Chapter 1

Introduction: Looking at Treatment Planning Through a Different Lens

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Do any of these situations sound familiar? One of your students has just been diagnosed with an autism spectrum disorder (ASD). Should you change the way you're working with him? If so, how? And why? Or maybe a student has been in one of your autism programs for a few months or even a few years, and despite his having made gains in certain areas, you have an increasingly uneasy feeling that many of his challenges are not being addressed at all. Or you feel that a patient had made considerable progress in one type of school and home program, but his progress is slowing down. Or he is only making gains in one area, and you believe he could progress more rapidly with a different kind of approach, at this new point in his development and learning, which is different from his earlier learning profile.

Like most of your colleagues, you read books and scan websites, go to occasional lectures and workshops, and peruse articles about treatments for autism and about the importance of using evidence-based practices, and you want to know that you are, at least, understanding and implementing proven practices. But what does that really mean for you, working with your student or client tomorrow? Does hearing about others' successes and reading about certain studies guarantee

that they will be useful in solving your specific student's problems? If an intervention has been effective with a large percentage of students according to one or even many studies, can you be sure that your student or patient will benefit from it? Or will your student fall into the category of children who demonstrated no significant change? Will you have overlooked a smaller study describing an approach designed for students more closely related to your student with a similar problem? Would it yield a better outcome for your student?

Defining Best Practices

Part of effective work with children involves continual monitoring and questioning what you are doing, wondering if you are taking the best instructional or therapeutic approach for your students, examining and reexamining your decisions about implementing available and emerging treatments, and considering and selecting certain interventions. Professionals in every discipline are bombarded with endless information on treatments for autism, and opinions vary as much as the treatments. One expert swears by one approach, whereas another is equally zealous but has the opposite opinion. Although research supports various approaches, professionals from different disciplines may interpret research results in entirely different ways. So the practicing professional—in an early intervention program, school, clinic, or other therapeutic setting, not to mention parents, who are eager to do the right thing for their child and want to get started as soon as possible—may be more confused than ever.

It is our premise that certitude regarding what is "the best treatment for children with autism" is a fallacy and can lead to ineffective and even harmful practice, while a cycle of continual questioning, planning, treating, monitoring, and revising informed by research as well as clinical expertise, leads to productive evolution in one's work with children.

Media Overload

It is almost impossible to flip through your morning newspaper, turn on the radio, or glance at a magazine in a grocery store check-out line without spotting something about autism. Although they offer a wealth of useful information and solid research, the popular media and especially the Internet also add to the confusion. Possible causes, personal accounts from celebrity parents, new brain imaging studies, and research findings on genetic links are only a few of the topics that may pop up on any given day. Of course, effective treatment (and some may dare to whisper the word "cure") is really what's on every practitioner's and parent's mind.

What should professionals do to provide the best help they can for their students or clients with an ASD diagnosis? What are the most important areas to work on? And in what order? What about the child who is too anxious to enter the classroom or office without melting down or the child who does the opposite of whatever you ask her to do? The child who bangs his head on the table in response to any demand? The child who seems to want to communicate but only makes an open vowel sound or screeches loudly when asked a question? The child who clearly wants to have friends but is so socially awkward that the other children avoid him? The preschooler whose parents have told you they want him "mainstreamed by first grade"? What treatments are going to help solve those problems or achieve those goals? Who should deliver them? Where? How? And for how many hours per week? And perhaps most important, what is the likely outcome? How do you know if you are doing the right thing? If you are helping?

Misinformation and misperceptions are rampant—about every treatment approach—and even about what autism is or isn't. But while opinions vary on all of these topics, virtually all professionals agree on one issue: Children with a diagnosis of autism should be educated and treated by providers with specialized training and experience with children with ASDs. The number of hours of

treatment, the approach or combination of approaches, the level of structure it should have and in what manner, and how to define and measure success, continue to be debated. No single answer will solve all of the problems of the child with whom you are working.

A New Way of Thinking About Autism Treatment

In *Treatment Planning for Children with Autism Spectrum Disorders*, we are not advocating for or rejecting a specific technique or intensive intervention program. And we are not describing a new treatment that we think will "fix" autism. Rather, we propose a way of thinking about specific challenges and goals for individual children at a given point in their development that is structured around our interpretation of the most evolved current model of evidence-based practices. Currently, many treatment programs for children with ASD are "top down," starting with the treatment approach the provider or program believes is best supported for children with ASD, and then fitting all children with that diagnosis, which includes children with an enormous range of profiles, strengths, and challenges, into that model. We think of this as a "Here's the solution. What's the problem?" approach.

We instead emphasize starting with identifying the key questions one is planning to address, within the context of specific children at a particular time in their development, with their combination of challenges and strengths, their treatment history, and considering what has or hasn't worked in the past. We then recommend considering best practices based on a review of relevant research on treatments for the specific problem, challenge, or goal, with subjects like the child with whom the practitioner is working. Key variables such as age, general level of ability, other individual characteristics, co-morbid diagnoses, and type of family and school situation also need to be considered, as well as family preferences. Based on all of this information, the provider develops a treatment plan to address a specific problem and work toward a specific goal. The provider then evaluates the effectiveness of

this treatment for this child over time, revising the plan if and when it ceases to be effective, the goals change, or the child changes.

Core Deficits of Autism

A diagnosis of autism is based on challenges across the domains of communication, social interaction, behavior, and play, according to the *DSM-IV-R* criteria (American Psychiatric Association, 2000). Challenges in each of these domains can range from mild to severe. Severity in one domain, such as communication, may not necessarily correlate with severity in any another, such as repetitive behaviors. Furthermore, children with an ASD diagnosis vary in IQ, from severe intellectual disability to intelligence in the superior range or extensive knowledge and competence in one particular area or subject, such as math or physics, or the ability to identify specific patterns. So devising a treatment plan to ameliorate the constant wandering or bolting of a nonverbal 3-year-old from storytime will be vastly different from a plan to support a talkative 8-year-old with Asperger's syndrome and far above-average intelligence, who is frequently running out of his classroom yelling "Everybody hates me!" Of course, it would be easier to apply one approach and set of strategies to every problem, but that wouldn't be sensible or responsible.

How the Book Is Organized

In Chapter 2 we discuss in some detail the subject of evidence-based practices (EBP), a subject that is on the minds of parents and professionals working directly with children, as well as the agencies that are making decisions about which treatments to fund.

Why There Is Confusion About EBP in Treating ASD

Evidence-based practice means using treatments that are supported by evidence indicating they are likely to be effective for the child

with whom you are working, and for the goals on which you are working. This seemingly simple concept turns out to be remarkably complicated, often with no single clear path, and is especially complex in the autism treatment field. The complexities stem from several issues, some specific to autism treatment and some more generally present in education and therapeutic treatment. These include disagreement about what constitutes evidence and about which problems should be treated, as well as which outcomes one should measure. Additionally, because children with autism are so varied, treatments established as successful for one group may have little applicability for another child with autism but with a very different profile. Many studies of different treatments have been found to produce effective change, and there is no agreed-upon path to determine which bodies of research one should consider.

The context of treatment, including where a treatment is provided and who provides it, may also affect success. Different providers, parents, and agencies have differing philosophies and beliefs about autism and treatment, which certainly influences which treatments they are likely to choose for their child or themselves. How this should be weighed is also controversial. We will discuss in more detail these and other challenges to treatment selection, including contemporary conceptualizations of EBP. It is important to note that EBP in autism treatment is a very complex and dynamic topic, one that has been discussed and written about in great detail (e.g., Reichbow, et al, 2011). Our purpose is to put forth a practical model for treatment planning for those working directly with children, incorporating current principles of EBP, and not to provide an exhaustive review or discussion of this topic.

We will discuss some guidelines for thinking about EBP in the context of your particular situation, such as whether you are working with a child at home or at school, in a large group, small group, or one-on-one situation, and perhaps most important, what may be possible within the parameters of those circumstances. We will talk

about a variety of treatment approaches, their developmental appropriateness, the usefulness and limitations of large-group research studies that look at treatment efficacy, and why children with the same diagnosis "on paper" vary in their presentations, not just in severity but also in their particular symptoms. For example, although one child may be extremely loud, active, and aggressive, another may be socially remote, silent, and underaroused. Yet both have an ASD diagnosis, display atypical behaviors, and are labeled, appropriately, as emotionally dysregulated. Treatment is more likely to be successful if one first identifies the problems and challenges that need intervention and then designs a treatment plan using one or several techniques, rather than assuming that one set of rules will solve all problems.

We will go on, in this chapter and in the case studies that follow, to describe why particular symptoms may be problematic in one situation and merit intervention but may not in another. One must determine under what circumstances and for whom the problem is a problem. Consider a 4-year-old who is beginning to get language, who may repeat the same words and phrases over and over, and understandably, may become annoying or disruptive in her preschool classroom, but her parents may be thrilled with her acquisition of language and not only tolerate it but encourage her constant chatter at home. Another 4-year-old, having recently mastered toilet training at school, has received a great deal of praise, naturally, but she constantly pulls her parents into the bathroom at home, sometimes several times an hour and during family meals, when dressing and undressing, at malls and at restaurants, thus delaying every family activity and creating chaos. In both of these situations, a behavior may be problematic in one setting but not in another, so a plan has to be designed that is flexible enough to address and shape the same behaviors in different settings.

In Chapter 3 we describe our treatment planning process. Although there are many ways to design and implement a plan, we think this is a sensible and flexible process that can be understood and implemented by parents and providers in various disciplines.

Case Studies

In the nine chapters that follow, we present case studies and describe different scenarios involving preschool-aged children through adolescents who have a diagnosis of an autism spectrum disorder, including Autistic Disorder, Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS), and Asperger Syndrome. We have not included cases involving children with Rett's Syndrome or Childhood Disintegrative Disorder, both categories within the ASD spectrum. However, we have worked with children in both of these categories, and many of the techniques we describe are certainly appropriate for these populations as well. Each of the case chapters:

- Describes the scenario
- Identifies specific issues that are problematic at school, during after-school activities, at home, and/or in the community
- Identifies and prioritizes goals
- Outlines a process for creating a treatment plan
- Discusses ways to determine if the plan is successful—and what to do if one or more aspects of the plan are not

Approaches and methodologies referred to throughout these case studies include, but are not limited to, the following:

Applied Behavior Analysis (ABA)
Cognitive Behavioral Therapy (CBT)
Collaborative Problem Solving (CPS)
DIR®/Floortime™
Pivotal Response Training (PRT)
SCERTS™ Model
Early Start Denver Model (ESDM)
Positive Behavioral Supports
Relationship Development Intervention (RDI)
Sensory Integration/Sensory Diets

Social Stories™
Replays®
PECS

In each case study we integrate discussions of approaches and strategies, how they are similar and different, and how they can or can't work together. One intervention may be better at targeting a particular problem in a particular child in a particular situation, although two or three other approaches have a research base indicating that they are effective for treating the same problem. Rather than simply describing approaches in a decontextualized fashion, listing the pros and cons of each and reviewing available research, we discuss these approaches within the context of a case study, describing thought processes regarding the whys and hows of implementing one or more interventions. The differing perspectives of all the stakeholders and the interplay of those perspectives are major factors in most of these cases. There are times when one or more treaters, parents, or team members might change direction, redefine the problem, or have to focus on another, more urgent problem that surfaces during treatment. The goal throughout is to help readers design a developmentally appropriate, achievable treatment plan and answer the following questions:

- What are the most important problems to address?
- How does one set realistic long- and short-term goals?
- What does the child need to learn and accomplish—in the next two weeks, two months, or even two years?
- How can one create a treatment program that is most likely to work for an individual child?
- How does one implement this plan at school and/or at home—or in other settings?
- How does one determine if the plan is effective? How does one define and measure success?

Many more questions can and should be addressed, but these are often the major questions professionals and parents think about, no matter what the specific circumstances, whether the child is 3 or 13 years old, in a public or private school program, living at home, or in a different residential setting.

Along with the growing number of children identified with ASDs—1 in 88 according to a recent report from the Centers for Disease Control and Prevention (2008)—there is an increasing need and demand for ways to identify treatment approaches and programs that are likely to succeed. Professionals in the field and family members—psychologists, specialty service providers, school counselors, occupational therapists and speech and language pathologists, teachers and parents—need to make recommendations and decisions about treatments. How does one go about doing that? This is the main question we want to help you answer.

About the Appendices

We assume our readers have some familiarity with at least some of the approaches referred to in the case studies. We have included brief descriptions of these approaches in Appendix A.

In the following chapter, we discuss the concept of evidence-based practices within the context of treating children with autism spectrum disorders. We have tried to make this discussion of material that can fall, well, somewhere between "somewhat dry" and "dreadfully dull" relevant and practical. It may even prove to be thought provoking.