Controversial Therapies for Autism and Intellectual Disabilities

Fad, Fashion, and Science in Professional Practice

Richard M. Foxx and James A. Mulick

ROUTLEDGE

Controversial Therapies for Autism and Intellectual Disabilities

One of the largest and most complex human services systems in history has evolved to address the needs of people with autism and intellectual disabilities, yet important questions remain for many professionals, administrators, and parents. What approaches to early intervention, education, treatment, therapy, and remediation really help those with autism and other intellectual disabilities improve their functioning and adaptation? Alternatively, what approaches represent wastes of time, effort, and resources?

Controversial Therapies for Autism and Intellectual Disabilities, Second Edition, brings together leading behavioral scientists and practitioners to shed much-needed light on the major controversies surrounding these questions. Expert authors review the origins, perpetuation, and resistance to scrutiny of questionable practices and offer a clear rationale for appraising the quality of various services.

The second edition of *Controversial Therapies for Autism and Intellectual Disabilities* has been fully revised and updated and includes entirely new chapters on psychology fads, why applied behavioral analysis is not a fad, rapid prompting, a parents' primer to find what autism treatment works, relationship therapies, the gluten-free, casein-free diet, evidence-based practices, state government regulation of behavioral treatment, and teaching ethics.

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Second Edition

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To Susan,
For sharing the vision
And to Alyssa and Bethany for taking it forward
RMF

To my dear wife of 45 years, Nancy Elizabeth Mulick
JAM

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Preface to the First Edition

Fad, Dubious, Controversial, Pseudo-Scientific, and Politically-Correct Treatments in Developmental Disabilities Services

Over the last 25 years the field of mental retardation and developmental disabilities has grown into one of the largest and most complex, and costly, human services systems in the United States and, indeed, in the world. In the United States, this service system, including child, family, and adult services, consumes billions of service dollars annually, at a level greatly disproportionate to the number of people with developmental disabilities served relative to the number of others served through other programs. The breadth and depth of the clinical field, and related research activities, attest to an extensive and now longstanding public policy commitment to the betterment of people with developmental disabilities in the United States and many other nations. At the same time, this field has certain essential features that are common to other human services and that challenge the fidelity and effectiveness of care at the individual, practitioner, provider agency, and local, state, and national service system levels. These features include shifting philosophical positions that often drive regulatory action and change where and how, but not how well, people with developmental disabilities are served and a broad reliance on the least trained and experienced personnel as the primary agents of service. These features are perhaps inherent both in the nature of the work to be done, which relies upon human agentry as a service delivery process, and on the constraints on resources that are determined first by public policy, and secondarily by the costs of providing services in a manner that conforms to market standards in the general community. Manual labor is involved in much of the work that needs to be done on behalf of people with developmental disabilities, and this work is done in real time. There are fewer opportunities for teaching service recipients self-care skills, fewer educated consumers of services, and there is often a degree of antagonism toward professionals who incorrectly estimate service needs or independence of people with developmental disabilities. There are also persisting tensions between some of those who advocate for services based on how much costly professional support is really needed. This is because some regard disability as merely a “state of mind” that requires only attitude change on the part of those without disabilities and view the recommendation or offer of professional services as “evidence of discrimination.” In contrast, others advocate for improved, validated, well-reviewed and critically evaluated services and supports for this vulnerable population.

Many allied health and human service disciplines do not emphasize scientific training in the preparation of practitioners and professionals. Unfortunately, over time many of these individuals rise to become influential managers in human services. As a result, the developmental disabilities field, like other human services fields, is pervaded by the delivery of services and design of supports that are less effective than they could be, and sometimes even damaging. Treatments often are provided based on unvalidated or even disproven models of human behavior or methods of intervention. Sometimes people with developmental disabilities may receive services that actually conflict and undermine effectiveness of care. These types of problems are not limited to adult human services. The education of people with developmental disabilities has been affected by the same forces. Expenditures for the education of children with special needs have continued to grow to the point where school districts budgets are stretched thin. Yet, many of these costs are for programs that are ineffective, poorly designed, and inappropriate and that actually retard student progress, or which are selected by practitioners (e.g., special educators, principals) based primarily on their endorsement or marketing by authorities or well-known professionals in education.

Workforce and employment dynamics are not the only factors that undermine the integrity of treatment or intervention. Parents of children with developmental disabilities, in particular parents of children with mental retardation or autism, are continually seeking, ever more assertively, to obtain more efficacious treatments and educational interventions than the ones they are being offered. The research literature documents both the inefficacy and efficacy of a wide variety of treatments and educational methods for children and youth with a variety of conditions. Research can be used as a fairly reliable guide to what actually works. However, effective treatments or interventions are not always among the choices that professionals inform or offer to parents. Sadly, parents tend to be hesitant to question credentialed professionals about the grounds for their recommendations, sometimes even hesitate to probe professional endorsement of what appear to be quite strange or illogical treatment options.

Local professionals, most of whom are not specialists in mental retardation or developmental disabilities, are most likely to recommend that parents use the types of services with which the professionals are most familiar. These are often not state-of-the-art, sometimes not even appropriate treatment or educational options, but merely the most common, and could be minimally effective or even damaging when used with some disability populations. Even specialists or local educational agencies may recommend methods that fall within their range of skills or that they provide, rather than referring children and families, or dependent adults and their families, to seek more appropriate and better validated alternatives.

Despite the fact that a large share of public health care funds is dedicated to services for people with developmental disabilities, generally a small proportion of these funds goes to pay for services delivered by clinical professionals who meet community standards of licensure or certification and who are disability specialists. One reason why is that fees for services are not lucrative or even, in many cases, competitive with reimbursement under managed care or sufficient to cover practitioner expenses. Specialists in some disabilities are exceedingly hard to find. In the not-for-profit service sector, which dominates adult developmental services, journeyman professionals typically lack funds to attend training in specialized topics, or to attend professional conferences, or to participate in extended training in empirically validated interventions. Often, as well, the ratio of professionals to the number of people with developmental disabilities they serve can be insufficient to permit them to effectively train and provide ongoing technical assistance to the staff who are often the actual direct therapists who carry out interventions. It is well-established that training is effective only when professional follow-up and technical assistance is available and provided. Thus, while there are numerous threats to the integrity of services, no one element of, or group of people, in the service system is responsible for the fragility of developmental disability services. Furthermore, shifting philosophical bases of care, which drive system reforms, have taken place at a rapid pace and have thereby perpetuated this fragile state.

Over the past 15 years there has been a continuing movement from full participation of scientist-practitioners in all facets of developmental services to their having a greatly diminished role. This has occurred as a consequence of the organizing frameworks for the field shifting from dominance of clinical care to educational models of services. Unfortunately, education in the U.S. has no unified model, and is itself in a perpetual state of disrepair and subsequent reform. Most licensed or certified educators lack many of the basic skills needed to be effective consumers of scientific research reports, or to faithfully communicate and translate demonstrated research findings into program and service innovations. Simply put, their training in the use and interpretation of research is often limited to a single collegiate graduate or undergraduate course and what they can pick up from public television and the Discovery Channel. Education in the U.S. is not a research-based profession (although there are a few sterling exceptions in some graduate training programs). As the field of developmental disabilities has turned increasingly to education as a touchstone for reform and improvement, supposed common sense, nevertheless uninformed by scientific research and evaluation studies, has become an ever greater component of that reform. As this "common" sense has pervaded the field, there has also been a growing susceptibility to repeating past mistakes at the level of service and policy, and to the adoption of fad treatments that have a patina of apparent effectiveness, but that may also have very negative side effects.

This book addresses the present status and perpetuation of fad treatments and elucidates the details of research in areas of controversy within the field. Fad, dubious, controversial, pseudo-scientific, and politically correct treatments are not readily designated as exclusively faddish or controversial; rather, a treatment may be both faddish and controversial, and politically correct as well—and in those instances, still not be worth a tinker's damn.

Here, and in the chapters that follow, fad treatments are considered to have several characteristics. The most important is that they are introduced, rapidly increase in use, soon become pervasive, and then, following some extended period of pervasive use, rapidly decrease over time and are abandoned. Concurrently, fad treatments are often promoted or adopted based on testimonials from recognized, otherwise authoritative or prominent professionals in a field, averring that they are highly effective in alleviating problems in everyday or advanced skill development that are common among people with developmental disabilities. Yet, no evidence is offered to back up these testimonials that are more than suggestive in nature, or that is based on research or investigation that meets credible standards. Sometimes fads are further perpetuated by testimonials by prominent scientists, who really are trained and expert in other scientific fields (e.g., chemistry, physics), but not in the behavioral sciences, and who may be susceptible to the misunderstanding of well-established behavioral science findings regarding the nature, impact, and alleviation of developmental disabilities. Most often fads are adopted and further disseminated by well-meaning professionals or paraprofessionals who do not have the skills, training, background, or inclination to investigate whether the methods they have been encouraged to adopt are well-grounded in valid research. Fad treatments sometimes decrease in use over time because researchers have investigated their effects and found them to be wanting, and conveyed *this* information to practitioners engaging in fad practices. Or fad treatments' demise may occur because they are succeeded by more novel (i.e., sometimes merely newer) fad treatments to address the same or kindred developmental and functional concerns. However, a final characteristic of fad treatments is that they are never *completely* abandoned; they persist in use by small groups of professionals and resurface through the activities of these professionals, or of advocates who are unaware of the history of similar therapies and their disuse, and believe the treatment they have rediscovered to be novel.

Treatments or therapies may be dubious or controversial because: a) their underlying theoretical (or at least stated) rationales are baseless, or require assumptions of their effectiveness; b) there is little or no unambiguous evidence of their benefits; c) the research underlying their use does not meet conventional standards of quality or specificity; or d) there are much simpler and better-verified explanations for apparent, superficial effects of their use. And, somewhat surprisingly, some therapies are both dubious and controversial because either their stated theoretical rationales have been effectively disproven or their stated benefits have been found, in evaluative and controlled research, to be evanescent or nil. Yet, some professionals who initially champion and promulgate such therapies broadly and assertively do not abandon their positions, but rather may harden them and may even attack the integrity of those who question whether the therapy works. The most sophisticated of advocates for dubious or controversial therapies will accurately note that scientific methods cannot formally disprove a premise that a therapy "works." However, these same methods can make it possible to discern that the assumptions underlying a therapy are unfounded and inconsistent with facts, and that under the circumstances when a therapy is purported to "work," in fact the observed effects are merely an appearance of benefit, far less notable and meaningful than claimed, or undetectable. Therapies are dubious when their rationales and purported effects are poorly substantiated; they are controversial when advocacy for their use persists despite evidence regarding the insubstantiality of rationale or impact. In some cases dubious and controversial treatments are acknowledged by many professionals except for those trained in the discipline that most commonly uses those treatments; in such cases, professional training programs in colleges and universities are the culprits that perpetuate these practices.

Pseudo-scientific practices of professionals and near-professionals are, simply stated, based on inadequate research designs that cannot actually document the effects claimed for a practice, or are based on a rationale that is stated in scientific terms, but is not itself founded on findings from relevant and basic scientific research. Pseudo-scientific practices persist in circumstances where practitioners adhere to applying outmoded methods of clinical service that are disconfirmed by research conducted subsequent to their graduate training. These practitioners fail to consult the ever-expanding research base of their disciplines as a foundation for improving practices, when they wholeheartedly and uncritically accept testimonial or anecdotal evidence of rationale from prominent authorities, or, in a small number of cases, when they knowingly pursue the perpetuation of practices that are lucrative but ineffective and groundless.

Finally, politically correct treatments are based on rationales that are somewhat scientific, non-scientific, pseudo-scientific, or even anti-scientific in nature. Such treatments are disseminated and adopted by professionals and managers because they resonate in their purported nature and effects with ideological perspectives, or because their use contributes to the realization of other, perhaps tangible, socially progressive goals or objectives of service delivery. There also is the element of financial and professional gain via obtaining of large governmental grants and the establishment of a new field. The rationale for such treatments, which may not even consist of a therapy intended to ameliorate functional limitations, induce skills, or cure ills, but instead to possibly enhance, or appear to enhance, the social status of people with developmental disabilities, may be no more complex than "to do the right thing." However resonant with political reasoning, politically correct treatments seldom resonate in the same manner with either scientific findings within a discipline or with thoughtful and critical common sense. When they do, they can be both effective or beneficial, and politically correct. Reliance on socially progressive public policy rationales for a treatment ignores the fact that such policies are ever-changing, revised because they reflect a political consensus rather than substantiated fact, or may even be inconsistent with the attainment of greater independence and community engagement by some or many people with developmental disabilities. On the other hand, within the body politic of national organizations that pride themselves upon their progressive policy postures, promotion and adherence to politically correct treatment selection can propel individual advocates to prominence, despite the fact that the treatments, or indeed, their particular policies they espouse, are without generality and of small benefit to the individuals for whom they would advocate. Because political and social acceptance, and not the attainment of known or identifiable benefits for the people who are served are the end goals, those who would advocate for treatments, therapies, or methods that may (or factually may not) "contribute" to the social well-being of people with developmental disabilities, may be among those most prone, and most motivated, to disregard or derogate findings from research that disconfirm their positions.

Any book that evaluates, across a number of disciplines, the various fads, treatments, and movements that have proved to be ineffective, dubious, harmful, or politically driven should acknowledge any biases on part of the editors and chapter authors. And we do—a shared bias towards science and empirically based treatments and decision making. Thus, our criterion for selecting authors was first and foremost that they had a history of critiquing faulty practices and spurious reasoning, especially in their own areas of expertise.

Using this criterion, we assembled a group of collaborators from a number of disciplines and theoretical perspectives who were bound to this project by a belief in science and seemed capable of sharing our outrage at what has been falsely done to individuals with developmental disabilities and their families. Once everyone was on board the book became a labor of love fueled by a shared desire to protect some of our most vulnerable citizens and their families and loved ones from experiences that offer hope but deliver little or nothing.

Throughout this book it may appear to some that many descriptions of effective, science based alternatives to fads and dubious treatments seem to be behaviorally based. This is an accurate reading and is based on the simple fact that there is a very large body of peer reviewed literature supporting the use of behavioral approaches with individuals with developmental disabilities and autism. However, nonbehavioral approaches that have empirical or scientific support can be found throughout the book as well. Simply put, the issue is not behavioral versus nonbehavioral approaches or models, but rather empirically supported versus empirically baseless treatments.

Another reason why this book may appear to favor interventions that are behavioral is that we are behavior analysts. However, as mentioned above, we did not select our chapter authors according to some behavior analytic litmus test but rather on the basis of their ability to handle a selected topic. In virtually every case, the individuals selected were among those best suited by history and knowledge to write that chapter. Indeed, our collaborators break down into three general categories: behavior analysts, individuals who would not describe themselves as behavior analysts but who favor or are sympathetic to behavioral analytic approaches because of the strong science underlying them, and those who appreciate or acknowledge the empirical base of behavior analysis but who would not identify with it professionally.

Some readers of this book also may conclude that in bringing together both research summaries and critiques of occasional or even prevalent practices in developmental services, we are indicting the field of developmental disabilities. Nothing could be further from the truth. Indeed, over the many years each of us has been involved in various aspects of developmental services we have found that the great majority of paraprofessionals and professionals are committed to the well-being of people with developmental disabilities. Professionals with different disciplinary backgrounds understandably differ in the factors they emphasize as indications of well-being or of progress in the field. But as in any circumstance, and they are common in human services, when social policy and clinical practice are interwoven, the integrity of both policy and research may be compromised. Policy formation is not the function of research, nor is the function of research to verify that politically correct or valued postures are correct in a larger or other sense. Policies can be contrafactual, in that their premises may not be factual, and often such policies have unintended impacts that are unforeseen. The formation and implementation of contrafactual policies cannot survive scrutiny of their outcomes when these are adequately researched, and scientific activity is a counterbalance to such policies, although science in itself does not constitute a sufficient basis for either social action or social policy. Our position is that when professionals waste public and private resources through the perpetuation of fad, dubious, controversial, ineffective, non-beneficial, politically correct, and sometimes damaging or depriving treatments, or advocate for disuse of effective and valuable treatments they claim to be unacceptable on political grounds, they diminish themselves as trusted professionals, their professions, and the people they would purport to serve. The very nature of professionalism requires responsibility on our part; responsibility to those we serve by displaying more self-reflection, more candor, more honesty, and the capacity to be more objective about one's practices and their implications. The chapters in this book cover a wide range of treatments and interventions that have become common in educational and adult service settings for people with developmental disabilities, but we have not been able to include the full range of practices that may be, or have been found to be, dubious in nature. It is not reasonable to expect that professionals will be able to rely on high quality scientific research as the foundation of every action taken and decision made in the course of providing services to vulnerable individuals. Nevertheless, in the chapters in this book we can see recurrent patterns where the actual benefits of interventions or common practices have been found, through systematic scrutiny, to be greatly deficient in what they deliver. Yet some or many practitioners and professionals persist in each of these practices, or in reviving them. Their professions deserve better, and even more, so do the people they serve.

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Preface

Fad, Dubious, Controversial, Pseudoscientific, and Politically Correct Treatments in Autism and Developmental Disabilities Services

A decade has passed since the first edition of this book was published. While much has changed in the world, the field of autism and intellectual disabilities continues to be fraught with fads, controversial, unsupported, disproven, invalidated, and politically correct treatments that either were present in 2005 and have not disappeared or have appeared since then. Both types are covered in this book.

In Part I on General Issues, Stuart Vyse has updated his chapter on “Where Do Fads Come From?” They are still coming, and the reasons remain as germane now as 10 years ago. Tristram Smith takes a similar tack in his chapter on the “Appeal of Unvalidated Treatments.” He updates why these treatments are so appealing with some examples of some new ones that have failed to pass muster. We have deliberately kept Newsom and Hovanitz’s chapter on “The Nature and Value of Empirically Validated Interventions” unchanged. It was primarily historical, and we feel that history needs to be known. Crighton “Buddy” Newsom passed away in 2008, leaving a tremendous intellectual void in our field. He coauthored this chapter with his wife Christine A. Hovanitz and, given its scholarship, continued relevance, and lasting importance, we left the chapter intact as a memorial to Buddy and the incisive product that he and Christine produced.

The four chapters in Part II on Historical, Cultural, and Psychological Issues are updates from the first edition. Elizabeth Kryszak helped us revise chapters we had written with John Jacobson by bringing a set of fresh eyes to the topics. We very much appreciate her efforts with Chapter 4, a history of fads from the 1800s to today, and with “Developmental Disabilities and the Paranormal” in Chapter 7. She is a young scientist and clinician to keep an eye on for the solid contributions she will certainly make in this field during her career. Stephen Greenspan has added new insights to why individuals are gullible when exposed to fads, including a very topical self-revelation. Jeanmarie Badar has joined Jim Kaufman and Devery Mock (now Ward) in revisiting the delusion of full inclusion and its many intended and unintended consequences in education.

The chapters on Field-Specific Issues in Part III represent major rewrites of topics from edition one. The chapter on the neutralization of special education has been significantly revised by Heward and Silvestri, to the point that they have switched the order of authorship. A similar major and insightful revamp was done in the chapter on fads and controversial treatments in speech and language pathology by Mareile Koenig and Cheryl Gunter. They changed the order of authorship in a chapter that is vastly different from their effort in the first edition. Tom Zane has added new material and perspective and four coauthors—Mary Jane Weiss, Sam Blanco, Lorraine Otte, and Josephine Southwick—to his chapter “Fads in Special Education.”

Part IV, Disorder- and Symptom-Specific Issues, remains the largest section of the book, with 6 of the 15 chapters being new. Updated and reworked chapters include “Autism: A Twenty-First Century Fad Magnet” by Bernard Metz, Jim Mulick, and Eric Butter, in which the “cure de jour” phenomenon is alive and well and expanding almost exponentially. Some fad classics that refuse to die and that appear to be repackaging themselves include "Sensory Integrative Therapy" by Tristram Smith, Daniel Mruzek, and Dennis Mozingo, "Auditory Integration Training" by Oliver Mudford and Chris Cullen, and "Gentle Teaching," in which Mudford and Cullen were joined in their review by Angela Arnold-Saritepe. "Facilitated Communication: The Ultimate Fad Treatment" by the editors and John Jacobson continues unabated with a new name: supported typing.

Several new chapters have been added. Gerald Koocher and Erica Gill cover animal-assisted therapies, aromatherapy, and hands-on therapies in a chapter titled "Pet Me, Sniff Me, Squeeze Me: Quack Therapies for Autism." Thomas Zane, Mary Jane Weiss, Kari Dunlop, and Josephine Southwick evaluate floor time and RID in a chapter on relationship-based therapies. The Clever Hans phenomenon rears its head every few years, with the latest version being rapid prompting. James Todd explores it in depth along with its stablemate, facilitated communication, in his chapter "Old Horses in New Stables." Two major dietary fads are addressed by Keith Williams and Richard Foxx in a chapter titled "The Gluten-Free, Casein-Free Diet."

Parents of children with autism and intellectual disabilities are often at loss as to what interventions they should pursue for their children. Shannon Kay has updated her chapter on "Helping Parents Separate the Wheat From the Chaff: Putting Autism Treatments to the Test." Recognizing that parents need a primer on negotiating the autism treatment minefield, Sabrina Freeman, a Ph.D. and mother of child with autism, has contributed a chapter version of her excellent book for parents, *The Complete Guide to Autism Treatments: A Parent's Handbook.* But specifically what does work? Richard Foxx discusses ABA and why it is not a fad, pseudoscience, or dubious or controversial treatment. No discussion of political correctness would be complete without addressing positive behavior support, which Mulick and Butter update in "Positive Behavior Support: A Paternalistic Utopian Delusion."

Two chapters address the treatment and reduction of behavior. Newsom and Kroeger's chapter on nonaversive treatment has been left intact from the book's first edition. It was a superb analysis then, and it remains as such. What is new is Kimberly's touching memorial to Buddy Newsom. As Buddy's longtime colleagues, we greatly miss his critical thinking skills and were moved by Kimberly's fitting tribute. Richard Foxx again addresses the myth of the nonaversive treatment of severe behavior with a new section on the perpetuation of the myth by individuals supporting functional analysis as a panacea.

Part V on ethical, legal, and political concerns contains five chapters. Two that appeared in the first edition have been updated and expanded. Peter Sturmey's chapter on ethics has a new concentration on applied behavior analysis. Richard Foxx's 25-year update on what has happened to the treatment of destructive behavior since the 1989 National Institutes of Health Consensus Conference reveals that much of what was recommended was not pursued, leaving a significant population of individuals essentially untreated.

In the first of three new chapters, Jon Bailey and Mary Burch cover the teaching of ethics in a behavior analysis graduate course. Thomas Zane, Mary Jane Weiss, Cheryl Davis, and Ian Melton follow with an examination of evidence-based practices across different disciplines and make recommendations for consistent standards. The book concludes with a review of the government regulation of behavioral treatment by Richard Foxx, Valerie LaCerra, Nina Carraghan, and Jessica Fedezko in the aptly titled "State Government Regulation of Behavioral Treatment: The Good, the Bad, and the Ugly."

In a perfect world, there would be no need for a second edition of a book on all the various practices that not only do not help individuals with autism spectrum disorders (ASD) and intellectual disabilities (ID) but in many cases hurt as well. For as long as there are parents and professional desperately seeking help or *to* help, there will always be individuals who take advantage of that very desperation.

In closing, not a day goes by that we don't think of our dear friend and colleague John Jacobson. He was especially in our thoughts as we worked on this book because we kept thinking "what would John think about this chapter?" and wishing we had his input on it. We greatly miss having him with us in the fight to bring quality treatment and education to individuals with handicapping conditions.

John was the driving force behind the book's first edition, which is not surprising to those who knew of his prodigious intellect and total commitment to empiricism, professionalism, and ethics. In following that path through the field of autism and intellectual disabilities, John took many steps and left many footprints. We hope this second edition is a fitting testament to his legacy and that journey.

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Part I

General Issues

Chapter 1

Where Do Fads Come From?

Stuart Vyse

But, above all, let it be considered that what is more wholesome than any particular belief is integrity of belief, and that to avoid looking into the support of any belief from fear that it may turn out rotten is quite as immoral as it is disadvantageous.

—Charles Sanders Peirce (1992)

It is wrong in all cases to believe on insufficient evidence; and where it is presumption to doubt and to investigate, there it is worse than presumption to believe.

—William K. Clifford (1886)

What's in a Fad?

Before anything can be said about how fad therapies emerge and why they are often adopted over more valuable approaches, we must understand what we are talking about. What is a fad therapy in the field of developmental disabilities, and how does it stand in relation to other, nonfad therapies? When language is used to define social or functional categories, it is often because doing so benefits someone by codifying an inherent value system. The motivations behind the establishment of these categories may be honorable or dishonorable. For example, the use of the label "mental retardation," based on definitions involving intellectual and adaptive functioning, made it possible for a segment of the population to receive educational and social services that enhanced their lives. At the same time, applying this label—as well as providing the services—often made these individuals more susceptible to stigmatization, prejudice, and discrimination (Danforth, 2002; Goode, 2002). Indeed, the current preference for the phrase "person with intellectual or developmental disability" is aimed at diminishing the stigmatizing effect of labeling by referencing a specific aspect of the person—one ability among many—and avoiding a global assessment of the individual.

Throughout this volume the treatments that are its subject will be described using adjectives such as "fad," "alternative," "controversial," "pseudoscientific," and "unsubstantiated," among others. It must be acknowledged that these are—in some sense—terms of derision, and they reveal the value system of the authors who use them. I will return to the definition of a fad later, but what of the other terms? For example, if a therapy is "alternative," it can only be so in relation to some other standard or orthodox therapy (Wolpe, 1999). That which distinguishes orthodox from alternative or unorthodox therapies may or may not be the level of scientific support. A therapy is "controversial" in relation to some issue of controversy brought, presumably, by those who are critical of its use. Thus, just as being honored often has more to do with the honorers than the honored, being controversial may have more to do with the views of a therapy's critics than with the therapy itself. Absent arguments against it, a therapy might be free of controversy, but being so says nothing of its value. The label "pseudoscientific" is a pejorative adjective that suggests the treatment in question appears to be—but is not—scientific. The therapy may employ a technical jargon that sounds authoritative, and it may include a theoretical support structure that makes reference to genuinely scientific content (e.g., neurotransmitters, the sensory system, the brain), all of which give it the look and feel of a scientifically based treatment. But if these trappings of science are not backed up by reliable evidence, the treatment is a sham that steals some of its appeal from the positive reputation genuine science has acquired over its history. Despite the abundant evidence to the contrary (e.g., Carroll, 2003; Shermer, 1997, and—for that matter—a book like this one), we live in an age of science. Although many people reject scientific thinking in important aspects of their lives, appeals to the scientific basis of a belief, product, or treatment often lend credibility to it. So powerful is the allure of science as a method of argument that some have even attempted to use it to support beliefs that are clearly beyond its limits, such as the existence of an afterlife and the possibility that the dead can communicate with the living (Schwartz, Russek, Nelson, & Barentsen, 2001).

But the label "unsubstantiated" or similar terms, such as "non–evidenced-based treatments" or "treatments unsupported by evidence," are a more direct indication of the philosophy of this volume. If the chapters that follow share a common bias, it is that developmental disabilities treatments should be backed up by evidence and that scientific evidence is to be valued over other forms. The only way to obtain this kind of evidence is through research conducted according to accepted standards of methodology in the behavioral, social, and medical sciences. This is an admittedly positivist stance, and some postmodernists have argued that objective truth is impossible in the social sciences (Flax, 2013; Gergen, 2001). But these arguments do not hold much sway in this arena. People with developmental disabilities and those who work with and care about them do not always leap to scientific evidence—or *sound* scientific evidence—as the best way of evaluating treatments for developmental disabilities, but most agree in principle that this is the kind of evidence that should matter. Most believe that a treatment should be chosen not on the basis of whether it is enjoyable to administer, is consistent with the user's personal philosophy, or seems logical but on the basis of whether it works. Unfortunately, there is less agreement about what constitutes proof of success. Although most of those concerned about people with developmental disabilities are seeking evidence for the treatments they are using, some have not embraced scientific evidence as the most valued kind, and others cannot separate out the good and bad information they encounter. The purpose of this book is to outline the standards for evaluating treatments and help differentiate treatments that have strong scientific support from those that have little or no support.

By using these labels to distinguish various treatments and therapies for developmental disabilities, we are establishing categories on the basis of the presence or absence of scientific support. This value system is also evident in the definition of a "fad" proposed by the editors of this book. A fad, for the purposes of this volume, is defined as "a procedure, method, or therapy that is adopted rapidly in the presence of little validating research, gains wide use or recognition, and then fades from use—usually in the face of disconfirming research, but often due to the adoption of a new fad" (J.W. Jacobson, personal communication, November 11, 2001). So a fad is a therapy that is not supported by scientific evidence and that has a fairly rapid rise and fall. The basic concern, however, is the question of evidence. There are other techniques—equally lacking in support—that nonetheless manage to maintain their popularity over relatively long periods of time. Though they are not fads, these more resilient therapies are also the appropriate concern of many of the chapters to follow. Understanding that these are relative terms, the short life span of a fad may sometimes be evidence of its lack of value, but conversely, the longer life of another therapy is not necessarily evidence of value. If popularity and longevity were correlated with usefulness, a book like this one might not be necessary. But for a variety of reasons, this is not so. In Darwinian terms, scientific support is not the only measure of a treatment's evolutionary fitness. Other factors may allow it to fill an ecological niche and survive repeated rounds of natural selection.

As we set up these categories of scientifically supported and unsupported—essentially, good and bad—treatments, it is useful to examine one's motives. Science has a long history of theoretical and technological triumphs, but over the years, scientific arguments have often been used to further unsavory social agendas. The eugenics movement of the late 19th and early 20th centuries attempted to use science to further classist and racist political agendas (Gould, 1981). The system of classification known as the *Diagnostic and Statistical Manual of Mental Disorders* (DSM; American Psychiatric Association, 2013) is purported to be a scientific aid to research, diagnosis, and treatment, but its publication by a professional organization, the American Psychiatric Association, serves to keep this profession at the top of the heap as the final arbiter of what represents a bona fide mental illness (Greenberg, 2013; Kutchins & Kirk, 1997). The link between this manual and health insurance reimbursement policies raises additional questions about the APA's motivations in publishing this document. One need only ask who benefits if the manual contains many mental disorders (the current total is approximately 300) rather than just a few.

But in the present case, some of the more disreputable motivations are less of a factor. Yes, we believe in science. This is an ideological stand of sorts. But it is one that benefits no particular product or profession. The most effective treatments described in these chapters have been and are being used by a variety of professionals and nonprofessionals. At this point in history, the promotion of scientific therapies does not benefit any one professional group exclusively. In the years since the first edition of this book appeared, there has been a great expansion in state laws restricting advertisement of behavior analytic services in the United States to those who have achieved certification by a national board (Behavior Analyst Certification Board, 2014), but certification is not restricted to any specific discipline or degree program. In addition, there are few products being sold in connection with a scientific approach to developmental disabilities treatment, and the professional books, periodicals, and manuals that are produced provide little profit motive for their authors and publishers. Certainly individual careers and treatment programs have benefited from the adoption and promotion of scientific therapies, and thanks to the development of state standards, insurance reimbursement for behavior analytic services is often possible. So proprietary and financial motives are at play. But so far, nothing remotely similar to the relationship between the American Psychiatric Association and the health insurance and pharmaceutical industries exists in this case. The primary social motive is improving the lives of people with developmental disabilities through the promotion of evidence-based, high-quality services.

Where Do Fads Come From, and Why Are There So Many?

Why is this book necessary? In a world in which scientifically validated, effective treatments exist for people with developmental disabilities, where do all the ineffective fad treatments come from? Why are they not naturally eliminated from the landscape and replaced by treatments that work? In the remainder of this chapter, I will outline the circumstances—essentially the market demands—that appear to encourage the development and promotion of fad therapies, and I will outline some of the reasons consumers—parents and professionals—choose them over other options. The story is one of the gradual adoption of science as the final arbiter of value, and it mirrors, in many respects, the history of modern medicine. Thus, as an introduction to the circumstances facing the field of developmental disabilities treatment, I will first outline the history of medicine in America. Although the following section is about United States history, the arc of the plot—from nonscientific therapies to scientifically validated ones—takes a similar path in Europe and other areas that have endorsed Western medical procedures. The specific events are different, but the endpoints are the same.

A Brief History of American Medicine

In the United States and other Westernized nations, effective research-validated procedures are now the dominant approach to medical problems, but this is a relatively new development. Rigorous medical research of the kind we value today became a widespread phenomenon only at the beginning of the 20th century. Before then, medical practice both here and in Europe was characterized by a diverse array of practitioners and techniques. Today, in the field of developmental disabilities, scientifically validated techniques exist, but unlike contemporary medicine, these methods have yet to emerge as the single dominant approach to treatment. An examination of the history of Western medicine provides a number of clues to the popularity of alternative, unsubstantiated treatments in developmental disabilities treatment.

American Medicine Before the Revolution

In the colonial period, medical services were provided by a variety of practitioners, the great majority of whom had no formal academic training. Barbers in England and the colonies were authorized to perform surgery, and training was passed on by the apprenticeship method. It was not until 1745 that surgeons separated from barbers to form their own guild (Duffy, 1993). Surgeons were not officially authorized to practice medicine, but in fact, they often served as general practitioners for the lower classes. Apothecaries also served the poor, providing drugs for the treatment of illness, and they were joined by a variety of other trades offering medical services, including folk healers, bloodletters, bonesetters, midwives, and herb doctors, among others.

In the American colonies, particularly in New England, a class of minister-physicians emerged. While studying theology, many ministers who dissented from the prevailing church in England had also studied medicine as an alternative means of employment in the event they were dismissed from the church. As a result, a number of the ministers who arrived in the colonies also provided medical services. Cotton Mather was such a minister-physician, and he wrote a very eloquent medical essay on a measles epidemic of 1713, which claimed five members of his household (Duffy, 1976).

In the 17th century, those colonialists who had received formal training—such as the minister-physicians—were at the top of the medical hierarchy and were the practitioners most likely to treat the ailments of the wealthy. Often these physicians had studied at the great hospitals and universities in England and on the Continent. The American Revolution interrupted contact with British institutions and slowed the adoption of new medical techniques, but by the time of the Revolution, one hospital and two medical schools were in operation in America. A number of medical societies had been formed, and several colonies had established medical licensure laws (Duffy, 1976). Nonetheless, the limited access to academic training meant that the majority of physicians acquired their skills by apprenticeship.

From the Revolution to 1900

Many of the forces that led to modern medicine of the 20th century were present in the period following the Revolution. Throughout the 18th century, physicians had attained the highest status of all those providing medical services, but medicine rarely brought them wealth. Furthermore, their methods were not free from criticism. The most important American doctor of the late 18th and early 19th centuries was Benjamin Rush. Rush attended college in New Jersey and apprenticed with a physician in Philadelphia, but to improve his chances of success as a doctor, Rush traveled to Britain to study medicine. He attended the University of Edinburgh and studied with noted physicians in London and Paris. Upon his return to America, Rush was appointed professor of chemistry at the College of Philadelphia. During the 1770s, Rush was swept up in the political furor of the times, and he was eventually elected to the Second Continental Congress and became a signer of the Declaration of Independence (Duffy, 1993). Following the war, Rush returned to his medical practice and, until his death in 1813, he was one of the most influential forces in American medicine.

During the 18th century and into the 19th, physicians who used the traditional methods taught in the medical schools of Europe sought to distinguish themselves from the other forms of medical practice. They called themselves the "regulars" and referred to various purveyors of folk medicine and nonstandard treatments as the "irregulars." Despite being of higher status and having the attention of the wealthy sick of the colonies, the regulars did not achieve dominance until the beginning of the 20th century, and their eventual success was achieved only after adopting very different methods.

The problem with American medicine before the end of the 19th century was that it was not based on what we would now think of as scientific evidence. Techniques that were extremely harmful to the patient were not recognized as such, and as a result, for several centuries, the regulars of the medical profession—both in Europe and in America—did more harm than good. This situation led Oliver Wendell Holmes to deliver this now-famous assessment in a lecture given at Harvard Medical School: "I firmly believe that if the whole *materia medica* could be sunk to the bottom of the sea, it would be all the better for mankind and all the worse for the fishes" (cited in Wolpe, 1999, p. 222). Holmes's indictment was justified. The standard medical philosophy of the day was based on a theory first articulated by the ancient Greek physicians, Hippocrates and Galen. It asserted that illnesses were caused by an imbalance of four basic bodily humors: yellow bile, black bile, phlegm, and blood. Imbalances could be caused by an excess of one of the humors or by the putrefaction or fermentation of one of them. The standard treatment was something that became known as heroic medicine. Physicians sought to alter the balance of humors by bleeding, cupping, or purging the patient. Cupping was accomplished by heating a glass cup or jar and placing it on the patient's skin. As the air in the cup cooled, it created a vacuum that was thought to draw materials out of the body. Wet cupping involved cutting the skin under the cup so that blood was drawn out of the wound. Purging involved the administration of strong herbal formulas that created violent vomiting and diarrhea.

Bloodletting was perhaps the most popular of all heroic treatments, involving the draining of large amounts of blood from the patient's body. Benjamin Rush erroneously believed that the body contained 25 pounds of blood (in fact it contains less than half that amount), and he recommended bleeding until four fifths of the fluid had been removed from the body. He used this technique throughout his career, and a paradoxical result of the Philadelphia yellow fever epidemic of 1793 was that Rush's popularity increased. The fever simply ran its course throughout the city, and Rush's methods of bleeding and purging patients undoubtedly increased the number of deaths. Nonetheless, perhaps due to his warm and enthusiastic personality, he drew many adherents to his techniques (Duffy, 1976).

Throughout the colonial period and well into the 19th century, heroic medicine was the standard approach of the most highly trained physicians. But the brutality of these methods fueled the development of other medical theories and techniques. In addition, the higher cost of treatment by physicians meant that people of the middle and lower classes continued to bring their ailments to a variety of irregular physicians.

During the 19th century, several strong rival therapies rose up to challenge the regulars. One of these was Thomsonianism. Samuel Thomson was born into a poor New Hampshire family in 1769, and as an adult, he developed an interest in botanicals. He had witnessed the death of his mother, which he blamed on the harsh medicines of her physician, and when his wife became ill and was subjected to bloodletting and purging, he rejected a physician's services in favor of those of a root and herb doctor. Based on these experiences, Thomson began to experiment with the use of botanicals to treat disease, and in 1822, he published a book describing his methods. During the next 20 years, Thomsonianism grew in popularity, both because it was a more humane alternative to the prevailing wisdom and because of its connection with a number of social movements of the time. Samuel Thomson was a religious fundamentalist, and his approach to medicine was aimed in large measure at returning the practice of medicine to the common person—a message that was consistent with the democratic ideals of Andrew Jackson's presidency. During the Jacksonian period, restrictions on eligibility to vote were greatly reduced, and more states moved toward popular elections for president. In addition, the period from the mid-19th century through the early 20th century was one of great social reform movements, and Thomsonians fought the establishment of medical licensure laws and supported efforts against the use of alcohol, tobacco, coffee, and tea (Duffy, 1976).

Another popular but irregular treatment in the 19th century—which retains considerable popularity today—was homeopathy. Homeopathic medicine was developed by the German physician Samuel Christian Hahnemann, who had obtained a medical degree from the University of Erlangen. Homeopathy was based on two principles. First was *similia similibus curantur* or "like cures like." This principle suggested that to cure a disease, one must find an herb or substance that produces the same symptoms as the disease in a healthy person. Hahnemann developed this principle after taking doses of cinchona bark, which produced fever in him and, when given to a patient with malaria, cured the patient's fever. The second principle of homeopathy effectively nullified any possible therapeutic effect of its treatments. Hahnemann believed that his medicines were most effective when they were highly diluted—a process that turned all homeopathic medicines into functional placebos. Nonetheless, because they did no harm to the patient, homeopathic physicians undoubtedly enjoyed better results than regular physicians using heroic methods because the body's own restorative functions were given a chance to operate (Duffy, 1993).

Homeopathy arrived in the United States in 1825, brought by physicians who had studied in Europe. It quickly made inroads in the eastern part of the country, and by 1935, the first homeopathic college in America was established in Allentown, Pennsylvania. The growing popularity of Thomsonianism and homeopathic medicine, as well as other competitors to the regulars, led to a number of defensive moves on the part of regular physicians. Chief among these was the "consultation clause." The American Medical Association was formed in 1847, but it is a testament to the strength of homeopathy that the first national medical organization in the United States was the American Institute of Homeopathy, which had been created 3 years earlier. By this time, the country had suffered epidemics of yellow fever and Asian cholera, and the benign interventions of the homeopathic physicians were far more effective than the standard methods of bleeding and purging. In southern states, which were more affected by these epidemics, homeopathy gained many converts. So when the American Medical Association was formed in 1847, it adopted its first Code of Ethics. This document included a number of useful principles regarding the physician–patient relationship, but it also included a clause regarding consultation:

> But no one can be considered as a regular practitioner, or fit associate in consultation, whose practice is based on an exclusive dogma, to the rejection of accumulated experience of the profession, and of the aids actually furnished by anatomy, physiology, pathology, and organic chemistry.
>
> (Bell & Hays, 1847/1999, Chapter II, Article IV. 1)

The effect of the consultation clause was to forbid any regular physician from taking on a patient who was also being seen by a homeopath, and no physician could consult with a homeopath, even if the patient requested it (Duffy, 1993). The consultation clause effectively defined who was a physician, and it also helped solidify the regulars' control over municipal and state hospitals. During the Civil War, homeopaths were not allowed in the Army Medical Corps; however, it is noteworthy that homeopathy was sufficiently strong in New York that in 1882, the Medical Society of the State of New York deleted the consultation clause from its version of the ethics code (Warner, 1999), an action that led to the establishment of two competing state medical societies. In addition, the exclusion of homeopathic physicians from regular hospitals forced them to establish their own, many of which achieved reputations superior to those of the regulars. Finally, homeopaths fought back rhetorically by labeling orthodox medicine "allopathy," a term that angered the regulars (Warner, 1999).

A particular irony of this history is that science was lost in the battle for professional dominance. If anything, those physicians who were the most scientifically based, such as the advocates for experimental physiology, tended to be among the opposition to the AMA code of ethics, and those who most harshly criticized experimental therapeutics were among the code's defenders (Warner, 1999). But by the late 19th century, the war of competing dogmas was beginning to fade, and many of the influential physicians of the era stressed the importance of scientific evidence in support of medical therapies. In a move that helped break down divisions within the profession, the University of Michigan, which had previously maintained separate departments of regular and homeopathic medicine, admitted a professor of homeopathy to the regular medicine department. Finally, by the beginning of the 20th century, scientific medicine began to emerge as the new orthodoxy. In the 1903 revision of its Code of Ethics, the AMA eliminated the consultation clause, and by 1910, Abraham Flexner, the president of the AMA, described allopathy and homeopathy alike as "medical sects" and urged that both must be abandoned in favor of "scientific medicine" (Warner, 1999, p. 65). Furthermore, during the early 20th century, gifts made by the Carnegie and Rockefeller foundations and other wealthy philanthropists helped build important new research institutes (Duffy, 1976). Although it represented a great step forward, the adoption of scientific methods by the field of medicine did not lead automatically to a morally sound and value-free profession. The late 19th and early 20th centuries were the era of social Darwinism, in which scientific arguments were used to further social agendas (Gould, 1981). Nonetheless, the rise of scientific medicine in the 20th century led to rapid technical advancement and rejection of medical dogma as the guide for medical practice.

The Origins of Fad Therapies

The history of medicine in America suggests a number of the factors that can lead to the success of nonscientific therapies. Since 1900, science has become the dominant judge of value in many domains, but it does not mean science-based therapies or beliefs are universally endorsed. Here are some of the conditions that appear to lead to the popularity of alternative, nonscientific therapies:

1. *Incomplete effectiveness of the available therapies.* When a person is ill or when a child is diagnosed with a developmental disorder, the current circumstance stands in stark contrast to normal expectation. As a result, the sick person is highly motivated to return to health, and the parents of the developmentally disabled child have a similar strong desire to bridge the gap between the child they hoped would be theirs and the one they have. In the case of a medical condition, if the available therapy is effective enough to eliminate the disease entirely (e.g., small pox, tuberculosis) or to make it no longer a significant threat (e.g., infections treated

with modern antibiotics), then alternative therapies are not needed. However, there are many conditions for which science has yet to produce a uniformly successful treatment. This was true earlier in the HIV epidemic in the United States, before the introduction of protease inhibitors and the more effective polypharmacy therapies now available ("People with AIDS," 1991), and it is the current state of affairs in the field of developmental disabilities. For example, a study of applied behavior analysis (ABA), the most effective therapy for autism, produced the highest levels of success in only 47% of participants (Lovaas, 1987), and there is considerable debate about whether the effectiveness of ABA has been exaggerated (e.g., Herbert & Brandsma, 2002; Rogers & Vismara, 2008). Under these circumstances, an alternative therapy—for example, facilitated communication (FC) or, as it now is more commonly called, assisted or supported typing—can gain rapid acceptance. In the absence of a completely effective treatment, facilitated communication is attractive because it instantly erases the intellectual gap for all children. The physical deficit that is purported to hide the child's true abilities remains, but facilitated communication's promise—the exchange of a pervasive developmental disability for a mere physical one—is very appealing to many.

2. *The best available treatment is onerous or distasteful for the parent or client.* Heroic medicine was an easy foil for more mild forms of treatment such as Thomsonianism and homeopathy. Contemporary alternative cancer therapies undoubtedly gain popularity from the substantial discomfort produced by chemotherapy and radiation therapy (Okie, 2000). In the field of developmental disabilities, the best therapies are expensive, are demanding to administer, and take years to complete—or are never fully completed. Thus, a gluten- and casein-free diet (Whitely, Rodgers, Savery, & Shattock, 1999) or holding therapy (Welch, 1988) may be appealing to some parents because they appear easier to administer or because the more effective treatment is thought to be "cold and manipulative" (Maurice, 1993, p. 63).

3. *The alternative treatment is supported by ideology.* Many treatments in both medicine and developmental disabilities have survived because the proponents and consumers have adopted a theory about the disease or disorder in question. All the regular and irregular treatments of American medicine before 1900 were based on a theory of disease: the heroic/humorial system of the regulars, Thomson's botanical treatments, and Hahnemann's homeopathy. Often belief, based on the ideological appeal of a therapy, is sufficient to sustain the use of a treatment in the absence of any evidence that it is effective.

The attractiveness of ideology is greatest if it extends beyond the specific condition and makes contact with a more general personal philosophy or, alternatively, draws credibility from its apparent relationship to another, validated theory. The success of Thomsonianism was spurred by its association with Jacksonian democracy and a variety of 19th-century social reform movements. Similarly, a variety of modern alternative medical therapies derive much of their appeal from broad cultural trends that reject traditional organized medicine in favor of approaches emphasizing diet, exercise, vitamins, and holistic health (Cassileth, 1989; Vyse, 2013). In the field of developmental disabilities, treatments based on holding (Welch, 1988) and dietary restrictions (Whitely et al., 1999) may benefit from their coherence with contemporary theories of parenting and nutrition, respectively. In addition, despite limited evidence of the effectiveness of gluten- and casein-free diets in the treatment of autism (Herbert, Sharp, & Gaudiano, 2002), these treatments gain a veneer of plausibility from their apparent similarity to dietary programs for validated metabolic disorders, such as phenylketonuria and diabetes. However, without sound evidence in support of these diets, they represent another case of pseudoscience.

4. *The treatment is promoted by a proprietary professional group.* Quite often, a therapy originates with a professional group and goes on to be promoted by members of that group. Ineffective treatments can survive if they are based on an appealing ideology and are backed up by the

authority of the profession. Furthermore, the promotion of a proprietary therapy strengthens the professional group. The regulars, who were most likely to be academically trained and who represented the standard medical approach from colonial times into the 19th century, had a proprietary interest in the methods of heroic medicine, and they sought to protect their professional turf with state licensing laws and the consultation clause of the American Medical Association (Wolpe, 1999).

Even today there are examples of unsubstantiated alternative therapies that have emerged from specific professional groups. In medicine, therapeutic touch (TT; Mackey, 1995) is a practice developed by Dolores Krieger, a professor of nursing, based on the premise that the body is surrounded by energy fields. Proponents argue that a variety of diseases and conditions can be treated by passing the hands a few inches above the body to smooth these energy fields. A recent review found that "the 'facts' of TT are that it has an unknown mechanism of action and its efficacy is questionable" (O'Mathuna, Pryjmachuck, Spencer, Stanwick, & Matthiesen, 2002, p. 171). TT is not exclusively practiced by nurses, but it remains closely associated with the nursing profession. In the field of developmental disabilities, sensory integration therapy (Ayres, 1979) has its origins in occupational therapy and is most often promoted by members of that profession—despite the absence of support for this therapy in the research published to date (Herbert et al., 2002; Zimmer & Desch, 2012).

It should be acknowledged that not all therapies primarily promoted by a single professional group are worthless. The use of drugs to treat physical, psychiatric, and developmental disorders has, until recently, been the exclusive privilege of physicians, and that privilege has been protected by state licensing laws and educational and accreditation standards. Without question, drug therapies are very effective in treating a wide variety of ailments; thus promotion by a professional group alone is not proof of ineffectiveness. Nonetheless, any therapy, whether effective or ineffective, gains strength from the authority granted to the professionals who promote it. In some cases, when combined with the ideological appeal of the therapy, the force of professional authority is surprisingly influential in maintaining the popularity of unsubstantiated treatments.

5. The treatment emerges in an era of science denial. Science has always had its detractors. Despite achieving the power of authority in many areas, dynamic scientific thinking has frequently come into conflict with more dogmatic or emotion-based ideas. Unfortunately, in the years since the first edition of this book was published, antiscience sentiments appear to have increased—particularly in the United States. As the first edition was being produced, the MMR vaccine controversy fueled by a fraudulent and ultimately retracted study by Andrew Wakefield and colleagues was just getting underway (*The Lancet*, 2010). In 2007, actress Jenny McCarthy blamed her son's autism on childhood vaccinations and began a popular campaign against vaccination that has had troubling success (*Frontline*, 2010). Recently, rates of several all-but-eradicated childhood diseases have begun to rise to levels not seen for decades, and public health officials point to lower rates of vaccination as the cause (Sifferlin, 2014). In addition, belief in evolution in the United States has been assessed at approximately 40%, which is a substantially lower rate than in most other developed countries (Miller, Scott, & Okamoto, 2006). Finally, thanks in part to a vigorous campaign waged by business interests, belief that global warming should be a concern is at approximately the same 40% rate (Mooney, 2005; Saad, 2014). Unfortunately, at this point in history, the evidence of a broad antiscience movement is abundant, with vocal representatives from religious, political, and corporate spheres. In this environment—an environment that devalues evidence and critical thinking—it is easy to see how nonscientific treatments for children and adults with developmental disabilities can flourish.

These are some of the broad historical and cultural factors—the market trends—that contribute to the development of questionable therapies, but what about the individual consumer? When there are better options available, why do parents and professionals often choose unsubstantiated treatments over those with better support? Much of the answer is beyond the scope of this chapter and will be left to those that follow, but in the most general sense, the question is one of belief. How do parents and professionals acquire the beliefs they use to guide their decisions? In 1877, the American pragmatist philosopher Charles Sanders Peirce published an article titled "The Fixation of Belief" that has become a classic of the philosophy of science. In it, Peirce describes four ways people acquire beliefs and assesses the relative value of each method. Peirce's categories apply to beliefs of all kinds, and they provide a useful framework for understanding the adoption of fad therapies.

Authority. Beliefs are acquired by the method of authority if we accept the word of another. Often we grant others the power to change our beliefs if they have higher social status or are assumed to have special knowledge. Religious beliefs are acquired by the method of authority, as are, in fact, most of our everyday beliefs. As a practical matter, it is impossible for any individual to test more than a few ideas empirically; thus, we must acquire much of our knowledge by the method of authority. For example, I believe the light on my desk glows because of the movement of electrons through its copper wires and tungsten element, but I have never observed this phenomenon directly—only its effects. Some authority instilled my belief in the action of electrons years ago. Although it is often necessary to take the word of others, authorities are frequently wrong. Unless we know the basis of a person's statements, we have little reason to trust in their authority.

The regulars of early American medicine were the authorities of their day, and it is a testament to the power of their position that their methods were dominant for centuries. In addition, early American homeopathic physicians undoubtedly gained some influence from the authority they commanded. Today, physicians and other health professionals are the primary medical authorities, and although most of them recommend procedures based on scientific evidence, much of the influence they enjoy is based on the authority granted them by contemporary society. In the field of developmental disabilities, where cures are hard to come by, parents are confronted with authorities from many helping professions advocating different—often contradictory—therapeutic approaches. To the extent they find these professionals persuasive solely because of their standing, parents fall into the trap of choosing therapies by the method of authority.

Tenacity. Sometimes we hold onto a belief out of loyalty—merely because it is our own. According to Peirce, the tenacious man ". . . goes through life, systematically keeping out of view all that might cause him to change his opinions" (Peirce, 1992, p. 116). At times, we are all guilty of defending our beliefs in the face of strong contradictory evidence, but to do so will often lead us astray. It is a basic tenet of scientific thinking that theories must be jettisoned or modified in the face of clear conflicting data.

The regulars of early American medicine represent a striking example of tenacity. Somehow, most were able to maintain belief in their methods in the face of what were often devastating effects. Of course, their judgment was undoubtedly affected by professional and financial incentives as well. Recognizing the superior effectiveness of homeopathic and Thomsonian therapies would have led many physicians to sacrifice the status afforded them by association with regular medicine. Nonetheless, as previously noted, some doctors, particularly in the southern states during the yellow fever and Asian cholera epidemics, were not blind to the devastating effects of heroic medicine and adopted the more benign methods of homeopathic medicine.

In the field of developmental disabilities, tenacity allows professionals and parents to remain committed to a therapy despite evidence that it is ineffective. If the ideology behind the therapy has a strong appeal, adherents will be reluctant to give it up. Today, despite ample evidence that facilitated communication is an ineffective, pseudoscientific technique (Herbert, Sharp, & Gaudiano, 2002; Jacobson, Mulick, & Schwartz, 1995), several websites are devoted to promoting FC, and the technique remains popular with many parents. Of the top 10 hits in a Google search of the phrase "supported typing" conducted on December 29, 2014, eight expressed neutral or supportive views of the procedure. In addition, it is easy to find many recent YouTube videos of parents and professionals demonstrating the use of FC. Of course, the promise (or dream) of FC—that one's child is merely physically disabled, not developmentally disabled—would be difficult to relinquish, and by now we have many years of evidence of the power of tenacity to maintain belief in the genuineness of communications produced through FC.

A priori. Beliefs are fixed by the *a priori* method if they make sense or feel right. This is a subjective measure of value, which is necessarily dependent upon the accidents of one's prior experiences. Although the *a priori* method is widely used, it cannot be a path to objective truth. Honest people using this method of reasoning will come to very different conclusions, and unless one embraces fully the postmodernist view of science, this is an unacceptable situation. Nonetheless, many people make judgments and choose actions on the basis of this kind of subjective assessment. In the fields of medicine and developmental disabilities treatment, *a priori* reasoning is particularly evident when an appeal is made directly to the consumer, as in the case of Thomsonianism. Thomson's approach was to remove the intervening authority of the physician and return medicine to the people. By aligning his approach with dominant political and social themes of the day, he increased the likelihood that his theory would conform to the sensibilities of his audience.

Any approach that makes use of a plausible ideology—particularly one that draws upon other broad, cultural themes—will make subjective sense to large numbers of people in search of a solution. For example, biological autism therapies, such as secretin (Horvath et al., 1998) and gluten- and casein-free diets (Whitely et al., 1999) gain an air of plausibility from the assumption that the etiology of autism is genetic or, in some sense, "biological." The underlying logic is that that biological therapies are best for biological conditions. Dietary treatments may also benefit from popular contemporary beliefs about nutrition and food allergies. But it is dangerous to rely on our intuitive response to a treatment, because the subjective appeal of an idea is no more reliable than word of an authority.

The scientific method. Peirce's answer to the problem of fixation of belief was the scientific method, but, of course, there is no one scientific method. There are several ways of conducting science, and researchers have long debated how behavioral science, in particular, should be done (Cohen, 1994; Johnston & Pennypacker, 1993; Sidman, 1960). Nonetheless, according to Peirce, when empirical methods are used with adequate controls they should lead to beliefs that have "external permanency" (1992, p. 120). Taking a strongly positivist stance, he asserted that there are "real things, whose characters are entirely independent of our ideas about them" (1999, p. 120), and if the appropriate tests are devised, we can find out what those real things are. In support of this view, he pointed to the many scientific advances that were evident to his readers in 1877.

The authors of this volume share Peirce's enthusiasm for the scientific method. Empirical evidence rigorously obtained is the best way to settle disputes about the value of a treatment. Of course, science is an iterative process that can lead in unexpected directions, particularly early in the process of discovery. For example, in researching the use of prism glasses as a treatment for children with autism, Kay (this volume) found only two published studies in the available databases, both of which reported positive effects. Thus, her case study may be the only published report of a negative outcome with this rather improbable therapy. Nonetheless, given adequate time, science typically produces an unequivocal estimate of the value of any therapy.

In Search of Bartholow's Future

Peirce's list makes good sense. Most, if not all, the beliefs we hold have been acquired by one or more of his four methods. But if, as individuals, we are to live by his suggestions, we will have a difficult time. If we are to use the scientific method to form our beliefs, a lifetime of testing will provide us with only a fraction of what is needed to live our lives. Because the goal of testing every important idea is impossible to achieve, we must rely on authorities to help us make our daily decisions, and parents of developmentally disabled children making decisions about their children's therapy have the same problem. They cannot all be scientists—indeed, there is no reason for them to be. There are plenty of behavioral scientists at work on these problems today. The person who wants to acquire sound beliefs about disabilities treatment need not conduct research him- or herself. Instead, the consumer must value scientific evidence, seek it out, and recognize it when he or she sees it.

And this is where the problem lies. We live in an age of science. The effects of science, in the form of technological innovations, are obvious throughout the Westernized world. In professional medicine, the scientific method is the dominant approach to settling issues of opinion. It does not always lead to uncontroversial truth (e.g., Taubes, 2002), but the profession has fully adopted the view that arguments must be based on scientific evidence. Fewer professionals in the field of developmental disabilities have made a similar commitment to science, and so a book like this one is necessary. But the fundamental problem that faces us is one of cultural values. We may have adopted the fruits of science in the form of advances in technology and medicine, but not enough of us have adopted scientific thinking as the primary way of "fixing knowledge" (Vyse, 1997, 2013). To be certain, science does not have the answer to every question. Science will not tell you whom to marry, what is the most meaningful part of your life, or whether there is a god. But for matters of testable fact, there is no better tool, and claims about treatments for people with developmental disabilities are easily testable. At least that is the belief of the authors of this volume. If we are to help people with developmental disabilities reach their fullest potential, we must teach the larger community the benefits of scientific evidence and thought (Vyse, 2013).

In 1872, Roberts Bartholow, an early advocate for the scientific approach to medicine, wrote in a textbook of the day:

> Homeopathy and allopathy are dreams of a by-gone time. Modern science is indifferent to Hippocrates and Hahnemann. The therapeutics of today rejects dogmas, and the therapeutics of the future will accept nothing that can not be demonstrated by the tests of science.
>
> (Bartholow, 1872, p. 636)

Bartholow's future may be here for medicine, but it has not yet arrived for the field of developmental disabilities treatment. More efforts like this volume will be needed before that time will come. But if the history of American medicine is an example, the effort will not be in vain. Bartholow's future is within our grasp.

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Chapter 2

The Nature and Value of Empirically Validated Interventions

Crighton Newsom and Christine A. Hovanitz

The Nature and Value of Empirically Validated Interventions

All professions involved in developmental disabilities have ethical standards that include a principle requiring that the individual professional provide competent treatment. In some cases, "competent" remains undefined (e.g., American Physical Therapy Association, 2000; Council for Exceptional Children, 1997). In other cases, competence is linked to scientific knowledge in the field. For example, the American Psychological Association's Ethical Standards state, "Psychologists' work is based upon established scientific and professional knowledge of the discipline" (American Psychological Association [APA], 2002). Physicians are expected to "continue to study, apply, and advance scientific knowledge" (American Medical Association, 2001). For various reasons, some of which we explore later, professional organizations typically avoid an explicit requirement that practitioners use *only* scientifically valid interventions. As a result, most of the professions involved in developmental disabilities tolerate clinicians who provide dubious therapies and managers who operate questionable residential, vocational, and community services.

In the absence of the universal acceptance of scientific criteria for identifying valid interventions, society has developed certain formal standards for judging the acceptability of treatments (Beutler, 1998). These come from the health service system and the legal system. *Cost-effectiveness criteria* predominate in health care accounting. Treatment acceptability is based largely on the number of people served and the cost of services. From this perspective, an optimal treatment is one that reaches the largest number of individuals and costs the least, regardless of patient outcome. The second and third standards are applied by courts in defining malpractice. According to the *standard of common practice*, an intervention is considered acceptable based on its frequency of use in the community. If many providers employ the technique, the method is considered appropriate. As with the cost-effectiveness criterion, the standard of common practice does not consider outcome; a treatment that proves ineffective or even harmful could be exempt from malpractice if it is popular. The third standard is the *doctrine of the respectable minority.* A treatment will not be considered malpractice if the treatment is based on an explicit theory and method of delivery and a "respectable" minority of professionals endorse the theory. Once again, objective success of the treatment is not part of the criterion; a harmful therapy could be considered acceptable under these conditions. Clearly, standards outside professional fields are grossly inadequate to inform and permit choices regarding effective interventions.

How does the conscientious practitioner, human service manager, or consumer identify empirically validated interventions? Some professional organizations have undertaken the task of establishing criteria for defining such interventions, as we describe in what follows. It is possible to summarize all sets of criteria in general terms by saying that empirically validated treatments are scientific treatments. Describing what makes an intervention "scientific" instead of "unscientific" requires a brief review of the essential elements of science.

Elements of a Scientific Approach

The heart of the scientific enterprise is the search for order in nature. *Order* refers to discoverable regularities in relationships between events, such as the relationship between energy, mass, and the speed of light, or between different reinforcement strategies and the percentages of correct responses on an academic task by children with developmental disabilities. The rules or statements that scientists make about such relationships may be expressed mathematically (e.g., $E = mc^2$) or, as is more often the case in the social sciences, verbally (e.g., “Higher-probability behaviors reinforce lower-probability behaviors when made contingent on them.”). In either case, such statements must be objective, testable, and replicable.

A statement is *objective* when the key terms are stated so explicitly and unambiguously that a community of knowledgeable listeners can agree on the meaning of the statement. Anyone who knows what *probability*, *reinforce*, and *contingent* mean in behavioral science will immediately understand the general rule expressed in the sentence quoted. Ambiguity is minimized by *operationalizing* the key terms in the statement, that is, defining them in terms of the measurement operations required to make the observations of interest. Measurements might entail counting how often or timing how long a behavior occurs. Continuing with the current example, an investigator might define “higher probability” by explaining that if we measure the duration of all a child’s behaviors in a situation in which there are no restrictions on behaviors, the one the child engages in for the greatest total duration is the highest-probability behavior in that situation. The *reliability* of one observer’s measurements can be checked by having an independent observer make the same measurements at the same time. Operational definitions make phenomena available for public evaluation, verification, and replication, which are impossible when events are described in terms of personal perception and intuition (Green, 1996).

As an example of the difficulties arising when personal perception and intuition are relied upon heavily, consider the following statement from a text on sensory integration about a boy with poor motor coordination. We have italicized the important but undefined terms:

> Speculating that the problem originated in Mario’s ability to *process and integrate* tactile inputs within the central nervous system, we conclude that a treatment program designed to include enriched tactile experiences derived from participation in activities that Mario *enjoys and finds meaningful* will increase the likelihood that he will *take in, process, and integrate* tactile inputs as a basis for *planning* motor actions. While we cannot directly observe if this occurs, we can observe if Mario’s motor behavior improves.
>
> (Fisher & Murray, 1991, p. 6, emphasis added)

This is not a scientific statement because the terms *finding meaningful*, *taking in*, *processing*, *integrating*, and *planning* can mean different things to different observers (and nothing at all to some observers). Without further specification, their use merely gives a patina of neurological respectability to casual, intuitive speculation.

Statements are *testable* to the extent that they can be verified or falsified by undertaking certain operations and manipulations (*conducting an experiment*) and measuring the effects of the manipulated variables on the phenomenon under study. Science is thus an active process that produces increasingly better descriptions of reality. Although scientists differ in the relative emphasis they place on inductive versus deductive strategies for doing research, all scientific research starts with a question implying some sort of hypothesis—a guess, a conjecture—about what might be related to something, for example, or which treatment works better than another, and then tests it out. It is the “testing it out” that crucially distinguishes science from other disciplines. A Nobel laureate once explained testability in elegantly simple terms:

> We may collect and classify facts, we may marvel at curiosities and idly wonder what accounts for them, but the activity that is characteristically scientific begins with an explanatory conjecture which at once becomes the subject of an energetic critical analysis. It is an instance of a far more general stratagem that underlies every enlargement of general understanding and every new solution of the problem of finding our way about the world. The regulation and control of hypotheses is more usefully described as a *cybernetic* than a logical process: the adjustment and reformulation of hypotheses through an examination of their deductive consequences is simply another setting for the ubiquitous phenomenon of negative feedback.
> (Medawar, 1963/1996, p. 31)

Scientists apply a number of "rules of evidence" in testing their ideas. A primary concern is the simplification of the conditions under which observations are made. This entails eliminating some factors that are not currently being studied to prevent them from affecting the results. Equally important is the practice of changing only one factor at a time in order to be sure which factor is actually causing the effects observed. When relatively strong variables (those having easily observed effects) are studied, single-case designs can be used (Barlow & Hersen, 1984). The level of a behavior is measured when the variable of interest is absent, as a control condition (*baseline*), which is then compared to the level of the behavior when the variable is present (*treatment*). If repeated introductions and withdrawals of the variable produce corresponding changes in the behavior, we attribute causal status to the variable. When a variable is expected to have a relatively weak effect or we are interested in the average results across a number of participants, appropriate group designs and statistical analyses are undertaken. For example, in a randomized control design, participants are assigned randomly to one of at least two groups, a treatment group and a control group. After the treatment is applied to the members of the former group, statistical tests indicate whether the level of behavior measured in the treatment group is significantly different from that in the control group (Kazdin, 1980).

Returning to the example of the boy with coordination problems, the hypothesized relationships between neurological variables and motor behavior clearly fail the testability criterion, as there is no way to manipulate *processing*, *integrating*, and *planning*. In spite of admitting the speculative nature of the assessment of the child's problem and an inability to observe the hypothesized events inside his body, the authors go on to prescribe a treatment that will purportedly change those events in such a way as to produce improved motor behavior. Such an approach will not provide evidence for the hypothetical causes of the problem and is not a guide to responsible treatment. Even if "activities that Mario enjoys and finds meaningful" were specified and their provision actually did improve motor behavior under conditions in which alternative explanations could be ruled out, the only scientifically valid statement possible would be, "Activities A, B, and C provided in accordance with schedule D resulted in improved motor behavior as indicated by changes in measured performances X, Y, and Z." Any additional attributions of *taking in*, *processing*, *integrating*, and *planning* would be superfluous, remaining just as speculative and potentially misleading as they were in the initial intuitive assessment.

Finally, statements about relationships between events are *replicable* if independent investigators can repeat the original operations and make the same observations. Statements about highly replicable findings may eventually acquire the status of well-established scientific *theories* or even *laws* if they successfully explain a range of phenomena and enable us to predict and influence them in those sciences where control is possible. Such statements never become infallible, however, and can be overturned in the light of compelling new evidence.

Science is the most self-critical and self-correcting kind of knowing there is. Its criteria of objectivity, testability, and replicability enable scientists to find convincing answers to the simple yet crucial question, "How do you know?" (Agnew & Pyke, 1969). A commitment to a scientific approach increases the breadth and quality of knowledge in a field, discriminates valid from invalid treatments, and enables interventions and services to become increasingly effective and beneficial (Barlow, Hayes, & Nelson, 1984; O'Donohue, 1997).

The foregoing core principles of science are evident in a variety of methodologies used in both basic and applied research and have long served the field of developmental disabilities very well. Numerous empirically validated treatments are available for a fairly wide variety of problems. Compilations of empirically validated interventions and service models appear regularly and enable the conscientious professional to keep up with developments in the field (e.g., Hanson, Wieseler, & Lakin, 2002; Iwata et al., 1997; Jacobson & Mulick, 1996; Konarski, Favell, & Favell, 1992; Paine, Bellamy, & Wilcox, 1984; Whitman, Scibak, & Reid, 1983).

Evaluating Scientific Evidence

In any field, when a number of treatments have been studied, it becomes possible to organize them according to some estimate of the quantity and quality of evidence supporting them. The first approach to organizing treatments is often simply to ask professionals in the field who know the research literature and have had considerable experience in using a number of treatments to rank them. The aggregated rankings are published under the auspices of the relevant professional association as "expert consensus guidelines" for the use of professionals and consumers in the field.

The American Association on Mental Retardation recently formed two expert groups to evaluate treatments for problem behaviors and psychiatric disorders, one group addressing psychosocial interventions and the other pharmacological interventions (Rush & Frances, 2000). Each judge rated several possible interventions for a variety of common behavior problems on a scale anchored at 9 ("extremely appropriate: this is your treatment of choice") and 1 ("extremely inappropriate: a treatment you would never use"). The results were averaged and categorized as *treatment of choice* (items rated 9 by at least half the judges) and *first-, second-, and third-line treatments.* For example, for a hypothetical person with severe/profound retardation and severe, persistent self-injurious or aggressive behavior, the psychosocial group ranked "managing the environment," "applied behavior analysis," and "client and/or family education" as first-line treatments of choice, "classical behavior therapy" as a second-line treatment, and "supportive counseling," "cognitive-behavioral therapy," and "psychotherapy" as third-line treatments. Specific behavior analysis procedures were ranked in similar fashion. The psychopharmacology experts provided ratings of drug classes and individual medications across a variety of psychiatric conditions and problem behaviors, as well as rating preferred ways of handling complications. Other questions, addressed by both groups, dealt with diagnosis, assessment procedures, and decisions about medication in initial treatment plans for different groups of clients. Expert consensus guidelines are obviously limited by several factors, including the range of interventions presented for rating, the number and types of problems and client groups addressed, and the sample of professionals serving as expert raters. Such guidelines do, however, provide some initial guidance that can be considered along with the particulars of a given case and they indicate which treatments have consensual validity among peers.

A more rigorous approach to guidelines development was used by the New York State Department of Health in creating its practice guidelines on assessment and intervention for young children with autism (New York State Department of Health, 1999). A panel of professionals, service providers, and parents screened the literature and reviewed the most relevant articles in depth to make recommendations regarding assessment and educational programming. Studies selected for in-depth review had to meet high standards for quality, including adequate information concerning the intervention methods, participants in the relevant age range, controlled experimental designs, and the evaluation of functional outcomes. The panel provided overall recommendations for early-intervention programs, with an indication of the strength of the scientific evidence for each recommendation, as well as detailed summaries of the evidence on each of 18 types of interventions ranging from intensive behavioral and educational intervention programs to diet therapies.

In advocating the value of empirically validated treatments in developmental disabilities, it is instructive to look at some recent developments in medicine, because this field often serves as the model of a well-established clinical discipline. Although medicine is based on solid science, practicing physicians historically received relatively little training in scientific methods and research, typically far less than most graduate students in the physical and social sciences. Over the past two decades, medicine has undergone a dramatic shift from its traditional focus on pathophysiology (the physiology and biochemistry of diseases) to an emphasis on "evidence-based practice" in the way it delivers services and in the way it trains medical students. Cost-containment issues drive much of this emphasis. But another, more important rationale also exists: It is the belief that physicians who are up to date as a function of their ability to read the current literature critically are thereby able to distinguish stronger from weaker evidence and likely to make better treatment decisions. Similarly, physicians who understand the properties of diagnostic tests and are able to use a quantitative approach are likely to make more accurate diagnoses.

In the traditional approach to medical practice, it was assumed that unsystematic observations from clinical experience were a valid way of building and maintaining one's knowledge about prognosis, diagnostic tests, and treatment efficacy. Further, it was assumed that the study and understanding of basic mechanisms of disease and pathophysiologic principles was a sufficient guide for practice. According to this paradigm, clinicians had a number of options for understanding a patient's signs and symptoms. They could reflect on their own experience, consider the underlying biology, go to a textbook, or ask an expert colleague. The Introduction and Discussion sections of a journal article would be considered an adequate way of gaining the relevant information from it.

In the evidence-based approach, clinical experience and intuition are supplemented with observations recorded systematically in a standardized way to facilitate later retrieval and analysis. The study of basic mechanisms of disease is necessary but not sufficient as a guide to diagnosis and treatment, since the rationales indicated by pathophysiologic principles may sometimes be incorrect. Understanding how to define patients' problems clearly, conduct focused literature searches, and apply basic rules of evidence to the "Method" and "Results" sections of published papers are deemed essential to correctly interpreting the literature and to derive a sound treatment strategy. The main benefits of such an approach are that it gives physicians a way to deal directly with the uncertainties of clinical medicine, and it enables them to cope with the growth of research and rapid technological innovation, as well as meet increasing demands for quality care (Evidence-Based Medicine Working Group, 1992).

The sheer size and importance of medicine in the United States confers many advantages, including not only a massive research establishment but also an extensive network of support for the analysis and dissemination of research findings. One part of this network is concerned with identifying empirically validated interventions, and it includes the Agency for Healthcare Research and Quality (AHRQ) of the U.S. Department of Health and Human Services. The AHRQ supports 12 Evidence-Based Practice Centers affiliated with universities in North America, which specialize in producing evidence reports and technology assessments based on the world's medical literature. One recent project had the goal of describing systems for assessing the quality of individual scientific articles and rating the strength of a body of evidence pertaining to any particular issue (West et al., 2002). The investigators identified 19 recommended grading systems for rating the quality of published studies and 7 for rating the strength of evidence. In the latter systems, "strength of evidence" is usually defined in terms of three dimensions: quality, quantity, and consistency. *Quality* refers to the methodological rigor of the studies on a topic and is defined as the extent to which their design, conduct, and analysis has minimized selection, measurement, and confounding biases. *Quantity* refers to the magnitude of treatment effect, the number of studies, and the overall sample size across all studies. *Consistency* is the extent to which similar findings are reported from both similar and different experimental designs. The foregoing dimensions were used in developing the criteria listed in Table 2.1, which shows one system for evaluating the strength of evidence on a topic (West et al., 2002, based on Greer, Mosser, Logan, & Halaas, 2000). An interesting aspect of the scheme shown in Table 2.1 is that unlike most other schemes, which evaluate reviews covering a large number of studies, it can be applied to as few as six "important" research papers on a given topic. This would seem to make it suitable for adaptation and use in other fields, such as those involved in developmental disabilities, where large numbers of experimental studies focusing on a particular treatment are the exception rather than the rule.

Turning to another discipline deeply involved in developmental disabilities, organized psychology has been slow to insist that the services it offers the public be empirically sound in spite of calls from influential psychologists over the years that it do just that (e.g., McFall, 1991; Rotter, 1971). This issue was given significant momentum by McFall's (1991) "Manifesto for a Science of Clinical Psychology," his presidential address to the Section for the Development of Clinical Psychology as an Experimental/Behavioral Science (subsequently renamed the Society for a Science of Clinical Psychology, a section of Division 12 [Clinical Psychology] of the APA). The cardinal principle of the manifesto was that "Scientific clinical psychology is the only legitimate and acceptable form of clinical psychology." There were two corollaries. The first was that psychological services should not be administered to the public (except under strict experimental control) until they have satisfied four criteria: (1) the exact nature of the service must be described clearly; (2) the claimed benefits must be stated explicitly; (3) these benefits must be validated scientifically; and (4) possible negative side effects that might outweigh benefits must be ruled out. The second corollary was that the primary and overriding objective of doctoral training programs in clinical psychology must be to produce the most competent clinical scientists possible.

In 1993, at the urging of its Society for a Science of Clinical Psychology, Division 12 adopted the report of a task force chaired by Diane Chambless that discussed the need to validate the treatments used by clinical psychologists. The Chambless report presented criteria for considering a treatment to be empirically supported and listed some of the interventions meeting those criteria. Two categories were created, "well-established treatments" and "probably efficacious

Table 2.1 Scheme for Grading Strength of Evidence in Medical Research

Grade	*Criteria*
I	Evidence from studies of strong design; results are both clinically important and consistent, with minor exceptions at most; results are free from serious doubts about generalizability, bias, and flaws in research design. Studies with negative results have sufficiently large samples to have adequate statistical power.
II	Evidence from studies of strong design, but there is some uncertainty due to inconsistencies or concern about generalizability, bias, research design flaws, or adequate sample size. Or evidence consistent from studies using weaker designs.
III	Evidence from a limited number of studies of weaker design. Studies with strong design either haven't been done or are inconclusive.
IV	Support solely from informed medical commentators based on clinical experience without substantiation from the published literature.

treatments." The most recent criteria for each appear in Table 2.2 (Chambless et al., 1998). For a treatment to be considered *well established*, it has to have been found significantly more efficacious than a comparison treatment or placebo in at least two group-design studies or a series of controlled single-subject studies by at least two independent research teams following a written treatment manual. The key criterion is the inclusion of some kind of comparison condition, which may be another treatment (including medication), a placebo, or a wait-list or assessment-only group. For single-case experiments, emphasis is placed on the need to establish a stable baseline over an adequate period of time to rule out preexisting trends. Acceptable designs include the well-known ABAB design as well as multiple-baseline designs across behaviors, settings, or participants. A single-case intervention may be considered *probably efficacious* if shown beneficial for at least three participants by a single research group. To be considered *well established*, at least three replications (with three or more participants each) by at least two independent research groups, along with an absence of conflicting results, are needed. As of 2001, 108 empirically supported treatments had been identified for adults and 37 for children (Chambless & Ollendick, 2001).

The value of identifying empirically supported treatments remains controversial in some quarters. One concern is with generalization from laboratory to clinic. Empirically supported therapies are developed under conditions that are far from typical. "Real-world" clients are less uniform demographically and more likely to have multiple diagnoses than are participants in clinical trials. Likewise, therapists in most treatment settings will be less specialized and at a lower level of training than occurs in high-quality intervention research. Thus, there is the belief that research on empirically supported therapies will simply not generalize to actual clinical conditions. However,

Table 2.2 Criteria for Empirically Supported Psychological Interventions

Well-Established Treatments

I. At least two good between-group design experiments demonstrating efficacy in one or more of the following ways:
  A. Superior (statistically significantly so) to pill or psychological placebo or to another treatment.
  B. Equivalent to an already established treatment in experiments with adequate sample sizes.
  OR
II. A large series of single case design experiments ($N > 9$) demonstrating efficacy. These experiments must have:
  A. Used experimental designs and
  B. Compared the intervention to another treatment as in IA.

Further criteria for both I and II:

III. Experiments must be conducted with treatment manuals.
IV. Characteristics of the client samples must be clearly specified.
V. Effects must have been demonstrated by at least two different investigators or investigating teams.

Probably Efficacious Treatments

I. Two experiments showing the treatment is superior (statistically significantly so) to a waiting-list control group.
  OR
II. One or more experiments meeting the Well-Established Treatment criteria IA or IB, III, and IV, but not V.
  OR
III. A small series of single-case-design experiments ($N \geq 3$) otherwise meeting the Well- Established Treatment criteria.

Note: From "Update on empirically validated therapies, II" by D.L. Chambless et al., 1998, *The Clinical Psychologist, 51*, p. 4. Copyright by Division 12, American Psychological Association. Reprinted with permission.

research examining this issue has failed to find serious problems in generalization, although it has found that treatment effects in the community may not be as great as they are in controlled studies (Chambless & Ollendick, 2001).

Some psychotherapists have expressed the fear that sole reliance on empirically supported therapies could lead to a restrictive list of treatments reimbursed by third parties (Silverman, 1996). In addition, a limited pool of acceptable treatments raises the question that innovative techniques not yet subject to empirical evaluation could be vulnerable to malpractice suits (Kovacs, 1996). Arguably, such suits could be an appropriate action for society to take in some cases, but a way to reduce the likelihood of legal problems has been described by O'Donohue (1997), discussed in the next section.

Proponents of empirically supported therapies offer strong arguments in their favor. In the absence of scientific criteria, it is highly doubtful that therapists can make sound clinical judgments with any consistency. Practitioners possess the same tendencies toward bias and inaccurate perception as anyone else. Only to the extent that judgment is informed by the accumulated systematic, objective knowledge of the larger field does professional training improve quality of intervention. A second but related issue revolves around the consequences for the mental health field if we do not use scientific research as the basis for intervention. Some have argued that a failure to promote and disseminate scientific evidence of effectiveness will result in a de-emphasis or eventual elimination of psychological interventions by the health care delivery system (Barlow, 1996). This concern reflects an assumption that the public or funding agencies will increasingly use scientific information to judge the appropriateness of interventions. In this view, a failure to seek empirical support could, and probably would, eventually result in the discrediting of psychosocial treatments of all types.

Behaving Scientifically

What about the situation in which the practitioner encounters a problem for which no clear evidence exists favoring one course of action over another? Such situations arise frequently enough, but their existence does not justify a treatment approach based only on tradition ("doing what we learned in graduate school") or habit ("doing what we've always done"). A better option is "behaving scientifically" as a professional or a human services manager, that is, to take an explicitly experimental approach to all intervention efforts (O'Donohue, 1997). This approach has several components. First, one assumes fallibility, the recognition that one's current beliefs, despite all the attractions they hold, may still be wrong. At the same time, this acknowledgement does not imply that the practitioner should abandon either accumulated research findings or methods of scientific inquiry that are solid for mere speculation. O'Donohue listed several kinds of errors that can occur in treatment provision (here modified to include examples from developmental disabilities):

1. False descriptive statements: We may claim, for example, that an adolescent or adult client never thought of suicide in the previous week when in fact he thought of it four times.
2. False causal statements: We may believe that our client's aggression is attention seeking when in fact it is escape motivated.
3. False ontological statements: We can believe that things exist when in fact they do not. For example, we may believe that a child with severe mental retardation has well-developed but hidden language skills waiting to be discovered through facilitated communication when in fact she does not.
4. False relational claims: We may believe that procedure A usually results in a greater reduction in self-injurious behavior than does procedure B when this is untrue.

5. False predictions: We may predict that an inclusive classroom placement will result in positive social benefits for a particular child, but it actually leads to teasing and isolation for this child.
6. False professional ethical claims: We can believe it is ethically permissible to impose certain restrictions on a client without informed consent when it is actually wrong. Alternatively, we may give a client excessive latitude in making choices beyond his or her ability to evaluate carefully, some of which can result in serious harm to the client or others.

The second component of behaving scientifically is an awareness that all treatment and service offerings are based on knowledge claims that should be examined with respect to the quality of their sources. In some cases, professionals and managers may be committed to a problematic epistemology, accepting ideology, authoritative pronouncements, or anecdotal evidence as equivalent to established scientific knowledge. In other cases, there may be acknowledgement of science as the best source of knowledge but only a weak commitment to following its tenets in selecting, implementing, and evaluating treatments and services.

Next, professionals and managers must realize that errors in treatment and service delivery can cause serious harm. At the very least, ineffective treatments and services have opportunity costs; they displace the opportunity to participate in other, more effective treatments and services. More immediate harm can occur when decisions are dictated by the false beliefs mentioned earlier. For example, using procedure A when procedure B is more effective needlessly prolongs the client's suffering (Van Houten et al., 1988). Providing treatments or services that are erroneously believed to benefit the client when they actually do not wastes everyone's resources. Such "epistemic mistakes" can destroy families stressed past the breaking point, lead to an adult client's inappropriate arrest and incarceration, or produce serious injury, illness, or death. The only certain way to minimize such outcomes is to conduct our professional behaviors in an explicitly self-critical, evaluative manner, that is to say, in a scientific manner. Thus, O'Donohue (1997) argues that the supreme duty in human services is an epistemic duty to respect truth, a duty that is no less important than the moral duty to respect human life.

It follows that a practitioner or manager who is motivated by something other than the truth when forming a belief, such as ideology or personal philosophy, will be intellectually irresponsible and negligent insofar as he or she considers only the evidence that supports a prematurely formed conclusion. O'Donohue (1997) gives the example of a therapist who practices facilitated communication in order to enjoy popularity with parents and colleagues, financial rewards, and avoidance of the more intensive, laborious effort required by a behavioral language training approach. The therapist refuses to read research evaluating facilitated communication and refuses to learn about behavior analysis procedures. By engaging in selective consumption of information, such a therapist is failing in his or her epistemic duties as a professional.

Finally, O'Donohue (1997) recommends that professional practice and services be informed by the following considerations:

1. Accept the general attitude that we may be wrong.
2. Find out if our beliefs are consistent with the scientific literature.
3. Seek criticism from peers, especially peers who have greater relevant scientific expertise. Ask our critics what their criticisms are and listen to them nondefensively.
4. Conduct clinical practice and manage human services in such a way as to gain frequent feedback about our decisions and actions through peer reviews, client satisfaction surveys, social validity interviews, program evaluations, long-term client follow-ups, and experimental research.
5. Give criticism to others, including those who are failing in their intellectual duties, and fulfill a duty to the public by criticizing unsound practices and services.

Early in the 21st century, the field of developmental disabilities finds itself faced with not only increasing demands for accountability from consumers, government agencies, and the general public but also threats to the scientific tenets that have fueled progress in treatment development and program innovation. These threats include well-intended but ungrounded theories and treatments such as sensory integration therapy (Smith, Mruzek, & Mozingo, 2003; this volume) and facilitated communication (Jacobson, Foxx, & Mulick, 2003; this volume). They also include the equally ungrounded epistemic relativism of postmodernist philosophies currently fashionable in the humanities, education, and the larger disabilities community. Postmodernists tend to ignore the long tradition of questioning basic assumptions that have characterized the philosophy of science from the time of Francis Bacon through the present and like to describe their work as challenging the logic and authority of science. The argument is made that science is a hopeless quest, because each culture and subculture constructs its own version of reality, and there is no way to say that any one version is better than any other. It is asserted that elite groups in a culture invariably define and use scientific knowledge in ways intended to oppress marginal groups (e.g., Foucault, 1980). Standard postmodernist themes of malice on the part of professionals and their oppression of groups of people with disabilities are evident in most postmodernist papers on developmental disabilities (e.g., Danforth, 2000; Goodley & Rapley, 2001; Peter, 2000).

Perhaps the most charitable view of postmodernist writings is that they may have sensitized those few workers in the field not already aware of them to the disparities in power between people with and without developmental disabilities. Less charitably, a close reading indicates that while advocating greater sensitivity toward and "liberation" of people with disabilities, postmodernist writings actually display a surprising lack of knowledge or concern about them and trivialize their problems as mere "social constructs," all the while exhibiting contempt for the people actually liberating them from harmful practices and systems. To these and other threats to progress in the field, we suggest that the appropriate response of individuals committed to a scientific approach is to expose the hollow assertions of antiscientific thinking as they surface (e.g., Koertge, 2000; Sokal & Bricmont, 1999) and to continue offering the better alternatives of evidence-based knowledge and empirically validated interventions.

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Chapter 3

The Appeal of Unvalidated Treatments

Tristram Smith

Most intellectual and developmental disabilities (IDDs) are now treatable but incurable. That is, current treatments can help individuals with IDDs in important ways but seldom eradicate the disability. For example, two treatments with solid scientific support are applied behavior analysis (ABA) and psychotropic medication. With ABA interventions, many individuals with IDDs learn skills they would not otherwise be able to master. These skills enable them to communicate, interact with others, take care of themselves, engage in leisure activities, and work at school or in a job. Still, the majority of individuals who receive ABA continue to have significant overall delays in these areas. Medications sometimes reduce behavior problems such as aggression, insistence on routines, and difficulty falling or staying asleep, but they seldom eliminate such problems. Beyond limited effectiveness, these treatments have other drawbacks. ABA is labor intensive, often involving many hours per week of intervention for years; medications are prone to unpleasant side effects and usually work only as long as the individual keeps taking them. Both ABA and medications require supervision by highly trained professionals.

It is not surprising, then, that virtually everyone who cares about individuals with IDDs is eager for new and better treatments. This eagerness is beneficial, and even essential, because it spurs treatment research and implementation of interventions found to be effective. Unfortunately, though, such eagerness also fuels the development of dubious remedies that purport to be everything that scientifically validated treatments are not: cures, risk-free antidotes, nostrums that laypersons can administer readily, and so on. Consumers often give credence to these remedies because they perceive them as having scientific support, a strong theoretical basis, or both (Levy & Hyman, 2008).

When scientifically validated treatments yield only modest improvements, unproven remedies described as having highly favorable outcomes, scientific backing, and theoretical justification may seem to be especially attractive alternatives. Nevertheless, such remedies turn out to be ineffective or worse, as documented in other chapters in this book. For this reason, it is a serious mistake to try each new treatment marketed for individuals with IDDs. To avoid doing more harm than good, service providers and families need to make careful and informed judgments to discern whether a remedy is plausible and worth exploring or whether it is a pseudoscientific approach with a low probability of success and unacceptable risks.

Evaluating treatments is complicated by the huge variety of interventions offered. These include (but are not limited to) megavitamins, diets, medications, detoxification regimens, sensorimotor therapies, relationship therapies, computer software packages, and educational curricula. Still, particular claims about outcomes, supporting evidence, and theory are informative as “red flags” that the treatment is pseudoscientific. Identifying such claims as distinct from claims made about scientifically validated treatments is a vital skill for service providers and families.

An additional complication is that even the most extensively studied treatments are not always presented responsibly. At times, proponents of ABA interventions exaggerate the magnitude of effects and quality of evidence in studies of these interventions (Lecavalier, 2013; Smith, Mruzek, & Peyton, 2008) or even promulgate interventions that have not been shown to be useful to individuals with IDDs or usable by their providers (Smith, 2013). Pharmaceutical companies may engage in overly aggressive marketing campaigns and charge exorbitant prices for new medications (Angell, 2004). As a result, providers and families often confront situations in which it is difficult to determine whether an intervention is scientifically based or pseudoscientific, and the truth may lie somewhere in between. Thus, it is important to be able to evaluate the soundness of the evidence and theoretical basis for an intervention. This chapter contrasts the claims made about scientific and pseudoscientific treatments and then illustrates how to evaluate them.

Claims About Treatments

Outcomes

Claims about scientifically validated treatments and pseudoscientific ones are summarized in Table 3.1. As indicated in the table, outcomes reported for validated interventions generally involve increasing skills in specific areas such as communication and self-care so that individuals with IDDs function better in everyday settings. In contrast, pseudoscientific interventions often are said to "cure" the disability; alternatively, the claimed benefits may appear important but ill defined.

Cure. Common synonyms for "cure" include "healing," "miracle," "breakthrough," and "revolution." Because any of these words implies that the treatment is all service providers and families could possibly have hoped for, the temptation to try the treatment is strong. However, such claims are as implausible as they are enticing. History shows that progress in IDDs occurs but happens slowly. To illustrate, Table 3.2 displays the years in which some common IDDs and their genetic origins were identified. As shown, the genetics of cerebral palsy and autism

Table 3.1 Characteristics of scientifically validated treatments and pseudoscientific interventions

Characteristics	*Scientifically Validated Treatments*	*Pseudoscientific Interventions*
Reported outcomes	Significant improvements in functioning in everyday situations	1. Cures 2. Important-sounding but vague benefits (e.g., increased focus) 3. Major gains that cannot be studied
Evidence	Controlled studies with objective measures of behaviors relevant to everyday functioning	1. Uncontrolled studies or studies with unvalidated measures 2. Sophisticated technology used in unvalidated ways 3. Opposition from the "establishment" 4. Criticisms of validated treatments 5. Subjective evidence —anecdotes —case histories —testimonials —surveys —popularity or longevity of treatment
Theory	Consistency with other knowledge	1. Hypothesis of underlying deficit in bonding or sensorimotor function 2. Natural intervention

spectrum disorder (ASD) remain largely unknown even though these syndromes were identified many years ago. The genetic bases of other IDDs listed in Table 3.2 were discovered 25 to 94 years after the disabilities were first described. Cures do not yet exist for any of these IDDs. Investigators have learned that it is quite difficult to work out the precise pathways through which a genetic abnormality influences brain development and results in an IDD (Bartesaghi, Guidi, & Ciani, 2011; van Bokhoven, 2011). It has also been quite difficult to identify gene therapies that might prevent or reverse these processes without serious side effects, although some promising avenues for research have been identified (von Bokhoven, 2011).

As is true for any other medical disorder or behavior problem, developing and validating an intervention for individuals with IDDs is a lengthy, multistage process. New medications are discovered and analyzed in a complex series of laboratory studies. If they appear promising, they are then tested in several phases in humans to determine their optimal dose, safety profile, and efficacy (Steinmetz & Spack, 2009). New behavioral interventions are usually piloted and refined in studies with small numbers of participants, then standardized into a manual that enables independent investigators to replicate the intervention, then tested on a larger scale in research centers, and then evaluated in community settings, as delivered by practitioners in those settings (Smith et al., 2007).

Given the complexities of identifying etiologies and validating treatments, claims that the cause and cure of an IDD have suddenly been discovered are almost certain to be false. Therefore, such claims should serve as a warning to avoid the treatment unless there is extremely compelling scientific evidence of effectiveness (as described in the next section). A number of recent examples confirm the wisdom of avoiding such treatments. Since 1990, new purported cures have included, among others, facilitated communication (FC; trained facilitators guiding individuals with IDDs to type messages on a keyboard), auditory integration training (playing music with certain sounds filtered out), gentle teaching (using unconditional acceptance and soft touch to respond to individuals with IDDs), secretin (a gastrointestinal hormone conventionally administered intravenously to treat peptic ulcers or evaluate pancreatic functioning), and chelation (a medical procedure in which an agent that binds to metal ions is administered to remove metals from the blood). Each of these interventions was in vogue for several years. However, all were found to be ineffective in controlled studies, and some of them created problems instead of eliminating them. For example, facilitators rather than individuals with IDDs turned out to be the authors of messages written with facilitated communication; some of the messages falsely alleged that the individuals with IDDs were abused by their caregivers (Jacobson, Mulick, & Schwartz, 1995). Chelation can have serious side effects and has resulted in several deaths of individuals with IDDs (Mitka, 2008).

Important-sounding but vague benefits. Examples of benefits that are described as important but are vague include "enhanced learning," "increased focus," "improved body awareness,"

Table 3.2 Years that selected intellectual and developmental disabilities and their genetic bases were identified

Disability	*Syndrome Identified*	*Genetic Origin Identified*
Down syndrome	1866	1959
Cerebral palsy	1860s	—
Phenylketonuria	1934	1984
Autism	1943	—
Prader-Willi syndrome	1956	1981
Williams syndrome	1961	1993
Rett Disorder	1963	1999

Note: From Dykens, Hodapp, and Finucane (2000) "reduced tactile defensiveness," "greater well-being," and "better sense of self." Although these benefits are not as alluring as the promise of a cure, they are cited more often by families as reasons for trying unvalidated treatments (Smith & Antolovich, 2000), and they are extremely difficult to measure clearly in research studies.

One reason these benefits are attractive is that they are portrayed as "deeper" and more fundamental than specific improvements in everyday functioning. However, fundamental change, if it occurs, should translate readily into specific, directly observable progress. For example, enhanced learning and better focus should be reflected in more rapid skill acquisition. Likewise, improved body awareness and reduced tactile defensiveness should be associated with increased skill and interest in motor activities, as well as improvements in social interaction such as approaching others more readily. Greater well-being and improved sense of self should lead to more positive affect. Therefore, claims of vague benefits signal that a treatment approach may not have benefits at all. They also portend a lack of careful, scientific evaluations of the treatment by proponents of the approach; the benefits are so vague that tests of whether they occur will be difficult or impossible.

Sensory integration therapy (SIT) provides an illustration, discussed in more detail in Chapter 15. In this approach, practitioners aim to correct the sensory processing of individuals with IDDs through exercises such as spinning their bodies, brushing their limbs, and squeezing their joints. Proponents contend that the treatment produces all the benefits listed at the beginning of the preceding paragraph (Fisher, Murray, & Bundy, 1991). Although the intervention originated in major research institutions in the early 1970s and is now provided to most children with ASD and many children with other IDDs in the United States (Green et al., 2006; Shore, 1994), proponents of this treatment have only recently begun conducting controlled studies on its effectiveness. Historically, they have relied on uncontrolled studies on nebulous outcomes such as whether children's eyes stop moving when they finish spinning (Ayres & Tickle, 1980). Controlled studies by independent investigators consistently show that the intervention is ineffective in treating behaviors related to everyday functioning, such as aggression or ritualistic behavior (Lang et al., 2012), although initial studies by proponents of SIT have yielded more promising results (Schaaf et al., 2014).

A variation of the vague benefit claim is the contention that the benefits of treatment disappear whenever the treatment comes under scrutiny by outsiders. For example, proponents of facilitated communication asserted that the presence of an objective observer disrupted the therapeutic relationship so severely that treatment gains were lost (Biklen & Cardinal, 1997). However, to provide clinically meaningful help to individuals with IDDs, benefits must not be so tenuous; rather, they must extend robustly across settings and people. Therefore, even if it is true that treatment gains occur but disappear under scrutiny, the treatment is not useful.

Evidence

In the preceding chapter, Newsom and Hovanitz noted that the effectiveness of validated treatments such as ABA and medications has been confirmed in multiple scientifically rigorous studies. These studies have controls to ensure that individuals who received the treatment improved to a greater extent than they would have without the treatment. For instance, investigators may compare a group that received the treatment to a similar group that did not. In addition, they use objective measures to ensure that the improvements were real rather than due to wishful thinking or investigator expectation. For example, the research assistants who collect the data may not know the purpose of the study, and investigators may compare data obtained by different research assistants for the same participant to test whether the data are reliable. Further, the measures pertain to concrete behaviors that are clearly important to individuals with IDDs and their caregivers such as whether they started talking, learned to dress themselves, stopped hitting, or mastered a job skill. These safeguards make scientifically rigorous studies the most dependable method for obtaining evidence on the effectiveness of a treatment. In contrast, rather than citing careful scientific studies, proponents of unvalidated treatments are likely to cite evidence regardless of its quality or relevance and make emotional appeals. Specifically, they often rely on uncontrolled studies or anecdotes, use impressive-sounding technology, and portray themselves as underdogs fighting the "establishment" and exposing the limitations of standard treatments. (For additional discussion of red flags for pseudoscientific treatments, see Finn, Bothe, & Bramlett, 2005.)

Uncontrolled Studies. Proponents of unvalidated treatments often make no distinction between rigorous and nonrigorous studies. For example, one of the most popular megavitamin therapies for ASD and other IDDs consists of giving vitamin B6 at doses that far exceed the recommended daily allowance set by the United States Food and Drug Administration (Kleijnen & Mattson, 1983; Smith, Oakes, & Selver, 2014). Proponents of this approach cite dozens of supporting studies, and they assert that this scientific support equals or exceeds that for any other intervention for individuals with IDDs (Rimland, 1998). Most parents who decide to use this intervention for their children view it as scientifically based (Smith & Antolovich, 2000). However, every supporting study is uncontrolled, based on subjective measures, or both (Nye & Brice, 2005), and the few available studies with experimental controls and objective measures indicate that B6 is ineffective (Nye & Brice, 2005). Thus, it is important to determine whether the studies cited in support of a treatment meet the same standards as those for scientifically validated treatments.

Anecdotes. The only evidence for many unvalidated interventions consists of anecdotes, testimonials from parents, or case reports. Proponents of such interventions often assert that, because treatments for IDDs are highly complex, the anecdotal impressions of caregivers and service providers offer a more appropriate source of information than do objective data. In the words of Bettelheim (1967, p. 6), a study of children with IDDs "cannot observe the rigors of a 'scientific' experiment since it must, in its course, pursue the vagarities of life which are nothing if not unpredictable."

However, complexity does not justify relying on subjective evidence; on the contrary, it may increase the need for controlled studies. For example, Bettelheim's therapy, which was supposed to provide unconditional love and acceptance, turned out to worsen children's behaviors. Investigators noted that controlled studies with precise measures were necessary to detect this problem for the very reasons that Bettelheim cited in support of subjective evidence: Because behaviors fluctuated over time, with numerous factors contributing to this fluctuation, controlled studies turned out to be the only way to isolate the effects of the treatment (Lovaas & Smith, 1994).

Diets provide another useful illustration. A popular intervention for individuals with IDDs is to place them on diets that forbid certain foods such as wheat and dairy products. Most parents who try such diets for their children report that the diets are effective (Smith & Antolovich, 2000). However, a variety of explanations for this report are possible: The diets may really work as intended, or the reported improvements may reflect parents' desire to see gains rather than actual progress (i.e., expectations of benefit may lead to subjective ratings of benefit even though no improvement in behavior occurred). Alternatively, the diets may have medical effects other than those attributed to them. For example, a wheat- and dairy-free diet may lead to protein deficiency (Arnold, Hyman, & Mooney, 1998), which may cause behavior change. The diets may have nonmedical effects such as parents' spending more time with their child in order to implement the diet. As well, the diets may deprive children of their favorite foods and thus may be similar in their effects to depriving children of other favorite objects such as television or computer games. This deprivation could motivate children to make behavior changes such as increasing their requests or seeking other things to do.

It is not humanly possible to sort out these alternative possibilities based on subjective evidence. Only studies that systematically control for each alternative will lead to an answer. For example, investigators can prepare foods that appear identical but differ in that some contain wheat and dairy while others do not. They can give these foods without informing the recipient or family which is which, and then they can compare the effects of foods that contain wheat and dairy to the effects of foods without these substances. If a difference emerges, the difference is likely to be due to wheat and dairy content, as opposed to other factors.

Subjective evidence may appear in different forms. One common form is a survey, in which many consumers rate the effectiveness of a treatment. Because of the large number of reports, surveys may seem more convincing than individual anecdotes, testimonials, and case reports. However, a survey is simply a compilation of individual selective impressions. For this reason, it is prone to the same sort of problems as individual reports and cannot substitute for a controlled study. Indeed, many treatments have received favorable survey ratings yet have not held up in controlled studies (Smith, 1996). The popularity or longevity of a treatment is another subjective form of evidence and does not necessarily mean that the treatment is effective. For example, Bettelheim (1987) asserted that, for many years, his psychoanalytic clinic for children with autism had 10 times as many applicants as openings. Notwithstanding its popularity, the treatment turned out to be harmful (Smith, 1996).

Technology. Pseudoscientific treatments often incorporate sophisticated medical or educational equipment such as computerized software, specialized laboratory tests of urine or blood, and biofeedback on brain waves measured by electroencephalogram. Of course, all of these forms of technology have legitimate uses, but it is not the technology itself that makes them legitimate. Rather, their legitimacy comes from studies that support their use for specific purposes. For example, urine tests have scientific support for assessing some kidney disorders but not for measuring neurotransmitter levels, gastrointestinal infections, or food allergies (Williams & Marshall, 1992). Similarly, electroencephalograms have scientific support when used to assess seizure disorders but not when used to treat attention deficit/hyperactivity disorder (Lohr, Meunier, Parker, & Kline, 2001). Consequently, it is necessary to establish whether the specific use of technology is reliable and whether controlled studies support its use for assessing or treating the particular problem to which it is applied.

Opposition from the "Establishment." Proponents of pseudoscientific treatments often contend either that they are unable to conduct rigorous studies or that such studies exist but are ignored or suppressed because of opposition from the "establishment." To illustrate, a popular but refuted view is that vaccines cause ASD. Proponents of this view repeatedly allege that governments and medical organizations are conspiring to cover up evidence that vaccines are harmful (Kennedy, 2005; Kirby, 2007; Tomljenovic, 2011). They charge that governments, medical organizations, and pharmaceutical companies are colluding in order to protect the profits of pharmaceutical companies and the physicians who use their products. Ironically and tragically, however, it has turned out that proponents of the vaccine–ASD connection were the ones covering up evidence and taking bribes (Offit, 2008). Newspaper reporters uncovered evidence that investigators who posited a vaccine–ASD link fabricated data in exchange for payments that, in some cases, totaled hundreds of thousands of dollars; these payments came from attorneys in class-action lawsuits against vaccine manufacturers (Deer, 2011). This scandal occurred even though a huge body of scientifically sound research shows that vaccines are *not* associated with ASD (Gerber & Offit, 2009).

As another example, proponents of facilitated communication contend that this intervention "gives voice" to individuals with IDDs, thereby "empowering people to be heard who might otherwise remain silent" (Bogdan & Biklen, 1998, p. 204) or who have been silenced. This political message of empowerment in the face of oppression revived interest in this intervention long after