>* Humor about child's 'quirks'.</li> <li>* Realistic expectations for child's future.</li> <li>* Rational balance between child and other aspects of life (e.g., having a new baby).</li> <li>* Sadness, but acceptance of how child's future will differ from others.</li> </ul>	<ul style="list-style-type: none"> <li>* Inability to feel that child is doing as well as can be expected.</li> <li>* Unable to utilize social support when offered.</li> <li>* 'Marty'; devotes self entirely to autistic child.</li> <li>* Can accept other family only if they are seen as being as devoted to autistic child.</li> <li>* Development of self-punishing psychosomatic illness.</li> </ul>

Adapted from Siegel (1996a).