

Triumphs in Early Autism Treatment

Ennio Cipani, PhD, a graduate of Florida State University, is a Licensed Psychologist and a Full Professor in the Department of Special Education at National University–Fresno. He has published numerous articles, chapters, books, and instructional material (including software) in the areas of child learning and behavior management in homes and schools. Of particular note of materials relevant for families are *Punishment on Trial: A Resource Guide to Child Discipline* (2004) and an e-manual entitled *A Six-Week Parenting Manual for Child Compliance* (www.mobipocket.com). He also is the author of the 2008 publication of the *ABA Cipani Elementary Arithmetic Curriculum* (Behavior Development Solutions). He has given many workshops at state and national conventions and has been doing in-home and school-based behavioral consultation for families and school personnel since 1982. He has dealt with many families and a variety of behavior problems, conducting assessment and intervention activities in homes and classrooms.

Triumphs in Early Autism Treatment

ENNIO CIPANI, PhD
Editor

 **SPRINGER PUBLISHING COMPANY**
NEW YORK

Copyright © 2008 Springer Publishing Company, LLC

All rights reserved.

No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise, without the prior permission of Springer Publishing Company, LLC.

Springer Publishing Company, LLC
11 West 42nd Street
New York, NY 10036
www.springerpub.com

Acquisitions Editor: Philip Laughlin
Production Editor: Julia Rosen
Cover design: Mimi Flow
Composition: Apex CoVantage

08 09 10 11 12 / 5 4 3 2 1

Library of Congress Cataloging-in-Publication Data

Triumphs in early autism treatment / Ennio Cipani, editor.
p. ; cm.

Includes bibliographical references and index.

ISBN 978-0-8261-5995-3 (alk. paper)

1. Autism in children—Treatment—Case studies. I. Cipani, Ennio.
[DNLM: 1. Autistic Disorder—therapy—Case Reports. 2. Child,
Preschool—Case Reports. 3. Early Intervention (Education)—Case
Reports. 4. Treatment Outcome—Case Reports. WM 203.5 T839 2008]
RJ506.A9T78 2008
618.92'85882—dc22

2008013309

Printed in the United States of America by Bang Printing.

This book was inspired by the clinical work and effort of many behavior analysts across the country, including those who authored/coauthored these cases. They have helped many families dare to hope and dream that their child's disability would be ameliorated and possibly overcome. It is also dedicated to Dr. Ivar Lovaas, a great researcher, teacher, and clinician of our times. He gave birth to the great proliferation of early intensive, behavioral, in-home treatment programs that have produced such dramatic results. Our field is indebted to him for his lifelong pursuit of scientific knowledge.

Contents

Contributors ix

Foreword xiii

Preface xv

SECTION I: SEVEN “BEST-OUTCOME” CASES 1

- 1 Diamond in the Rough 3
Audrey Gifford
- 2 Maggie Mae 41
Audrey Gifford
- 3 Hey, Look, It’s a Train! 55
Rebecca P. F. MacDonald
- 4 Good Golly Miss Molly! 71
Audrey Gifford
- 5 The Case of Nicholas B. 89
Glen O. Sallows and Tamlynn D. Graupner
- 6 A Parent’s Story: Jake and Nick 113
**Justin Leaf, Ronald Leaf, and
Jamison Dayharsh Leaf**

**SECTION II: A HISTORICAL VIEW OF ABA ADVANCES IN
THE TREATMENT OF AUTISM 139**

7 Autism: The Early Years 141

Ennio Cipani

**8 A Study in Perseverance: The Emergence of
Early Intensive Behavioral Intervention 151**

**Tristram Smith, Daniel W. Mruzek,
and Robert T. Peyton**

Appendix A: Why Is Joint Attention Important? 171

Appendix B: Summary of Joint Attention Curriculum Sequence 173

Appendix C: Why Artie Can't Learn! 175

**Appendix D: What Do We Know About Early Intensive
Behavioral Intervention? 185**

Robert T. Peyton, Daniel W. Mruzek, and Tristram Smith

References 201

Index 205

Contributors

Audrey Gifford, MEd, BCBA, is a parent of a child who has recovered from autism. She spent many years teaching both regular education and special education. She received extensive specialized training in ABA and DTT as well as other behavioral methodologies before sitting for her BCBA certification. In 1998, she founded Bridges Behavioral Language Systems in the Sacramento, California, area to provide intensive ABA services to young children with autism. She lives in Citrus Heights, California, with her husband and the youngest three of their six children.

Bridges Behavioral Language Systems currently serves approximately 70 children in that area. Bridges is certified by the California State Department of Education as a nonpublic agency and is contracted with several local school districts to provide services to children. Bridges is vendorized under Title 17 by Alta California Regional Center to provide services. Bridges provides intensive home-based early intervention services to young children with autistic spectrum disorders.

Temple Grandin, PhD, MS, is a Professor of Animal Science at Colorado State University. She obtained her BA at Franklin Pierce College, her MS in Animal Science at Arizona State University, and her PhD in Animal Science from the University of Illinois in 1989. She has appeared on television shows such as *20/20*, *48 Hours*, *CNN Larry King Live*, *PrimeTime Live*, the *Today Show*, and many shows in other countries. She has been featured in *People Magazine*, the *New York Times*, *Forbes*, *U.S. News and World Report*, *Time Magazine*, the *New York Times Book Review*, and *Discover Magazine*. Interviews with Dr. Grandin have been broadcast on *National Public Radio*. She has also authored over 300 articles in both scientific journals and livestock periodicals on animal handling, welfare, and facility design. She is the author of *Thinking in Pictures*, *Emergence: Labeled Autistic*, and *Animals in Translation*, which was a *New York Times* best-seller.

Tamlynn D. Graupner, MS, is Cofounder and CEO of the Wisconsin Early Autism Project. She has supervised the administration of therapy programs for more than 1,000 Wisconsin children. Graupner is currently completing a doctoral program in Pediatric Neuropsychology, and holds a BS in Psychology and Behavioral Science from the University of South Florida and an MS in early childhood development—early childhood administration from the University of Nebraska. Graupner's research interests include the study of brain differences in children with autism prior to and following intensive ABA therapy.

Justin Leaf, MA, is a graduate student at the University of Kansas who has worked in the field of autism for 6 years. Justin began his career working for Dr. Ron Leaf, Dr. Jon McEachin, and Dr. Mitchell Taubman at Autism Partnership, both as a behavior therapist and as a research coordinator. His research interests center on improving social skills for children with autism, developing friendships for children with autism, and comparing different teaching strategies. He is currently a private behavioral consultant in the Kansas City and Lawrence area, as well as the Codirector of The Social Skills Group at the University of Kansas.

Ronald Leaf, PhD, is a Licensed Psychologist who has more than 35 years of experience in the field of autism. Dr. Leaf began his career working with Dr. Ivar Lovaas, under whom he received his doctorate while subsequently doing undergraduate work at UCLA. While there, he served as Clinic Supervisor, Research Psychologist, Interim Director of the Autism Project, and Lecturer. Dr. Leaf was extensively involved in several research investigations, contributed to the *Me Book*, and is a coauthor of the *Me Book Videotapes*, a series of instructional tapes for teaching autistic children. He is also the coauthor of *A Work in Progress*. Dr. Leaf is a Co-Director of Autism Partnership. He is also the Executive Director of the Behavior Therapy and Learning Center, a mental health agency that consults with parents, care providers, and school personnel.

The Autism Partnership was formed in 1994 to meet the tremendous need for comprehensive services to families with autistic children. The agency has developed a comprehensive treatment program that provides a variety of services, based upon the founders' extensive and unique experiences in providing behavioral treatment to children, adolescents, and adults. The senior staff was intimately involved in the treatment program developed at the UCLA Young Autism Project and has continued to make advances in the delivery of services to autistic children. The goal is to build on those previous efforts by adapting and refining the treatment and making it more widely available. The emphasis at the Autism Partnership is a positive and systematic approach to teaching skills and reducing behavior problems.

Jamison Dayharsh Leaf, MS, is a Licensed Marriage and Family Therapist. Leaf is the Director of the Behavior Therapy and Learning Center. She began working with children with autism in the late 1970s at UCLA on the Young Autism Project, where she served as a Senior Therapist, Research Assistant, and Teaching Assistant. Jamie has worked with Dr. Leaf and Dr. McEachin at the Young Autism Project, the Behavior Therapy and Learning Center, Straight Talk, and the Autism Partnership. She earned her Master's Degree in Counseling Psychology at Loyola Marymount University in 1983. Jamie has consulted on a national and international basis to families that have children with developmental disabilities, including children with Autism Spectrum Disorder. Jamie coauthored *A Work in Progress*, a published book on behavioral treatment. Jamie provides counseling for parents of children with ASD as well as high-functioning children with ASD.

Rebecca P. F. MacDonald, PhD, BCBA, is a Licensed Psychologist in Massachusetts and a Board Certified Behavior Analyst (BCBA) who serves as the Director of the Intensive Instructional Preschool Program for children with autism at the

New England Center for Children. She is an Adjunct Professor in the Master's in Applied Behavior Analysis (MABA) Program at Northeastern University and an Adjunct Professor in the Special Education Department at Simmons College. MacDonald received her doctorate in Developmental and Child Psychology from the University of Kansas in 1983. Dr. MacDonald began at The New England Center for Children as the Clinical Director in 1983. She then taught for 3 years in the Graduate School of Education at Simmons College in Boston (1992–1995). In 1995, she returned to the New England Center for Children in her current position. Dr. MacDonald has presented her research at numerous conferences over the past 20 years and published studies that have appeared in the *Journal of Applied Behavior Analysis*, *Research in Developmental Disabilities*, and *Behavioral Interventions*. Her research interests currently include assessment and teaching joint attention, teaching play and social reciprocity to children with autism using video modeling, and measuring clinical outcomes of early intensive behavior intervention. (The NECC Preschool Playroom [2007] is a computerized video modeling curriculum for teaching play to young children with autism. More information is available at www.neccautismplay.com)

Founded by Vincent Strully Jr. in 1975, the New England Center for Children (NECC®), which is located in Southborough, Massachusetts, provides state-of-the-art education and individualized treatment, with care and respect, for children with autism and related disabilities. As a not-for-profit treatment and education center dedicated to opening doors to bring out human potential and creating productive lives, NECC operates a school in Greater Boston and in Abu Dhabi, United Arab Emirates, for children from around the world. NECC's programs serve 230 children, primarily between the ages of 18 months and 22 years, who have been diagnosed with autism, Pervasive Developmental Disorder (PDD), and Asperger's syndrome. NECC also operates classrooms and provides consulting services to New England's public school systems, serving an additional 180 children.

In 2000, the United States Department of Education awarded NECC the National Award for Model Professional Development. NECC is the only private special education school ever to receive this award. NECC was also recognized by the Society for the Advancement of Behavior Analysis for Enduring Programmatic Contributions to Behavior Analysis in 2005. For more information, please visit www.necc.org.

Daniel W. Mruzek, PhD, is a Psychologist and Assistant Professor at the Strong Center for Developmental Disabilities at the University of Rochester Medical Center. He is Psychology Discipline Coordinator in the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program and an investigator in the University of Rochester's Center for Studies to Advance Autism Research and Treatment in a study on early, intensive behavioral intervention for children with autism.

Robert T. Peyton, PhD, BCBA, received his MA in Human Development and his PhD in Child and Developmental Psychology from the University of Kansas, Department of Human Development and Family Living. He was an intern at the Johns Hopkins Hospital, Kennedy Krieger Institute, where he completed rotations on the

inpatient neurobehavioral unit and pervasive developmental disorders clinic. His postdoctoral fellowship was at the University of Rochester Medical Center, Strong Center for Developmental Disabilities. He has been involved in research on functional analysis and antecedent-based interventions for children with autism, school-wide interventions using positive behavioral supports, the detection and treatment of dementia, and an evaluation of the drug risperidone for people with developmental disabilities.

Glen O. Sallows, PhD, is Cofounder and President of the Wisconsin Early Autism Project (WEAP). He has been working in the field of autism for more than 25 years and has supervised programs for more than 1,000 Wisconsin children. He received his doctorate in Clinical Psychology from the University of Oregon and trained with Dr. Ivar Lovaas at UCLA prior to starting WEAP in 1993 with Tamlynn D. Graupner, MS. Sallows and Graupner continue to study the effectiveness of ABA therapy and have brought this treatment to children in the United States, Great Britain, Canada, Central America, and Australia.

WEAP is a private, licensed mental health clinic with five locations in Wisconsin. WEAP provides intensive behavioral in-home treatment and a variety of other clinical services for individuals and families that are challenged by autism. WEAP is part of the international research team working directly with Dr. Ivar Lovaas of UCLA. Sallows and Graupner are the first research team worldwide to replicate the results achieved by Dr. Lovaas (*American Journal on Mental Retardation*, November 2005), showing that approximately half of children treated in the study reached best outcome and were indistinguishable from their peers after treatment.

Tristram Smith, PhD, is an Associate Professor of Pediatrics at the University of Rochester Medical Center (URMC). He serves as the Research Director for the Multisite Young Autism Project, which is a federally funded study on early, intensive behavioral intervention based on the UCLA/Lovaas model for children with autism. He is also an investigator in a study in the Center for Studies to Advance Autism Research and Treatment at the University of Rochester. He has authored or coauthored a number of the most widely cited studies on treatment outcomes for individuals with autism spectrum disorders.

Foreword

Both parents and professionals who work with young children with autism should read this book. Many hours of intensive one-to-one behavioral therapy can bring about great improvements, especially when it is started at an early age. The worst thing that can be done with an autistic 2- or 3-year-old is nothing. When I was two, I had all of the full blown symptoms of autism. By age two and a half I was in a therapy program for many hours a week. If my parents had let me sit in the corner at a young age, I probably would not be a college professor today.

Temple Grandin, author
Thinking in Pictures

Preface

What is “best-outcome” status in the realm of behavioral treatment for children with autism? The term “best outcome” was used in the now-classic treatment study published in 1987 by Dr. Ivar Lovaas of UCLA.¹ In this research study, Lovaas found that 17 of the 19 young children who received 40 hours per week of intensive behavioral treatment showed dramatic gains when compared to children who did not receive such intensive treatment. But what was perhaps even more striking were the results obtained for a subset of those 17 children. Nine of those children had progressed to such a level that they had achieved normal intellectual and educational functioning! They were considered indistinguishable from nondisabled, same-aged peers in their early elementary grade classrooms. This finding was groundbreaking! Further, their progress proved to be durable and resilient over time. A team of UCLA researchers published a 1993 follow-up study² when these same nine children were between 10 and 16 years of age. They found that these children had maintained the “best-outcome” status, that is, they were indistinguishable from same-aged peers in intellectual and educational functioning.

The term “best outcome” referred to the outcome achieved by these nine children of the 1987 and 1993 publication. The use of the term in this book represents those children who receive early intensive behavioral treatment over a period of time and progress in skill development to such a degree that they become indistinguishable from their peers in everyday life. In the seven cases portrayed in this book, you will see that these children now exist in educational or workplace environments without anyone suspecting that they were disabled with autism. Each of these children received early in-home behavioral intervention (more commonly referred to as applied

behavior analysis or ABA³) for a lengthy period of time in order to achieve such dramatic results.

ABOUT THIS BOOK

There are many books on the behavioral treatment of autism. This book is not an ABA treatment manual. This book is a longitudinal view of the intellectual and behavioral progress of seven children who were provided early intensive ABA intervention. Each case is written from the ABA professional rendering the consultation.⁴ This book presents seven cases of young children who have achieved “best-outcome” status. These children received early intensive behavioral interventions as young children and years later (in one case almost two decades later) have become indistinguishable from their same-aged peers. While there are some variations in the individualized treatment programs for these seven children, there is commonality in their adherence to the basic principles of ABA and a sincere and enduring dedication to evaluating the efficacy of any regimen or procedures on client behavior and learning. With regard to the latter, it is an essential tenet of ABA to make such evaluation an objective measurement of behavior.

WHY A BOOK ON “BEST-OUTCOME” CASES?

I believe that a book composed of clinical cases portraying best outcome from intensive ABA treatment efforts, written from the perspective of the treating ABA professionals, is needed. It can not only document the growth achieved by the children being treated but also provide some “insight” into how certain learning and behavioral problems presented by children with autism are handled effectively. The children described in this book were initially diagnosed with autism. The material presented for each case provides sufficient evidence of the particular child’s initial deficits of language, social, and adaptive skills. Additionally, the children described herein demonstrated behaviors that significantly interfered with learning at intake

for treatment. Failure to ameliorate and eventually eliminate such behaviors would spell doom to any efforts, and the authors give the reader a view of how such intractable problems are treated effectively in early behavioral intervention efforts.⁵

In addition to the seven cases presented in the first section, the second section of this book provides a historical view of behavioral treatment for children with autism. The two chapters in it demonstrate the scientific basis that forms the foundation of the ABA approach. Unlike other proposed treatments for autism, ABA has an extensive history of empirically demonstrating that its procedures and program models are effective. I included these two chapters to provide the reader with this information. While there are many claims from other professionals that a variety of psychosocial treatments “work” for children with autism, ABA has decades of proof to back up its claims.

As the reader will discover, the use of the basic principles of ABA, beginning in the 1960s, gave hope to parents who struggled to find ways to help their child become more like other children. The ABA approach also gave rise to the exposure of a terrible unfounded myth about the etiology of autism, that the parents’ psychopathology was the cause of their child’s disability.

The first chapter in the second section of the book provides a review of the early years of autism treatment. This chapter culminates in the early 1970s with a classic study published by Dr. Ivar Lovaas and colleagues at UCLA. The second chapter in Section II presents a major landmark study demonstrating that some children, called “best outcome,” who are treated with 40 hours of ABA per week at an early age can “be indistinguishable from same-aged peers” in educational and intellectual functioning. These children “lose” the symptoms of their disability for all practical respects. This groundbreaking research gave rise to the clinical application of early ABA intervention across many sites in our country, starting with the spread from southern California/Los Angeles to other parts in California (particularly the Central Valley near Stockton, Modesto, and Sacramento) and then to other states, such as Florida. There have been several follow-up studies, described in this last chapter, that have demonstrated that such results are attainable across a variety of demonstration sites.

This impressive display of the effectiveness of ABA in controlled empirical research is unmatched in the field of autism treatment.

The Appendices in this book are also noteworthy. The first two, Appendix A and Appendix B, deal with joint attention and provide both an examination of the importance of joint attention and a curriculum guide for developing joint attention in young children with autism. In Appendix C, I discuss why an intensive ABA approach works when other typical strategies do not. In the final Appendix, Tristram Smith and colleagues examine in detail the ABA early intensive research studies conducted to date.

I hope you enjoy reading the cases and the history of behavioral treatment. It is our hope that this book will instill hope in all parents that child behavior can change. But behavior change requires a carpenter with the right tools. As a fellow parent, I urge you to become the best carpenter you can be.

NOTES

1. This study (Lovaas, 1987) is reported in greater detail in chapter 8, by Tristram Smith and colleagues, in Section II of this book.
2. McEachin, Smith, & Lovaas, 1993.
3. For more information on ABA, please go to www.fabaworld.org or www.abainternational.org.
4. The first case, “Diamond in the Rough,” is authored by a Board Certified Behavior Analyst (BCBA) who is also the mother of Lisa.
5. While the overwhelming majority of the children in early ABA intensive treatment efforts improve a number of behaviors and gain skills in language, social, and pre-academic areas, only a certain percentage achieve “best-outcome” status and become indistinguishable from their same-aged peers, as in the case of the seven individuals in this book.

Seven “Best-
Outcome” Cases

SECTION
I

1

Diamond in the Rough

AUDREY GIFFORD

Graduation ceremonies mark the commencement of the next stage of the life of each graduate. For college graduates, that usually means the beginning of truly adult responsibilities. Starting a career, moving to a new city, perhaps settling down and eventually starting a family are all very real possibilities for the new graduate. It is the time for each graduate to start to mold the mark he or she will make on the world. Most graduates have an overwhelming array of options to choose from for how and where they will live and work. Last spring, my daughter Lisa (not her real name) graduated from college.

Lisa was more than ready to take on the responsibilities of adult life. She never forgets an appointment or to send in a form on time. She makes sure that everyone knows about family gatherings, even in our large family with several adult (and younger) children. She cares for her younger brother and sisters with competence and is a little overspoiling. She is frighteningly intelligent.

She worked her way through college with part-time jobs. She worked at Target for a while and also started her own side business

Audrey Gifford is both a parent of Lisa and a Board Certified Behavior Analyst.

buying and selling textbooks online and through thrift stores. This was so profitable she was able to buy herself a new (used) car while still in school. That replaced the very elderly Volvo she bought as a sophomore in college.

Lisa just started her new job—the one she really wanted, working for the State in a way that affects the environment. She has friends. She has an on-again, off-again relationship with a boyfriend, a fairly typical situation for a 22-year-old. She likes her new job and seems to get along with the people there. She is all grown up and on her own, and her younger sisters claimed her room long ago when she first left for college. And, like all mothers, I am shocked that she could possibly be so wise and grown up!

I would be proud of Lisa regardless of her history. But her success is all the more poignant, because 20 years ago she seemed to have no hope of a future like this. She was severely and (as far as anyone could predict at the time) permanently handicapped. I was told in no uncertain terms that she would never have a job, would never marry, and would live in a supported-living group home environment at best. I was told that my response to this news should be to enroll in a grief class to learn to accept the inevitable. At the time, I was very worried that she might never even be toilet trained by the time she grew up or that she would never be able to speak.

THE EARLY YEARS

I never dreamed that a child with disabilities could be born into *my* family. Those children happened to other people—saintly types like the people in books and movies, certainly not to ordinary people like me. Lisa was born 2 years after her older brother. We lived in a suburban home in a small town, and I was thrilled to have two healthy children, a boy and a girl, exactly as planned.

A few months after Lisa was born, I began to worry that something was wrong. There were eerie incidents from the very beginning. As a tiny baby, Lisa seemed to sleep an awful lot. She never cried to be taken out of her crib in the mornings. Every day after I woke up, I went into her room, saw her contentedly sitting in the

crib, and lifted her out. This was very different from the way her brother had woken up each morning. He was early, insistent, hungry, and loud! Lisa refused to sleep in our bed as a small child, something her brother wanted to do all the time. Even when her diaper had leaked and her own sheets were wet, she would leave our bed, go back to her crib, and stand there until I got up and changed her sheets. As a baby, when I put her down at night to sleep, she stayed very still. She was still in the same position I put her down when I came to get her in the morning. The covers had not moved. She was almost like a doll. She loved to be held, but only by me, and only in a certain position. She stiffened and seemed to be made of wood if held by anyone else or if I held her so that she faced me. She would happily spend all day seated (facing forward, away from me) on my lap in a rocking chair.

She was a very quiet baby. She never babbled. I did not know what her voice sounded like at all (except to cry) for many years. If given the chance, she rocked or stared into space. She stared at reflective surfaces such as mirrors and the blank television screen any time she was able to see them. (I was so frightened by this that she did not get a mirror in her bedroom until she was a teenager.) She never said “mama,” “dada,” or even that mainstay of toddlerhood—“Mine!” She seemed unaware that the rest of the world was worthy of her attention. She did not flinch at loud noises or cry when she stepped into scalding bathwater. She once stepped into bath water so warm it made her foot turn red, yet she never uttered a sound. She did not seem to be aware of what was beneath her feet. She calmly walked into a pool when she was around a year old and seemed surprised that she fell when she hit the water. A few months after that, she walked off the edge of a kitchen counter and hurt herself very badly. She put her teeth all the way through the skin beneath her lip and needed six stitches. She did not cry when she fell. She did not even cry while the six stitches were placed. Even the doctor that put in her stitches seemed a bit spooked by her apparent lack of concern. Many times I had serious doubts that she could feel pain at all. On the other hand, Lisa had frequent, very impressive tantrums about utterly ridiculous issues. She screamed inconsolably if her chair was moved from its usual spot or a little bit of ketchup was put on her plate.

Lisa did not imitate anyone else as an infant or toddler. She did not try to pretend to help with chores as other children do or try to copy her brother's play in any way. She spent her days lining dolls up on the windowsills and blocks along the edges of tables. She did not look at people, and if her head was turned toward someone she did not seem to focus. Early on I had thought she had wonderful eye contact because she seemed to stare at me when I nursed her. That changed as soon as she was weaned. She never played with any other children, including her brother. There are no pictures of her and her brother together as young children.

The potty training that had been accomplished so easily by her brother was a complete disaster for Lisa and was all the more painful because it fueled my ever-increasing suspicions. Most frightening of all, Lisa often banged her head on the nearest hard surface, including cement floors and glass patio doors. She banged her head over and over, oblivious to anything else. Some days she did this several times a day. Other days she did not do it at all.

As Lisa grew older and her behavior became more bizarre, my suspicions grew impossible to ignore. At each pediatrician visit, I considered telling the doctor about my concerns, then decided to not mention them. I was hesitant to broach the subject with him, for fear he would consider me an overanxious mother, or, worse, that he would say I was right. Her pediatrician never asked me about her language.

Lisa was interested in things, not people. She hated all foods, especially chocolate and anything that had any "mushy" texture at all. That included ketchup, pudding, whipped cream, frosting, and especially soup. She hated all the foods her brother loved. (He saw this as a positive.) She loved to walk along the fence in the backyard. We did not realize it at the time but she was engaging in what is called "self-stimulatory" behavior. She was watching the streams of sunlight through the spaces between the boards in the fence.

Once we set up a picnic in the backyard. All of the things were ready on the backyard picnic table, even some foods she was likely to at least pick at. Lisa tantrummed every time she was carried out to her highchair at the backyard table. Finally we moved the table so that it was in sight of the dining table, moved Lisa's high chair back to the

dining room, and had our picnic where I could see her through the glass doors while she ate alone in the dining room.

I found myself looking for ways to “prove” there was nothing wrong with Lisa. When she lined up the blocks, she often sorted them by colors—I told myself a child with mental retardation surely would not do that! It started to become difficult to see other young children in public—I often saw children younger and smaller than Lisa talking in the grocery store, and all I could do was look at my mute little girl and try not to cry. A younger little girl who lived down the street was playing outside one day, talking in sentences. Her mother was standing near her, and I asked, “Was that the baby talking?” The mother looked at me in surprise and said, “Well, yes, of course.” That was the first time I picked up the phone to call the doctor; after holding it for a moment, I put it back down. I was not ready yet.

When Lisa was about 18 months old, she had her regularly scheduled DPT shot. I placed her on the couch when we came home. She did not seem uncomfortable; she just did not get up to walk anywhere. This was not a problem until an hour went by. Then 2 hours, and more. By the next morning, Lisa still had not taken a step, and when we propped her up on her feet she simply fell over. We took her to the emergency room, where we were told she was simply reacting to the DPT shot. She never cried or seemed hurt. Three days after the shot, she started walking again as if the entire episode had never happened.

A friend of the family was a professional behavior analyst. He worked with handicapped children and adults. We sat on my couch one day watching Lisa bang her head on the floor. I asked him if we should be concerned about her development. He looked at me and would only say that if I was worried we should have her checked. That was another day when I picked up the phone to call the doctor. And put it back down.

One day, the neighbor with the young daughter came to visit. As usual, Lisa ran away from the front of the house when the visitors entered. As we visited, the small daughter played and talked to her mother. Lisa had, of course, rebuffed attempts to play with her. The mother was trying to get her young daughter to stop talking to the adults so much during the visit. The little girl talked incessantly, and it was hard for the mother to carry on a conversation with me. She

looked at Lisa, sitting alone with the toys I had set out for her, and remarked, “She plays so well alone!” I even managed to smile at that.

As Lisa neared her second birthday, Christmas arrived. She was 23 months old and had still never said a word or indicated she understood anything that was said to her. On Christmas morning, we opened all her presents for her. She was not interested in any of them. Later that day, a family friend came over dressed as Santa. He was very gentle and soft-spoken with Lisa, but she resisted him and finally said “Go away!” I was ecstatic! Not only had she spoken, but she had put two words together! I rounded up all the family that were there for Christmas and asked—“Did you hear her? Did you hear her?!” She did not say another word for 9 months.

But, for a little while longer, I was able to convince myself that Lisa was okay. As 1987 arrived, I was unaware of all the changes that would be made that year, both in Lisa’s life and in the lives of many children with autism. It was the year she was finally diagnosed, as well as the year that a seminal study was published that gave hope to the lives of these children and their families. All that spring I waited for her next words to come. We lived in almond country, and the almonds bloomed again, beautiful and bright in the springtime sky, but our world kept getting darker.

My suspicions continued to mount until the day I found myself becoming furious with Lisa when I told her to get in the car. Any other 2-year-old would have raced to the door, eager to go on an outing. Lisa sat on the floor, completely unresponsive to me. In disgust, I got in the car and backed into the driveway without her. When she still did not appear in the doorway, I stormed back into the house. Lisa was still sitting on the floor where I had left her, unaware and unconcerned that I had gone. By now I had become very angry and shouted at her. She did not seem to hear. I was far angrier than I should have been—after all, she had never come when called at any time before, so why should this time have been different? I was angry because at last I had to face the possibility that Lisa was not just stubborn, but that she truly could not understand what I wanted and did not care. I was terrified to call the doctor. I was embarrassed by my fears and afraid I would waste the pediatrician’s time. I was afraid I might be reprimanded for not telling the pediatrician about my fears earlier. Mostly I was afraid

I would be told I was right. Finally, that June, I made an appointment and kept it to see what was wrong with my child.

JUNE 1987 (2 YEARS, 5 MONTHS OLD)

There was a Denver Developmental Screening chart on the wall at the pediatrician's office. Lisa was not able to do any of the skills it said she should be able to perform except the motor skills. The doctor examined Lisa and talked to me about what she could do. When I said she had never spoken, he said, "You mean *never!*?" He said she was significantly delayed—at least 8 to 10 months—and referred her for a hearing exam and to see a developmental specialist.

At last my long-standing, deep-seated suspicions had been confirmed, and, perversely, I refused to believe it. I told myself (and all my friends and family) that the screening was not very thorough. I told myself that a 10-month delay for a 2-year-old child was not really significant. I was not ready to deal with this information yet. An appointment was made to have Lisa's hearing checked. In the days while we waited for the hearing test, I often stood behind her, shaking keys and banging pots and pans. She responded sometimes. Other times she did not even flinch.

Lisa sometimes went to a local nursery school for day care while I worked for a few hours, 2 times a week. One day at school, an air conditioner apparently exploded, causing a very loud noise. One of the nursery school teachers came to me when I picked Lisa up to tell me that she was looking at Lisa when the explosion occurred. Lisa did not even flinch. I began to hope it was just a hearing problem. Much later, the nursery school teacher told me that Lisa spent a great deal of her time every day hiding in a "cubby"—a locker without a door—at nursery school. After a few months, the school asked to have her "stay home and mature for while."

I fought back tears as we received the results of the hearing exam. Lisa's hearing was perfect. There were only more dire explanations left for her delays. Over the summer, I started to try to get her to say a few words. Between June and September, Lisa spoke a total of about 20 words.

SEPTEMBER 1987 (2 YEARS, 8 MONTHS OLD)

In September, Lisa was duly evaluated by Dr. Louise King at our local school district. Lisa spent most of the evaluation peeling the labels off of a box of 64 crayons. The official report noted that she could not be persuaded to perform imitative tasks. Most days she did not speak more than one or two words, if at all. The report issued later noted that exchanging a favorite object for a less favored one was “a challenge.” It noted that Lisa responded more to gestures than to verbal requests and that imitative tasks could not be elicited. The examiner had considered the Stanford-Binet IQ test but decided that the Bayley Scales of Infant Development test was a better choice because it was more manipulative, even though Lisa was old for that test. During the test Lisa could not be enticed to imitate getting a toy with a stick, imitate stirring with a spoon, or imitate a crayon stroke. She did hold a crayon, put cubes in a cup, uncover a box, and turn the pages of a book. She was unable to name objects, follow directions with a doll, point to body parts, point to pictures, hand the examiner objects, or differentiate a scribble from a stroke. Her other test results were in the normal range in gross motor area only. The psychologist refused to discuss the test results with me at the evaluation session, and an appointment was made to discuss the results.

I dressed in my most professional manner for this meeting. I hoped it would make me less likely to break down and cry. I was ready to believe that the professionals were right and that something was seriously wrong with my child. We arrived at the school early and were ushered into an empty classroom being used for storage, where we were seated on very small yellow plastic chairs. Several other professionals arrived with the psychologist. Lisa’s assessment results were explained to us in the gravest of terms. Your daughter, we were told, is seriously delayed in all areas. She will attend special schools and classes for her entire childhood. She will never read or write at more than a rudimentary “survival” level, and that only if she is very lucky. As an adult, she will probably live in a group home, though she may live semi-independently with an extensive support system if she receives intensive training. Her father asked, “Is there no hope, then?” The professionals replied that there was always hope. There was always the one in a million.

No one uttered the dreaded words “mental retardation” to us. That would come in a letter several weeks after the meeting. Their implication, however, was clear. I asked if Lisa could be autistic, because she could do very hard puzzles. They said of course not, that autism was a very rare condition. The “autistic” label would come from the doctors, but the school never did officially admit that Lisa was not mentally retarded. They insisted that she had an IQ in the high 50s and never changed that stance. When I presented my reasons to believe that she was more intelligent than that, I was treated as if my reasons were simply symptoms of denial of reality on my part. The report that came later (it was not presented at the meeting) was the first time I saw her test scores. Some were below the first percentile (see Table 1.1).

I walked out of that meeting in a daze. There was nothing to be done immediately, though I would have given the world to be told there was something I could do to help Lisa. I know I took care of the children the rest of that day and the rest of the week, but I do not remember what I did. I did not even cry that day. That began on the weekend, when I had some time to think. The worst of the grief and anger and racking sobs came then and continued to some degree for

Table 1.1

SEPTEMBER 1987 RIPON UNIFIED SCHOOL DISTRICT TEST SCORES

Bayley Scales of Infant Development

Lisa was already 2 months above the upper limit for the Bayley at the time of testing (32 months of age)

Chronological age: 32 months

Mental development estimate: 17–19 months

Vineland Adaptive Behavior Scales

(at 32 months of age)

Communication: standard 62, age equivalent 13 months

Daily living: standard 70, age equivalent 19 months

Socialization: standard 61, age equivalent 11 months

Developmental Test of Visual Motor Integration

Less than 2 years 6 months (only score given)

many years. For a while I cried openly whenever I saw a child Lisa's age (or younger) talking and playing on a playground or at the store. It was a long time before I could stand to visit friends with "normal" children Lisa's age. It seemed to be forever before I could go an hour without thinking of Lisa's problems, and longer still before her problems lost their place in the center of my life. Every morning for at least a year, I woke up having forgotten. For a few blissful moments, life was as it used to be; then I would remember and all of it would come crashing down. I called my sister almost daily, simply to cry on the phone. She listened while she worked and was a great support to me.

After the meeting, Lisa was enrolled two mornings a week in a special education class for severely handicapped children under the age of 3 with mental retardation. There were no other options presented or available. In fact, that district was unusual in that it provided services of any kind for children under 3. The school people said that the class was an "enriched environment." Lisa came from an upper-middle-class home with two college-educated parents. How could the class be more enriched than what she already had? But I was shy and did not share my concerns.

The first day Lisa went to that class, I watched through a one-way mirror. All of the children were obviously severely mentally retarded. I cried as I watched her there. I was afraid that she would never learn there. She never did anything well in groups. Sometimes I watched, and, when she did not answer fast enough, her turn was skipped. One professional told me, "Learn to feel okay if she never learns." Another school professional told me that imitation could not be taught.

There were other heartbreaking moments. On the mornings Lisa went to the special class, the small yellow bus came to pick her up. The neighborhood children called this the "tard" bus. I was horrified several times by the appearance of the bus driver. Some drivers had biker tattoos (before tattoos were fashionable) and spoke barely coherent English. One time, the bus bringing her home was very late. When the bus finally arrived, the driver presented me with a bag of cherries. The driver said she was late because she had stopped to go to the grocery store, *leaving the children on the bus in the parking lot*, on the way home. She seemed to have no problem with this idea. I resigned myself to driving the 40-minute trip each way.

On the whole, the people actually working at the school site seemed intelligent, upbeat, and cheerful. They accepted the children for what they were. They were acting in the best interests of the children to the best of their knowledge. They simply did not believe that anything could be done except palliative measures. They knew that these children were doomed to be severely handicapped for life. It was unlikely that any of them were aware yet of the seminal Lovaas study that had just been published, and even less likely that they would see that study as a reason to change their practices. (This is still a huge problem for many public schools.) Special education was the only place that welcomed these children. However, it was a permanent place for them, as well. There was no expectation that any of them would ever leave special education for a “normal” school or a normal life. It was important to me that the people who worked with Lisa believe she could learn. I felt as if I was always telling the school people that she could learn much more than they hoped for. She had great problem-solving skills, even though she could not talk.

I was the only person trying to provide any typical peers for Lisa. I felt she needed some children to learn from, because she was above the skill levels of the children in her classroom and none of them had the social skills she needed to learn. Educating children with handicaps alongside their typically developing peers was simply not done at that time. Children like Lisa were segregated from their typically developing peers at a very young age and generally never spent much time with them for the rest of their lives. They spent their childhood in special schools on segregated campuses with no typically developing children (as Lisa’s class was) and passed their adult lives in group homes and, sometimes, sheltered workshops. In these places, only the supervisors were not handicapped. It was very rare to see people with mental challenges in the larger society. You did not see them in stores, at bus stops, or at restaurants, as you do today.

So I took Lisa to a different small nursery school in our town two mornings a week to give her that exposure to typical children. I told them she was “very shy” and hoped she would be allowed to stay. Support in typical school environments using a trained aide was of course unheard of at that time. Even now there is rarely a systematic

databased reinforcement and prompting system for children in these situations, but for Lisa it was a start.

OCTOBER 20, 1987 (2 YEARS, 9 MONTHS OLD)

I loved October when I was growing up. The weather was finally tolerable, and, in a more innocent era, the days were still long enough to play a good while after supper until the streetlights came on. All the kids on our street would go to the school yard and swing as high as we could, seeing who could kick their shoes the farthest distance from the swing, and the real daredevils would even jump off. But never me—I was too much of a coward. October held all the promise of Christmas, and the tingling comfortable anticipation of the magic of that holiday. But 1987 was not a good October.

In October of 1987, Lisa was seen by a developmental pediatrician, Dr. Christel Cranston, at the Sacramento campus of the UC Davis Medical Center. This was decades before the MIND (Medical Investigation of Neurodevelopmental Disorders) Institute was founded there. Lisa's UC Davis evaluation noted very late speech, with her first word at 21 months and no other words until 27 months. She still did not imitate words, gestural games, or activities. The doctor noted that she was very good at puzzles. She displayed a preference for sameness. She still played only by herself. She sorted objects and lined them up. Her head banging was noted, as well as her staring, her not blinking when fingers were waved in front of her eyes, and her inconsistent response to sound. She had just had a battery of formal tests done by the school district, so no new testing was done, but the clinical evaluation was long and thorough.

At this visit Lisa was diagnosed with PDD-NOS (Pervasive Developmental Disorder, Not Otherwise Specified—an autistic spectrum disorder), as well as distortions in the development of basic psychological functions. At last I had a diagnosis I could agree with. Although she was now learning the names of objects, she did not use them in age-appropriate conversation. For example, if an airplane flew overhead she did not point it out to anyone and say "Airplane!" as a typical child would. She was now simply able to give the names of some objects

when she was asked to do that, but still could not use verbs in a phrase. Her learning was not fast enough to “make up” for the time that had past. She was falling further behind all the time. By now, I had started to have serious reservations that the special class was helping her develop at all, and, in fact, I was afraid that some of the things they wanted her to do (e.g., use sign language) were making her less normal.

I started keeping a journal around that time.

November 3, 1987 (2 years, 10 months old) journal entry

Yesterday I think Lisa pooped in the potty—a great step forward if she did, as she does everything else but eliminate in the potty process. I have my doubts though. I saw her pick poop up off the floor and put in the potty, then want praise. Frustrating.

Last week she put two words together! Can dress herself except shoes, some symbolic play (could be lining up) frequent tantrums when frustrated.

Haven't seen her bang her head in a while. Understands some directions but cannot tell how much comes from visual cues (When I get my purse she should get in car. When I point to garbage that means she should throw it away, etc.)

She loves cats.

Many of her words are backward tikitikat = kitty cat

Some days I hope.

What's happening to her brother?

Wish grad school was not looking so impossible right now

November 10, 1987 (2 years, 10 months old) journal entry

Says peek-a-boo ka cheeka chakoo

Inflection is right anyway.

I have taken her off Nutra-sweet—long shot but it won't hurt—very long shot. She stopped progressing around time she started stealing my soda. When I cut back, she improved. Will try. Anyway. Still NO success at toileting.

November 13, 1987 (2 years, 10 months old) journal entry

Another mystery poop in the potty but I think she dumped it out of her diaper.

She says thank you “dank oo.” She still cannot touch her nose when asked. It’s like a year was left out and she skipped all of the 2-year-old skills and started on the niceties before the basics are there.

Will she fill in the gaps?

A nurse from the state regional center suggested a Neurological Exam (EEG). I am thinking about it.

I sat for 10–20 minutes on the side of the bathtub every couple of hours waiting for Lisa to produce something while she sat on the potty for countless months. I felt as if my entire life revolved around taking her to the bathroom, and there had been no progress despite my efforts.

DECEMBER 3 AND 10, 1987 (2 YEARS, 11 MONTHS OLD)

Elsie Ratto-Joy, a speech therapist referred by Lisa’s pediatrician, attempted to do a formal speech evaluation. Lisa was not able to complete the evaluation as she was not able to attend to the tasks well enough to obtain a score. The evaluator noted that Lisa seemed oblivious to spoken directions but sometimes responded a few minutes later. She had poor eye contact and was able to attend to tasks for only about 1 minute. She again was found to have significant delays in receptive and expressive language, as well as social skills. It was also noted that, after brief “training,” Lisa could respond to “What do you want?” with two-word phrases (want...). The speech therapist used *discrete trial* techniques during the “brief training,” though at the time I was not able to recognize those. With this training, in only a few minutes she had taught Lisa something that she had not been able to learn in 3 months of special education classes.

December 18, 1987 (2 years, 11 months old) journal entry

Last month a behaviorist from the Regional Center came. She advised me to take away the diapers. Lisa finally started using the potty! She wets her pants only once every 3 or 4 days now. She is initiating sometimes and the end is in sight.

Later on I noted that the behaviorist did not tell me about ABA (applied behavior analysis). She may not have known about it at that time.

JANUARY 1988 (3 YEARS OLD)

Lisa turned 3 years old in January 1988. I went to the University of the Pacific (UOP) and asked to audit some courses in special education. I was not at all sure that Lisa was benefiting from her special class with the children with mental retardation. I wanted to know how to truly evaluate programs for her so that I could see what should be happening for her at school. I explained my circumstances to Dr. Ennio Cipani, who was the coordinator of the severely handicapped special education graduate department at UOP. He allowed me to enroll as a student in his program. I was set to start in the fall.

February 23, 1988 (3 years, 1 month old) journal entry

Lisa can name things but still has no verbs. School wants her to do sign language. I want that phased out. She can copy lines, circles, and crosses. After 6 months of special ed, these are the highlights of her language learning to date:

1. Sometimes (rarely) she will hand you an object if you name it.
2. She answered me once when I said "What do you want?" She said "Story!"

She is still so very far behind.

She continues to excel at puzzles, but everyone keeps telling me she has mental retardation and that I need to stop being in denial about that. (They did not change anything after receiving the UC Davis report.) I suppose there are worse things than having mental retardation.

I see some spontaneous speech now. Her teacher at special ed says she "spaces out" a lot there.

What happens to her when we die? Will her brother have to take care of her when we are gone? Can we do that to him? Could she maybe do a make-work job at my mom's store?

She tested at 19 months in expressive language in speech. She can do two words if they use the cards from speech.

Lisa's speech pathologist later cofounded an ABA program in the Modesto, California, area. I believe she was using discrete trial techniques with Lisa even in 1988. Certainly Lisa responded more to this approach (which we privately funded) than she did to any of the school

options. Lisa's speech therapy sessions were her only possible opportunity for discrete trial training. Speech therapy was only available to her for an hour per week. That was not intensive enough for her to make up her delays. She had not learned very much as an infant. She had to learn faster than a normal child if she was going to catch up.

APRIL 1988 (3 YEARS, 3 MONTHS) SPECIAL OLYMPICS

I understand there are children and families who benefit from participating in Special Olympics. But for Lisa and our family it was heart-breaking. Lisa's experience there illustrated some of the issues that we faced and raises questions about some of the basic assumptions that adults often seem to make about children with special needs. All the children in Lisa's class were sent to a field trip one day to participate in Special Olympics. It was assumed that all of the children would do this, and the option of declining was not discussed. All the children were taken to the site on special school buses. Once at the site, the children were taken off the bus and herded over to a group of teenagers. They had never met the teenagers before. It appeared to me that the teenagers were there for the purpose of acquiring service hours or some sort of class credit.

All of the participants were handicapped. There were no typical children there, so all the children (including Lisa) were presented as disabled children to a huge group of total strangers. While I did not doubt that Lisa had a serious disability, I was not comfortable having this fact publicized in this manner. We lived in a small community. The volunteers and other adults there who saw Lisa would know that she was a participant. I was afraid that years down the road that would reflect on whether they allowed their own children to play with her or invite her to birthday parties or they would otherwise judge her before she had a chance to prove herself.

Not surprisingly, Lisa did not like being pulled along by the wrist by a totally unknown young girl. I did not think Lisa should be pulled along by the wrist, especially because she was pulling away and crying. When I approached to take Lisa to the designated activity, the

teenager told me I was not allowed to be near Lisa. I was speechless and furious. Lisa's teacher saw that interaction and took Lisa herself to the activities.

The children were "motored through" various gymnastic types of activities. They had never done any of these things before and never would again. There was no indication that any of these preschoolers found anything rewarding about the experience. I believed that their crying was a loud and insistent indication that many of them (including Lisa) found the entire experience extremely unpleasant. Even the teacher looked embarrassed by the whole spectacle. Lisa simply panicked. It was an appalling experience all the way around. As far as I could tell, none of these 3- and 4-year-old toddlers with mental retardation had any idea what was going on. Many cried hysterically and seemed to find the entire experience an overwhelming, pointless nightmare. I took Lisa home after less than an hour.

AUGUST 1988 (3 YEARS, 7 MONTHS OLD)

In August, I started graduate school at the UOP. This was the first place I learned about the ABA therapy that has been repeatedly shown to be the most effective treatment for children with autism. In one of my classes, a videotape was shown of the "before and after" children that had been treated by Dr. Lovaas at UCLA. I was floored. These children had made huge gains.

Dr. Cipani allowed me to bring Lisa to a class that involved supervised "hands on" work with children with severe disabilities. All of the graduate students (including me) could work with her (and other children) using discrete trial training and other ABA techniques. In addition to discrete trial training, I learned about reinforcers, prompting, shaping, fading, and many more ABA techniques. The program Lisa was given seems very primitive compared to what my clients are given now, but for her it was enough. We saw huge gains, and I began to spend more and more time each day working with Lisa in this manner.

While all parents are teachers, we became language teachers and had the advantage of being able to provide an environment that

reinforced (rewarded) language attempts to communicate 24 hours per day. I remember riding in the car running pronouns over and over. We would say “Point to your door, point to my door” over and over until she was able to do this, even out of order and with other requests in between.

I noted in my journal that one day the school used a reward system, though I do not think it was based on any specific criteria or data. The reward was always chocolate. Lisa had always hated chocolate. To this day, she still hates chocolate. Even as a fledgling graduate student, I could see that trying to motivate her with something she hated was not a good idea.

Lisa spent less and less time at her special class and more time with Dr. Cipani and me. She worked alongside his typically developing young daughter, Vanessa, as well. Even though Vanessa was a year younger than Lisa, we were often asked if Lisa was the younger, because of her delayed language and small stature. That was a painful question every time I heard it. I felt Lisa looked close to “normal” when she and Vanessa worked together. These questions were a reminder of just how far she still had to go.

OCTOBER 27, 1988 (3 YEARS, 9 MONTHS OLD)

The school district was pressuring me to have Lisa spend more time in special education and no time at all with typical peers, even though I paid for that myself. We had asked our health insurance company to at least cover the costs of Lisa’s speech therapy. The insurance company said that we could be covered for speech for her only if we could prove that it was helping. They said we had to take her to the Stanford autism clinic to see if she was improving. We made an appointment for January 1989.

OCTOBER AND NOVEMBER 1988 (3 YEARS, 9 AND 10 MONTHS OLD)

At that time, we focused almost exclusively on language. Social skills were given less emphasis. Effective procedures to teach social skills

(not just placing a child in an environment with a group of peers and hoping she will pick them up) were much less sophisticated than they are now, and Lisa had social issues that lasted at least into middle school. I often wish I had known then what I know now; many of these problems could have been addressed when she was still very young.

That fall, I noted that Lisa responded for the first time with compassion to another creature. The neighbor's cat had had kittens, and Lisa petted one in particular with gentleness and love. We had never seen her care so much for anything before. We asked the neighbor if we could buy the cat. He does not know it, but he could have named any price—I would have happily paid it! We taught prepositions, nouns, verbs, colors, shapes, and letter names. That spring we discovered that Lisa had taught herself to read! She picked up a book, *Love You Forever*, at a neighbor's house and proceeded to read almost the entire book on her own.

Once we discovered that Lisa could read, Dr. Cipani added a reading component to her vocal language drills.¹ She was shown pictures with the "S" made more obvious to teach plurals. There was a period of about 6 to 9 months when Lisa read with more skill than she spoke.

Lisa was making very fast progress but was still a long way behind her typically developing peers. We took a trip to Disneyland over the Christmas holidays. Lisa became so upset at the Trip to the Moon ride that the operators had to stop the ride and let her off. Lisa and I went behind the ride and ran into a walking Mickey Mouse character. Lisa saw that and started to climb up my dress, with a new wave of terror. Mickey Mouse sat down on a bench, and we sat on the far end. He gradually and slowly reached out his hand, and after about 15 minutes she allowed him to touch the bench a few feet away from her without screaming.

As Lisa made progress with her ABA therapy, I became more critical of what she was doing in school. I insisted that keeping her in a classroom full of children with mental retardation and who had no language or social skills was not appropriate. The administrators offered what was supposed to be a class for communicatively handicapped children. Lisa attended for about a week, until I discovered that the entire class was deaf. They did not speak either.

I pulled her out of that class, and we began again searching for a better place for her. No one considered offering ABA for 40 hours per week and a typical preschool with support, as is now the standard for my clients. The ABA she received (including the discrete trial from speech) was all paid for out of our pocket.

DECEMBER 1988 (3 YEARS, 11 MONTHS OLD)

At graduate school, I was learning about autism and other disorders. Lisa went to many classes with me. She was very quiet and just sat there (she had quiet stims) during the lectures. People often told me how lucky I was that she was so well behaved. I had learned to just smile and try not to look too pained by them.

A diagnosis of autism was still rare, and there was even less consensus about its etiology than there is now. One of the older theories about the causes of autism was that children became autistic because their mothers were cold and distant—they were called “refrigerator moms.” One of the professors in one of my classes made that claim while I was present. When I argued that my oldest child did not have the disorder, in spite of the fact that I was the mother of both children, he said I must have parented Lisa differently for her to have developed the disease. That theory has now been widely discredited. At the time, I remember sitting there with tears in my eyes, more than a little shocked that anyone could tell me to my face (and in front of a class) that I had somehow been so horribly cold and distant to my own child that I had caused this.

During December, I called UCLA to see if we could get some help from Dr. Lovaas. We were told the therapy would cost \$50,000 a year, there were no openings, and we would have to move the entire family to Los Angeles. Also, Lisa was too old. Now I see my own clients not infrequently making enormous sacrifices to obtain therapy for their children. But, in 1988, I was astonished. I could not believe that such an effective therapy was not covered by our health insurance. It never occurred to us to ask the school district to provide it. Now that some districts and state regional centers provide these services, some families are able to help their children get the therapy

they need when they could not pay for it otherwise. Although many families still must make great sacrifices because their local district or regional centers refuse to pay, at least some of these entities are starting to provide what the children need. Some families are able to access ABA through health insurance, but this is even more rare, even in the face of new laws that try to force insurance companies to help these children. In December 1988, there were no public funding options for ABA at all. We had another child to consider, and if we moved, there would be no income at all. We made barely more than \$50,000 a year. We would have to find a way to do this on our own.

By this time, Lisa was working all the time. It seemed that during her every waking moment she was either in therapy or being “run” by me or one of the graduate students. Her day was filled with demands that she use language to request everything—“grunt and point” did not cut it. Once Lisa could name an item reliably, we insisted she ask with longer phrases (“Cookie, please”). When that phrase was solid, we insisted she ask with longer phrases still (“I want a cookie, please”). We learned to use specific praise (“Good talking!”) instead of vague praise (“Good job!”). We learned that the normal sequence of developing skills is not written in stone. Lisa could identify every letter in the alphabet before she could differentiate between “yours” and “mine.” She could read before she could use the past tense. She put together 100-piece puzzles before she could speak at all. We had to work with the skills she had to give her the ones she did not have. There was no “cookbook” or other prewritten manual to use, as simply mimicking the usual developmental learning sequence was not always appropriate for her. The only time she was not held to these standards was the two mornings a week she went to the special class the district provided.

Christmas day 1988 (3 years, 11 months old) journal entry

(evening of Christmas day) This year Lisa was finally able to open presents. She responded to some of the excitement of Christmas for the first time. She’s still afraid of Santa Claus but she was better today. She spent a lot of the time running around in circles, stimming in mirrors, but at least she was excited and happy at Christmas instead of overwhelmed and scared.

JANUARY 17, 1989 (ALMOST 4 YEARS OLD)

January 17 was the day of the Stockton, CA schoolyard massacre. If the Stanford appointment had not happened that day, Lisa would have gone to a speech appointment on the block where the massacre occurred, and at the same time. She was examined by Dr. Bryna Seigal and Dr. Roland Ciaranello. They noted diminished social referencing and said that she had just started to observe the play of other children. At this time she could play one interactive game with her brother. She did not show interest in her peers. By this time, she could greet the children who came to our house but then left them to play alone in her room. It was noted she could complete 40- to 80-piece puzzles. Some perseverative topics were also noted—day and night, sun and moon, and animal noises. Echolalia was noted. There was no spontaneous imitation of language, and she had poor topic maintenance. There was no turn taking. Her eye contact was poor and was even worse in interactive situations. She was still reversing pronouns and referred to herself in the third person. She lacked social responsiveness and social referencing. Some overly concrete imitation was noted—Lisa included an unnecessary gesture to reach the goal. It was observed that she solved puzzles by content (not just by shape). The doctors said this indicated higher level cognitive processing than is usually seen in an autistic child at this performance mental age.

The doctors' report expressed concerns about Lisa being in a special education class because all they taught were adaptive skills; academic skills were not addressed. I was continuing to work on academics as well as language, and at the regular preschool she attended three afternoons a week she was at least exposed to colors, letters, and numbers in a group setting. On Lisa's Merrill Palmer testing, her score was 76 overall (4½-year level), but her verbal IQ was very delayed—at the 2½-year level.

The Stanford evaluation concluded that at the age of 2½, Lisa met the full criteria for autistic disorder. At that time, she showed a lack of awareness of others, abnormal comfort seeking, impaired initiation, abnormal nonverbal communication, absence of imaginative activity, abnormal prosody, abnormal speech, stereotyped body movements, and restricted range of interests. The doctors felt that

she had improved since she was 2, and at the time of this evaluation she was diagnosed as PDD-NOS—part of the autism spectrum.

I was elated—at last someone official agreed that she was not mentally retarded! The school, however, ignored the recommendation. The special education teacher told me, “No one wants their kid to be the highest functioning one in the class.”

FEBRUARY 1989 (4 YEARS, 1 MONTH OLD)

Lisa came down with chicken pox while we were visiting her grandparents. She ran a high fever and developed the hallmark spots. Chickenpox was a very common disease at that time and was not considered serious in children. But Lisa was affected in very serious ways. She lost all the skills she had so recently developed. She became mute and unresponsive, lost her toilet training, and reverted to simply stimming all day. She started banging her head again, over and over. She remained like this even when the fever and spots had started to subside. I took her to the emergency room, and the doctors did not understand why I was panicked. A week after the spots had subsided, Lisa began to regain the skills she had lost, except for toilet training. It was many years before she could run a fever without throwing me into a complete panic.

Two months later, the doctor found chicken pox scars on Lisa's urethra. Lisa did not yet have the language to tell me it hurt. She had a minor surgical operation to correct this and regained her toileting skills after that.

SPRING 1989 (4 YEARS, 2 MONTHS OLD)

We had given the special ed classroom with the children with mental retardation another try, but again I took Lisa out of that class. She was gaining speech by leaps and bounds, and I did not think she was gaining it in that class. She was far beyond the other kids, who also had no social skills. I had been told there was an option in Escalon, a nearby town, where the children were taught language and did not

have mental retardation. After some argument with the district, the change was permitted, and she was allowed to switch to the new class. I had great hopes that at last she would be taught something at school that she did not already know. She had long since surpassed the level of the classes the district had offered her before. They kept insisting she had mental retardation. I felt my objections to what they were offering were interpreted as still more denial on my part.

The “individualization” the district claimed to be present in the classroom had consisted of minor and inconsequential changes inconsistently applied—one child might be given a different crayon or more help with a particular task, but all the children completed the same tasks every day. Most days I did not see even this level of individualization. All the children participated in the same group activities every day. “One-on-one” time was nonexistent.

Special education was a place children never left. Once placed, a child was doomed to be in special classes forever, until she “graduated” to special adult services and group homes. Regular education preschool was never provided by the district. Of course, neither was the ABA. Lisa’s weekly schedule included two to three mornings of regular preschool, two mornings of special class, and graduate school (which Lisa often attended—she was given ABA there) with me three nights a week, as well as all day, every day, running drills in the car, at home, whenever and wherever she was, more or less constantly. We had nowhere near the sophistication we have now, but we had (barely) enough.

April 15, 1989 (4 years, 3 months) journal entry

Easter Sunday

She has come such a long way!

Just came back from [the friend who saw her banging her head when she was very young]. He says he never told me about Lisa because he knew she had autism and was scared to tell me. Lisa has not been tested for a while. I hope to put her in regular kindergarten. I am afraid the school will say she cannot because she still officially has mental retardation. I think she will need a new IQ test to get them to let her in.

Some days I think she seems pretty close to normal, except that she tends to persevere on favored topics for months.

And there are other things:

She will not go to Christy's [the neighbor child's] house to play when I try to take her.

She has never been invited to a birthday party. No one in special ed invites kids to birthdays. And of course the regular ed kids would never invite her.

Six months ago [a mom of one of Lisa's brother's friends] casually mentioned that her son would have a big party and of course she would invite Lisa. I looked forward to that for months, but the invitation never came. I am sure that mom never knew why I was so frosty to her after that.

Other kids consider her babyish. They tolerate her and baby her. They do not invite her to their parties, though.

Lisa can sing lots of songs now. She can play interactive games with me. We've worked on that a lot.

She is still not good at picking up on subtle social cues—she only realizes kids are mad at her if they hit her.² She is always asking, "Is that silly?" She cannot tell without help. She still won't eat anything mushy except what has been run in trials.

JUNE 1989 (4 YEARS, 5 MONTHS)

Lisa's speech was tested again. Her one-word vocabulary was pretty good—she actually was in the average range! After so many scores that had been below the first percentile, that 53rd percentile looked like heaven! On another test (the SPELT-PRE), she was still below the first percentile. She had no plural nouns, present progressives, pronouns, past tense, linking verbs, present tense, or irregular past tense. Her receptive language was characterized by syntactic defects as well as pragmatic deficits. She was unable to track the referent in a sentence and did not shift to the conversational partner's model. She also had articulation issues. She was only 60% understandable in conversational speech (see Table 1.2).

September 1989 (4 years, 8 months) journal entry

Lisa can put 2–3 word sentences together and can put longer ones together if she is motivated. She refers to herself as Lisa but will say

Table 1.2

**JUNE 1989—TEST SCORES, MODESTO, CALIFORNIA
(TEST ADMINISTERED BY SPEECH PATHOLOGIST)**

Chronological age, 4 years, 4 months (52 months)

EOWPVT (Expressive One Word Picture Vocabulary Test)

Raw score: 47
 Language age: 4 years, 7 months
 Standard score: 101 (53rd percentile)

(SICD) Sequenced Inventory of Communication Development

Overall receptive communication age: 44 months

RECEPTIVE

<i>Language age in months</i>	<i>Items correct</i>	<i>Items incorrect</i>
40	84%	Directions involving plurals
44	89%	Identifying coins
48	67%	Speech/sound discrimination
48 +	50%	3-step commands

Overall expressive communication age: 40 months

EXPRESSIVE

<i>Language age in months</i>	<i>Items correct</i>	<i>Items incorrect</i>
36	75%	Regular plurals
40	70%	If-what questions
44	75%	Response to “how” questions
48	62%	Repetition of digits and words, using “how” questions
48 +	56%	Use of conjunctions serially

SPELT (Structured Photographic Expressive Language Test–Pre)

Raw score: 10 (below first percentile)

No use of or improper use of plural nouns, present progressives, pronouns, past tense, copula, present tense, or irregular past tense. Expressive language was characterized by syntactic defects as well as pragmatic deficits. Lisa was unable to track the referent in a sentence. She did not shift from the conversational partner’s model to an appropriate response. For example, if the examiner’s model was a plural pronoun and her response required a singular pronoun, she was unable to make that shift even though she used singular pronouns in her spontaneous speech.

Compton Phonological Assessment of Children

Lisa was 60% intelligible (understandable) in conversational speech. She was 75% intelligible with contextual cues.

“I” for “I want.” She reverses pronouns. She says things like hurt “me-self.” She can do a lot with visual cues. She understands what, where, and possibly who questions. She knows all her body parts. She needs 10–20 seconds to process things sometimes and will often say “uh” to give herself time to think. She rarely repeats questions you ask her. She knows all colors and shapes. She can count to 12, and sometimes to 15. She recognizes most numbers but gets 6 and 9 mixed up. She is so good at puzzles! I don’t know if she understands same or different, but she has been able to match for a long time.

She will not initiate conversation with anyone but me. She will not defend her place in line and gets overwhelmed in crowds and withdraws. She understands taking turns but rarely plays interactively. She will now display affection to a crying child.

She holds her crayons in a funny way.

She can cut with scissors but holds the scissors oddly as well.*

Can copy a +, 0, sometimes triangle, and once drew an A, but that may have been luck. She can make a face but has to be prompted or she’ll color it in until it is unrecognizable.

She can eat independently but takes apart her sandwiches. She sometimes goes around the house frantically saying “go potty” until someone walks in the bathroom doorway with her. Other than that she is potty trained.

She dresses herself except for tying shoes, but she tends to dawdle. She does not like to wash her hands.

October 1989 (4 years, 9 months) journal entry

Saturday night Lisa put several sentences together for a questionable purpose—to throw a neighbor child out of the house. She did not touch her physically. I heard her say “girl out of my house, out of my house!” Lisa kept crying and would not talk about it—I was thrilled at all those words, if not the intent. I never did find out if it was justified. We have to do something about her social skills. . . .

*In 2007, Lisa related this story about her thoughts during her educational program in 1989:

Bizarre—another memory—must have been September or October 1989—the rest of my special ed class was putting artwork together with precut leaves while I was cutting the leaves, but then I was cutting them too slowly so they gave me the precut leaves. I think it was the end of the day or something.

Thanksgiving 1989 (4 years, 10 months) journal entry

I have volunteered to be a Campfire leader (in all my copious spare time) so that I can get other kids to play with her. Also, they let boys join as well, so I have a way for her brother to actually get to spend some time with me, as well.

There was a problem at the special school. The teacher I had originally placed Lisa with had gone on maternity leave (twins) and they had a new person in there. I watched the new substitute teacher in the class. She did not let Lisa have the time she needed to answer the questions she asked. She did not call on her when she finally did raise her hand—that was a difficult skill Lisa had been working on a long time with us at home. She ignored her attempts to communicate. I did not talk to the teacher at all while I observed or afterward. Later that week the principal called and said I could not go into the class because I made the teacher nervous. She was afraid I would intimidate the substitute teacher. Once again, I pulled Lisa out of special ed. She was getting more from what I was doing with her anyway.

She is finally able to say something she wants for Christmas! She says she wants an elephant!³

April 19, 1990 (5 years, 3 months) journal entry

I wonder if she dreams. Her father says he has seen her eyes move when she sleeps. She did not understand when we asked her if she dreams. She cannot describe them.

She cannot follow a TV plot. It is hard to even get her to watch something for more than 1–2 minutes in the first place.

It occurs to me that she can finally sleep aligned with the bed. She always slept in whatever position she found herself—horizontal, diagonal, whatever position she first lay down. Her covers are actually messed up now in the morning!

A friend said to me last weekend that when her son was put in regular ed he was way above average in academics but fell apart without one-to-one teaching. Now he is back in resource. Depressing, but I appreciate the warning.

April 26, 1990 (5 years, 3 months) journal entry

She is doing a lot better in her regular ed class than anywhere else except the one-on-one. Today a minibus came by to take her out of her regular preschool class to go to Special Olympics. Luckily I showed up

as the bus got there, so she did not get on. The regular ed school had no idea why the bus wanted her, but they thought they had to let her go with them.

After all our efforts to get her to function in a normal environment, they would take her back! I am still furious!

May 25, 1990 (5 years, 4 months) journal entry

Lisa was taken for a follow-up visit to Stanford. Dr. Seigal saw no need for further special education except possibly in speech and language. We cried in the car a little. This was just as shocking as when she was first diagnosed. She is still perseverating, still wets her pants every week or two, still stims off mirrors, still won't eat mushy food, but at least one person thinks she is pretty close to normal!

Her reading is very good—better than her brother's at this age. She still has some mild hand stims—licking hand and blowing spit bubbles. She has a few minor eye stims as well.

Current perseverative topic: clothing sizes.

Dr. Siegel says watch for learning disabilities.

Lisa licked the closet mirrors right after we got home.

Oh well.

This July we go back to Maine to see my grandparents. Dr. Seigal says Lisa now responds to the outside world without contrived reinforcement and that she is past the threshold where she could still regress.⁴ I sure hope she is right. I'm scared of being disappointed again. It will probably be a while before I dare consider her out of the woods.

JUNE 1990 (5 YEARS, 5 MONTHS)

Dr. Cipani did a new IQ test on Lisa that spring. I had asked him to do that so that we could get the district to allow her to attend a regular kindergarten. The district had already shown that it would ignore anything from the Stanford autism clinic in favor of its own tests. He tested her on the verbal portion only because that was her weakest area. In that test she obtained a score of 120.

August 24, 1990 (5 years, 7 months) journal entry

Today the baby-sitter called me at work. Lisa threw up in the Mervyn's parking lot—went white as a sheet and looked like she'd faint. She had

seemed fine before. Lisa stopped talking and would not let anyone touch her. No fever or headbanging or stiffening up. By that evening she was fine, though it was very scary when she would not let anyone touch her. She even ate soup!

August 1990 (5 years, 7 months) notes to present for IEP to enter kindergarten

Skills I wanted her to learn:

How to deal with the cafeteria and not let every child get in front of her. Her local public school offered kindergarten classes for the full school day.

How to compete with other kids for teacher attention in regular ed.

Specific incentives (reinforcement) for her to interact with other kids in games, taking turns, and so on.

Let her academics grow—teach them that she can excel at something—she spent so long testing below the first percentile that I have become a little nuts about proving that she does not have mental retardation. She is far above the academic level of her class—please teach her something new.

Please make sure she plays with kids outside at recess.

Please insist on her using full sentences, and please and thank you; she still has lots of reversed pronouns and problems with plurals.

Please do not look at her and say “uh huh” when you don’t understand. After you do this, she quits talking.

As far as I know, none of those suggestions were ever implemented, but Lisa was allowed to attend regular education kindergarten with the teacher who had taught her brother. She was exited out of special education as she no longer showed enough delays to be eligible for it. It was almost the end of the greatest challenges for her.

September 13, 1990 (5 years, 9 months old) journal entry

[After a few weeks of kindergarten] I finally called her teacher today to see how she is doing. She says she was very pleased with Lisa. She was surprised she did not play much with the classmates she knew from down the street but has other friends. She participates and follows through directions and plays interactively in the classroom. She is not playing

with other kids on the playground. She stays by herself at recess. No one seems to feel any need to prompt her or anyone else to play together.
She does not seem to need the one-on-one from me anymore.

JANUARY 1991 (SIXTH BIRTHDAY)

Lisa was exited from the Valley Mountain Regional Center system as she was no longer eligible for services. The social worker told me she was going to look up exactly how to do that as it had never happened to any of her clients before.

April 13, 1991 (6 years, 2 months old) journal entry

Lisa was tested on the Woodcock Johnson last week. She is reading at the third-grade level (3.0), and her math is at second-grade level (2.0).

Not bad for a kindergarten child with mental retardation!

She is no longer as shy at school. She even plays with kids on playground.

When I asked about her past, she says, "I had extra help learning to talk because my brain did not work right. I used to be scared all the time." I said, "Why didn't you like hugs?" She said, "I didn't?" I shook my head no.

Lisa said, "No wonder I was scared all the time!"

JUNE 1991 (6 YEARS, 4 MONTHS)

Kindergarten graduation was a new phenomenon at that time. Lisa's brother had not done anything like it, so I had no idea how important it was. I had not planned to attend (it was at 10 A.M. on a work day), but once I got to work and told the other people there what was going on, they told me it was something I definitely did not want to miss.

So I arrived as the ceremony started. The children sang some songs and recited a few poems. The teacher made a little speech, and at the end the children all distributed pink carnations to their mothers. Lisa was indistinguishable from her peers, and as she handed me the flower I found myself crying.

It was a landmark day.

SEPTEMBER 1991 (6 YEARS OLD)

Lisa started first grade with all her classmates. She had not had an IEP for a year at that point. Her teacher did not talk to me much, but after a month I discovered that Lisa had been placed in the lowest reading group. She was placed in the lowest group for all the subjects that had groups. When I asked her teacher why, she did not give me an answer. Lisa's friend from Campfire told me that her teacher treated Lisa like she was stupid. That was the last year Lisa attended a public school.

AUGUST 1992 (7 YEARS OLD)

We moved to Lodi over the summer, and I enrolled Lisa in a private school. No one there knew of her history, and I was determined to make sure that they never did. I was convinced that her entire first-grade year had been wasted because the teacher had assumed she was still handicapped. I knew that these lowered expectations not only denied Lisa the chance to learn at an appropriate level but that they could start to convince Lisa herself that she could not learn. I needed her in an environment where she was not prejudged because of all the paperwork in her school files.

The new school asked for her "cum" folder. This was the cumulative folder that schools keep with the records on all children. Usually a child in second grade would have only a few report cards and perhaps an immunization record. Lisa's "cum" file was enormous. It was full of all of her special education files, including the ones the district ignored from Stanford. "Cum" files were available to teachers as a matter of course.

So when I asked for the "cum" file to give to the new school, I said I would hand-deliver it. On the way to the new school, I edited the file. All of the references to special education were taken out and filed at my house. The new school did not know about Lisa's history for 4 years, and then only in sixth grade, when she had a seizure in the classroom. By then, of course, she had long since proven herself to be an excellent student.

Lisa was very quiet at the beginning of the second-grade year in her new private school. The teacher considered her shy, but not out of the ordinary range. And in this school, without her history following her, she was invited to birthday parties, and children actually came to hers!

THIRD GRADE (8 YEARS OLD)

By third grade, Lisa had bloomed. She had a few real friends. A little girl from France was a favorite—perhaps they both knew what it was like to be in a foreign world. She liked to play teacher, and her classroom teacher encouraged this. Lisa still struggled with minor social issues, but she was getting better. None of her teachers noted any difficulties. Lisa did not tell me about her problems with kids at school until many years later. Lisa gradually improved her social skills throughout her school years.

SUMMER 1995 (10 YEARS OLD)

Around fifth grade, Lisa was part of a project done by the local FEAT (Families for Early Autism Treatment) group to show what children with autism could achieve. She was one of a group of children in a swimming pool who spoke to the interviewer. The point of the tape was to show that she was not distinguishable from her peers. Lisa and some friends all happily participated—they did not need any excuse to get into a pool!

JUNIOR HIGH

In junior high, Lisa had the usual troubles of an adolescent. She was socially awkward and needed to learn to use vocabulary that was “dumbed down” for an audience of her peers. At the time, I attributed that to her extreme intelligence, rather than to her history of autism, but of course the autism could have been at least a contributing

factor. She seemed to be involved in at least some unauthorized “toilet papering” of neighborhood trees. I was never sure exactly what happened there, but I hoped it was at least a social event. She once said she did not know how to carry on a conversation on the phone for hours on end, the way many of her peers did. I still do not have that skill either. . . .

HIGH SCHOOL

Lisa’s high school years were a time of great social and academic growth. She was in a wonderful all-girls’ school. She was welcomed and made true friends—at least one of whom she still sees. She had her first romance. No one at the high school was aware of her history, until one incident when she was hurt by a horse and had to see the school counselor, and another time when a cover letter from a special education packet from her preschool years mysteriously appeared in her high school file.

She finally was given a mirror for her room.

In her senior year (2002–2003) Lisa faced the stresses all the seniors face about college. She had excellent grades and SAT scores—710 verbal, 720 math. She received many high school honors, including graduating summa cum laude and being a National Honor Society member and a California Scholarship Federation member for life. She was also the recipient of the Bank of America Science award. She had done a great deal of volunteer work with the homeless in soup kitchens and had helped me with my work with children with autism, as well. She applied to some very prestigious universities. None of them knew of her history. She was accepted to all of them except MIT, but even there she was interviewed. Among the schools that accepted her were UC Berkeley’s College of Chemistry and Harvey Mudd. She chose Berkeley.

Lisa’s high school graduation was a very formal affair. It took place at Memorial Auditorium in Sacramento. Each of the girls wore a long white gown and carried a red rose. The honors for each girl were listed both in the program and as she was walking to the podium. I knew that this ceremony would be an emotional milestone, so I thought

I could adequately prepare myself. It had been a great many years since I had thought of Lisa as a handicapped person, but milestones like this were always a reminder of just how far she had come, and how close she had come to a lifetime of being handicapped.

But, despite my best efforts, I still cried at Lisa's graduation. From the time she was first diagnosed until the time she went to kindergarten, I had been convinced this day would never arrive and that we would have only the dreary prospect of a sheltered workshop or supported living services to look forward to at this time.

COLLEGE YEARS

Lisa transferred from Berkeley after her freshman year and completed her degree at Sacramento State University. She did well at Sacramento State and graduated cum laude with honors from there, as well. In May 2006, she took the Graduate Record Exam (GRE) and obtained the following scores (200–800 scale): 690 verbal (96th percentile for GRE takers), 790 quantitative (90th percentile for GRE takers). She also scored 5.0 on a 1–6 scale in analytical writing. Her degree is in economics with a math minor. She had come a very long way from those endless scores below the first percentile.

During Lisa's college years, she wrote a letter to Dr. Cipani. She has agreed to allow me to share it:

From Lisa to Dr. Cipani

I'd like to thank you for helping me learn how to interact with the world. I was isolated and I became a part of the world. I learned how to play tag, annoy my brother, and ask for things. I later learned how to stand up for myself and figure out whether someone's likely to be lying. Now I am in college. I can always say I wished I'd learned the social stuff earlier rather than painfully later on, but you did the best you could and you knew how to enter my world. You didn't view me as some hopeless, worthless child unworthy of the help you knew I needed. You didn't assume that just because I did not learn to communicate through normal means, I was incapable of learning how to communicate, laugh, cry, love, work, and play.

Through your skill and patience, you helped me escape from the prison my mind had created. When I was incapable of communication, I could not learn about or understand other people. I suspect that most people did not understand me much better than I understood them. My world was probably just as foreign to them as yours was to me, especially back when few knew what autism was. By entering my world in ways I could understand, you helped guide me into the mainstream world, which has given me a chance to control my own destiny. I still haven't figured out what my goals in life are, but hopefully I'll figure that out. Even if I don't achieve all of my goals, I will have had a chance, which is all that anyone can ask for. It is more than I would have had without your intervention.

SPRING 2007

When I was approached about this book project, I was asked if Lisa would contribute some of her thoughts. The following is from Lisa.

I don't remember much from before I could talk. The memories I do have are brief and disconnected from one another. I remember focusing intently on an object, such as a crayon or a piece of wire (you know Mom, those twisties you use for the garbage) and being able to focus intently on that item, to the exclusion of everything else. I remember thinking that people could read my mind, thinking that they knew exactly what I wanted. I can even remember hearing and understanding some words but not understanding that they were an attempt to communicate. Hearing a sound from an air conditioning vent means the air conditioner is on, but it does not mean the air conditioner wants to engage me socially. It was not that I did not care about what they said, but rather that I did not know that they were trying to say anything to me. I vaguely recall interpreting human words, from family and teachers alike, in a similar manner.

Due to ABA, I developed the language skills to speak and listen. With that foundation, I quickly developed the academic skills necessary to function in a regular school environment and more gradually developed the social and emotional coping skills needed to be a well-adjusted person. From 7th to 12th grade in particular, thanks in great part to peer and teacher support from the parochial schools I attended, I greatly im-

proved my self-confidence and social skills. I have been working in a variety of part-time jobs since I graduated from high school, jobs ranging from cashier to tutor to online seller. I am about to graduate from college with an economics major and mathematics minor. I am still figuring out what I want to do with my life. There was a time when job interviews terrified me, but I have gradually improved my skill in that and other areas, and I know that I am not the only person who has ever been nervous at a job interview.

I have several friends, a couple of whom I talk to on a near-daily basis. I am thinking of either entering the workforce or joining AmeriCorps and then going on to graduate school. I consider myself a nerd because I like computer games and am in my campus math club, but not in a negative context. Am I still autistic? It depends how you define autism. By the time I was 5 years old, I no longer met the diagnostic criteria for autism or PDD. I was an odd child, but as I later improved my social skills and found peers whose interests aligned with mine, I grew into a well-adjusted adolescent and adult. Whatever physical issues caused the autism are still there, and I do still have to manage occasional bouts with insomnia. More important however, is the fact that I am generally well adjusted to my environment. My life is profoundly better than it would have been if I had not received effective intervention.

Lisa _____

NOTES

1. The use of text to teach vocal language when appropriate has been incorporated into many of our programs for several years now and is starting to appear more often in the peer-reviewed literature. At this time, however, it was fairly experimental.
2. The teaching of how to respond to social cues was still many years in the future for ABA programming.
3. I combed through many stores that fall and finally found a toy elephant—we still have it.
4. Today the criteria for autism are measured with standardized tests, such as the ADOS, that had not been developed at that time. Had these been available then, I would not have considered Lisa's symptoms to have diminished to the point where she could be considered no longer handicapped. The social skills deficits were not seen as all that important in that era. While I do not believe that Lisa now meets any of the criteria for being handicapped, I also believe that she would have been considered as no longer meeting the criteria for any autistic spectrum disorder before the age of 6 or 7.