A woman, a child, and a dog are running away from the camera in a grassy field during a golden sunset. The woman is in the center, wearing a grey long-sleeved shirt and dark pants, with her hair blowing in the wind. To her left is a small child in a blue shirt and dark pants. To her right is a small dog on a leash. The background is a bright, hazy sky with the sun low on the horizon, creating a warm, golden glow.

Treatment
Planning for
Children with
Autism Spectrum
Disorders

An Individualized,
Problem-Solving
Approach

Naomi Chedd Karen Levine

TREATMENT PLANNING FOR CHILDREN WITH
AUTISM SPECTRUM DISORDERS

Praise for *Treatment Planning for Children with Autism Spectrum Disorders: An Individualized, Problem-Solving Approach*

“In the complex and challenging world of Autism Spectrum Disorders, this book offers a welcome, needed and thoroughly useful approach to planning treatment, whatever the setting, resources or problems. Chedd and Levine have managed to create a guide for educators, therapists and parents that is all at once practical and relevant, insightful and thought-provoking.”

Richard Bromfield, Ph.D.

Harvard Medical School

Author, *Embracing Asperger's: A Primer for Parents and Professionals and Doing Therapy with Children and Adolescents with Asperger Syndrome*

“After introducing best practices for intervention in autism, Chedd and Levine present vivid case studies that bring alive the concept of matching methodologies and techniques to the widely diverse needs of individuals on the autism spectrum. My highest recommendation for anyone wishing to learn more about supporting those with autism.”

Stephen M. Shore, Ed.D.

Assistant Professor of Special Education

Adelphi University

Co-author of *Autism for Dummies* and *Seven Keys to Unlock Autism: Making Miracles in the Classroom*

“Chedd and Levine make clear the foundations of Evidence Based Practice: vetting relevant research and using clinical judgment and experience to offer clients and families a range of options so that they can choose based on their own culture, values and individual needs in a true process of informed consent. In case examples Chedd and Levine demonstrate critical aspects of comprehensive assessment and the central organizing principle of ongoing reflective efforts to adjust the course of intervention. This book drives forward the effort to offer families rational choices and responsive intervention for children with Evidence Based Practices for Autism Spectrum Disorders.”

Joshua D. Feder, M.D.

Director of Research, Interdisciplinary Council on Developmental and Learning Disorders
Graduate School

“Service providers and parents of children with ASD are often overwhelmed and greatly stressed by the explosion of “treatments” for autism, and the marketing and claims of effectiveness of specific approaches. Now that declarations such as ‘Only *this* approach works for children with ASD’ are no longer considered credible, there is an urgent need to support parents and professionals with a systematic process to guide individualized treatment planning based on evidence-based practice. Levine and Chedd have taken a huge step in meeting this need in this thought-provoking book that is both rooted in years of clinical experience and in-depth knowledge of the most current research, but exceptionally practical with intriguing case vignettes. A timely and much needed resource.”

Barry M. Prizant, Ph.D., CCC-SLP

Director, Childhood Communication Services

Adjunct Professor

Center for the Study of Human Development

Brown University

Co-Author: of “The SCERTS® Model”

TREATMENT
PLANNING
FOR CHILDREN
WITH AUTISM
SPECTRUM
DISORDERS

AN INDIVIDUALIZED,
PROBLEM-SOLVING
APPROACH

NAOMI CHEDD
KAREN LEVINE




WILEY

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Cover Design: John Wiley & Sons, Inc.

Cover Images: sky image: © Andrei Radzkou/iStockphoto

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Published by John Wiley & Sons, Inc., Hoboken, New Jersey.

Published simultaneously in Canada.

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Library of Congress Cataloging-in-Publication Data:

Chedd, Naomi, 1952–

Treatment planning for children with autism spectrum disorders : an individualized, problem-solving approach/Naomi Chedd, Karen Levine.

p. cm.

Includes bibliographical references and index.

ISBN 978-0-470-88223-8 (pbk.); ISBN 978-1-118-25944-3 (ebk.);

ISBN 978-1-118-23482-2 (ebk.); ISBN 978-1-118-22106-8 (ebk.)

I. Autism in children—Treatment. I. Levine, Karen, 1959- II. Title.

RJ506.A9C4424 2013

618.92'85882—dc23

2012017191

Printed in the United States of America

10 9 8 7 6 5 4 3 2 1

DEDICATION

For Graham, Harry, Kinsey, and Adam and in memory of my mother.

—N. C.

*For David, Sue, Dan, Tim, Maureen, Seth, Kelsey,
Brendon, and Rebekah.*

—K. L.

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PREFACE

Treatment planning for children with autism spectrum disorders (ASD) requires educators and therapists to have a combination of big hearts filled with an appreciation for diverse and complex children, as well as keen and flexible minds that are able to make sense of confusing, sometimes conflicting, and ever-evolving clinical and research fields. How can this child be helped today with this problem or developmental challenge? This is the question those designing and implementing treatment plans need to answer. An approach to thinking about how to answer that question is what this book is about.

As clinicians and consultants to many families of children with autism spectrum disorders and other developmental disabilities and the schools and agencies that educate them, we have seen a broad range of interventions and combinations of interventions work in different ways for different children. Some work well for certain challenges for certain individuals at a specific point in their development, “fixing” or minimizing a problem and/or helping children learn and apply new skills, increase social interactions, form relationships, and enjoy activities that previously eluded

them. And some treatment programs, although based on copious research and planned and implemented with the greatest of skill and thoughtfulness, have been ineffective in helping with a particular challenge of a specific child. Some of the approaches we have used are well established and have a great deal of literature to back them up; others are not as widely known but are rooted in solid theory and a growing body of research. And still others are cutting edge, under investigation, or still in the formative stage. We think it is worth examining approaches in all of these categories. We have sometimes combined them in an effort to truly individualize treatment, or we have departed from a traditional program and experimented with something different, integrating it into the current program, such as an intensive early intervention program based on ABA or DIR[®]/Floortime[™] principles, in an effort to solve a specific problem that may not respond to the particular approach or that has arisen during the course of treatment.

It is our intention in this book to focus on approaches to working with children who are experiencing specific problems, rather than recommending one particular treatment model or approach, so we have described a range of problems and solutions or potential solutions. This compilation of problems is based on our experiences with children of different ages and developmental stages; extensive discussions with parents and other family members, school staff, and service providers in a variety of fields; and an ongoing analysis of our own assumptions and practices. As we work with our clients, we first ask, “What is the problem?” and “For whom is it a problem?” and then systematically work toward a solution.

Most families come to us with multiple problems or a seemingly simple problem, which upon closer examination is multifactorial and may require a very creative approach. Or the problem may not lie with the child at all but with some environmental or interpersonal factor. Along the way, we continually ask, “What and how is this child learning?” “Could this child make greater gains?”

“Would something more or something different help? Is some specific factor getting in the way of this child’s development that, if resolved, would enhance other aspects of development?” Ultimately, we ask, “Could life be better for this child and this family? And if so, what can help get us from here to there?”

Although some medical and physical problems have one clear, agreed-upon, research-supported, tried-and-true treatment, such as setting and casting a broken leg or performing the Heimlich maneuver if one is choking on a piece of food, treating children with autism and the challenges associated with it are not as clearcut because of several factors that are not present and/or do not affect the course of treatment in other conditions.

First, the diagnosis of autism includes an enormous diversity of presentations, including the presence of co-morbid diagnoses in at least 70% of children (e.g., Simonoff et al., 2008). Second, there is a range of cognitive functioning, from severely intellectually disabled to gifted, as well as uneven cognitive profiles, which may include far above-average competence in one area and far below-average functioning in another. Within the diagnostic category of autism spectrum disorders, challenges are present across a broad range of domains, including communication, social interaction, play, and behavior, and to different degrees in each category for different children.

Another factor influencing complexity in choice of treatment is that children with autism are cared for, educated, and treated in a broad range of contexts: school, home, therapeutic settings, and community organizations, and by family members and professionals with a wide range of knowledge, skills, training, and past experience. So what initially appears to be a reasonable and sound treatment approach that could be well executed in a school setting may be difficult or even impossible to carry out at home or in the community. For many approaches, the need for consistency is critical—perhaps the most critical factor—in achieving success with that treatment.

Finally, there are many treatments with differing amounts of research support for each of the challenges associated with ASD, such as anxiety, as well as a whole array of treatments developed specifically for children with ASD, with no clear agreement in the field on what the best treatment is for any specific challenge (National Research Council, 2001). All of these factors make treatment planning difficult but present new possibilities for improvement and some exciting options for enhancing the quality of life for children and their families.

Therapists, teachers, parents, and autism specialists are all working “in the trenches,” trying to use the best approach possible to achieve the best outcome for each child. By design and by chance, they sometimes come up with just the right combination of treatments that solve one or more of the problems associated with autism, and these deserve a closer look. We wrote this book, not to offer a new, different, or better type of treatment, but rather, to provide a new way of thinking about the challenges of autism and to present a systematic process for thinking about and deciding what to do to help this child and this family today, when there are many roads, many routes, many destinations, and no perfectly crafted, error-free navigation system to get you there.

We welcome your reactions and suggestions as we continue to seek new and better ways to help the children with whom we work. They and their families deserve no less.

ACKNOWLEDGMENTS

We want to thank many people who have encouraged and advised us and provided constructive and thoughtful comments. Our perspectives have evolved during the writing process, due in large part to the insights of others who have tackled this complex topic, especially Barry Prizant, Gary Mesibov, and Victoria Shea. Richard Bromfield, a true kindred spirit, has provided invaluable support and suggestions all along the way. Our thinking about the children we treat is continually inspired by the work of our colleagues, including therapists, teachers, and those we supervise. Thanks also to our editor, Rachel Livsey, for her guidance and extreme patience. And also our deepest gratitude to Peggy Alexander for her wisdom and humor, and for believing in us from the very start.

We want to thank our families for cooking (and ordering out for pizza), cleaning up, walking the dogs, chauffeuring kids to music lessons and band practice, and sitting on the first base line, cheering us on until the last out was called.

We also would like to thank the following colleagues who either reviewed the proposal or first draft of this book and provided valuable feedback: Sylvia Diehl, University of South Florida;

Michelle Aldridge, The University of Texas at Dallas; Susan Longtin, Brooklyn College; and Amy Laurent, University of Rhode Island and Emerson College. Special thanks to Josh Feder and Ruth Glynn-Owen for their encouraging and helpful comments reviewing early versions of Chapter 2 on Evidence-Based Practice.

We especially want to thank the children and families with whom we have the privilege of working, for sharing with us their challenges and triumphs, for being our best teachers, and for reminding us every day what is important.

ABOUT THE AUTHORS

Naomi Chedd, MA, LMHC, is a Licensed Mental Health Counselor specializing in working with children and adolescents with Autism Spectrum Disorders, Prader-Willi Syndrome, and other developmental disabilities and their families. She is a frequently invited speaker at local and national conferences. She also trains school-based professional and paraprofessional staff on effective practices for working with children with developmental disabilities and mental health problems.

Naomi has written numerous articles for popular and professional publications and is co-author with Karen Levine, PhD, of *Replays: Using Play to Enhance Emotional and Behavioral Development for Children with Autism Spectrum Disorders* (Jessica Kingsley, 2007). She lives in Brookline, Massachusetts, with her husband and three children.

Karen Levine, PhD, is an instructor at Harvard Medical School and a practicing psychologist in Lexington, Massachusetts. She was the co-founder and co-director of the autism program at Boston Children's Hospital in the 1990s and of the Autism Center at Cambridge Health Alliance. With Naomi Chedd, she authored *Replays: Using Play to Enhance Emotional and Behavioral Development for Children with Autism Spectrum Disorders* (Jessica Kingsley, 2007).

Karen has also authored numerous articles and book chapters. She served on the Massachusetts Governor's Autism Commission in 2011. She is the recipient of the 2010 Federation for Children with Special Needs Founders Award, and the 2000 Boston Institute for the Development of Infants and Parents Award for Excellence.

INTRODUCTION: LOOKING AT TREATMENT PLANNING THROUGH A DIFFERENT LENS

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., Reichow, 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