

Preface

We have been involved in the area of intellectual disabilities in one way or another for our entire careers. Between us, we have worked directly with individuals with intellectual disabilities, directed programs delivering behavioral services to these individuals, trained and supervised staff to provide services, assisted states in developing their service delivery systems, taught undergraduate and graduate students in the field of applied behavior analysis (ABA), helped to develop ABA professional credentials, conducted and published applied research focusing on both clinical and service delivery issues, and served on countless committees and task forces devoted to improving services to this population.

Throughout all of these activities, we have often found ourselves frustrated with the gap between what is possible and the daily reality in the delivery of behavioral services to individuals with intellectual disabilities. We know what state-of-the-art behavioral services look like and what they can do for people who face significant impairments in their ability to learn. We know what is possible under the best of circumstances, and even with our background we find it truly impressive. To those who are not trained in our field, really sophisticated behavioral services must sometimes look like magic. They can transform lives, often with what might appear to be remarkably little effort, given the challenges with which many caregivers have often long struggled.

With this kind of potential, we find it sad—and sometimes tragic—that this level of behavioral services is often not available when it is needed. The daily reality is that families, staff, and even professionals in other fields frequently do not have a good understanding of what behavioral services to ask for—to insist on—or how to distinguish inadequate efforts from genuinely good services. There are so many barriers to obtaining good behavioral services that knowing exactly what one is looking for can bring its own frustrations. Compared to what is possible, even accepting practical limitations, the quality of behavioral services typically available is often too weak and ineffective.

From our perspective, it is like being a physician trying to help provide medical services in a third world country. You look around and see so many medical problems that you know how to treat, if only the country had a good medical system, adequate funding, skilled medical personnel, the necessary equipment and medicines, and so on. Meanwhile, you see people suffering and leading lives diminished by poor health.

This book is an effort to help those who care for individuals with intellectual disabilities minimize the shortfall between the behavioral services these individuals need and those that they receive. These chapters are a guide to the behavioral aspects of intellectual disabilities, why behavioral services are needed, what makes good behavioral services, and how to obtain them. We want caregivers to know what services to ask for, how to be sure they are getting what they need, and what to do if they are not satisfied.

Our definition of behavioral services is comprehensive. A person's behavior includes everything they do, and individuals with intellectual disabilities sometimes do things that raise concerns for families and caregivers. These behaviors are typically described as challenging, a euphemism for behavior that causes problems for the individual and others. Although the phrase "behavioral services" includes interventions that address such problems, these services also address what is usually a far more significant challenge—learning to do the many things required to live as independent and fulfilling a life as possible. This focus of behavioral services is more easily unappreciated than efforts to resolve problems, but the professionals who are trained to provide these services know better.

We have developed this book for families, agency staff, and professionals in other fields, rather than for our students or colleagues. We have not assumed that readers have any particular background in this area, and we have tried to avoid getting too technical. The chapters cover the full range of topics families and others ought to know about to understand the diverse behavioral issues that are often a part of intellectual disabilities and to find the professional assistance needed by the person they are caring for. The chapters begin by providing basic information about intellectual disabilities and end with an overview of how services are organized, delivered, and funded in the United States. In-between, they cover just about all of the features that make up good behavioral services. We have tried to treat these topics at a "just right" level of detail—not so little as to be unhelpful, but not so much that it gets hard to read. For any one reader, a chapter may go too far or not far enough, but the book will at least identify the professionals who can offer more personalized guidance.

The chapter authors deserve a lot of credit for accepting our mandate to write not for their usual professional readership, but for a broad range of caregivers who are primarily interested in information that can help them navigate unfamiliar topics and a complicated service delivery system. The authors graciously tolerated our editorial efforts to blend their writing into a relatively consistent level and style.

They share with us long careers in this area, as well as our concern with helping families and other caregivers get access to the quality of behavioral services that will make a meaningful difference in the lives of the individuals they care for.

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Chapter 1

Penny's Promise

James M. Johnston

PROLOGUE

This chapter tells the true story of a young lady—I will call her Penny—and those who worked with her. This report is closely based on the doctoral dissertation of the student who directed her training program. Because this document includes personal details that are not appropriate to reveal, this reference is not included. Penny's father gave permission some years ago for this story to be told.

Penny's circumstances in her early years should be understood in the context of how intellectual disabilities were addressed by pediatricians, state institutions or developmental centers, and caregivers in the middle of the last century. Although her placement in a state institution as an infant and the lack of systematic services offered there might seem shameful and even inhumane by today's standards, this is where matters were back then. Everyone involved with her was doing the best that they knew to do for a child with her characteristics. Much has changed since then, though not enough.

It is also important to appreciate that the extent of Penny's difficulties in learning does not represent all individuals with intellectual disabilities. As Chapter 2 will explain, less than 10 percent of this population is profoundly disabled. Most are able to learn much more—and much more quickly—than Penny, especially when services are available from infancy onward. As if to make up for her disadvantages, for a time Penny was at least given access to unusually intensive, evidence-based

teaching services. Even today, it can be difficult to arrange for this type of explicit training for hours and hours seven days a week, as was provided for her.

The treatment model Penny was offered is called Applied Behavior Analysis or ABA. Chapter 6, among others, describes and explains it in some detail, although some of its basic features will emerge in Penny's story. In brief, ABA is a distinct and well-established technology developed through scientific research on how behavior is influenced by learning processes. ABA has been the most effective approach to helping individuals with intellectual disabilities learn important life skills since the 1950s and 1960s. Over the ensuing decades, the technology has grown increasingly sophisticated and powerful. Its focus is on arranging the details of a person's environment in ways that harness the power of learning processes that result in desired changes in behavior.

A NEW BABY

The couple was excited about the impending birth of their third child. Their oldest, an adorable young girl, was a daily blessing, but the death of their three-year-old son during surgery a year earlier had been terribly difficult. They knew they would never truly get over his loss, and the prospect of another child in the family was all the more important.

Penny was born in November 1958 weighing seven pounds and three ounces—a beautiful and apparently healthy baby. By two months of age, she seemed to be allergic to milk, but there were no other problems. By three months, however, her parents began to worry. Although healthy, she seemed to be hyperactive, and her eyes were uncoordinated with each other in their movements and her tongue seemed to be unusually large. A month later, the pediatrician noted delayed bone development, but other medical tests were unrevealing (e.g., her waking EEG was normal and tests for PKU or phenylketonuria were negative).

Nevertheless, her parents continued to be concerned. Over the next few months, they noticed that Penny did not reach for her bottle or other objects. Although she appeared to be aware of what was going on around her and laughed when they played with her, she did not seem as social as their other children had been at this age. Her movements were jerky, and her oversized tongue protruded most of the time. She was awake most of the night.

By seven months, her parents were desperate for a diagnosis or an explanation of what was wrong. The doctor ruled out PKU and cretinism, but suggested that she was probably mentally retarded. She was certainly developing slowly. As the next few months passed, it became clear that this diagnosis was correct, although the cause and severity of her disability were unclear.

Penny's parents applied for her admission to a state developmental center—a common recourse at the time—but it was some months before a placement was

Box 1.1

Genetic Metabolic Disorders

Phenylketonuria or PKU is one of a number of genetic metabolic disorders. It causes the liver to fail to produce an essential amino acid, which in turn leads to biochemical problems that damage the brain and nervous system. As the baby consumes milk, the damage accumulates and is irreversible. The newborn seems healthy at first but in a few months shows developmental delays, becomes listless or irritable, and may have seizures. If untreated, the damage continues and leads to serious intellectual disabilities.

Fortunately, PKU can be easily diagnosed, and treatment for PKU is no more complicated than stringently following a special diet. If the diet is started within two months and is carefully adhered to, most damage can be prevented. The required

diet is not easy for children to follow, however, because it restricts foods such as milk and milk products. Furthermore, because this is an inherited disorder, if individuals with PKU have their own children they will pass on the recessive genes for the disorder.

Cretinism or hypothyroidism is another genetic disorder that leads to biochemical problems. Individuals with this disorder have an underactive thyroid gland, which leads to delays in growth and development from birth. The baby has distinctive physical features and severe mental retardation occurs quickly. As with PKU, however, this condition can be detected early on. If treatment is started within ten weeks, the most severe damage can be avoided.

available. At the age of 18 months, however, Penny became another resident of a state institution with the diagnosis of “retardation, cause unknown.”

LIFE IN A STATE INSTITUTION

Services in a state institution in 1960 for individuals diagnosed as intellectually disabled (uniformly referred to as mental retardation during this era) were basic and unsophisticated by today's standards. The center was overcrowded and understaffed, and any funds for supplementary services tended to focus on “residents” who showed some hope of profiting from them. Training and various therapies were not really an option for “low grade” individuals such as Penny. Her IQ on admission was recorded as 32, and it was even lower when she was tested four years later. Further efforts to assess her level of functioning were unsuccessful, and her adaptive behavior was minimal.

In 1973, reports of what was considered “self-injurious behavior” began to appear in her records. She chewed on her fingers and toes, occasionally banged her head, and regularly ruminated (regurgitated and reswallowed her food) following meals. None of these behaviors were present when she was admitted 13 years earlier, and there was no evidence in her records about why she learned to do these things.

At about this time, Penny was assigned a foster grandparent, who received a small stipend for giving Penny some personal attention and taking her outdoors for a while each day. Although this did not amount to a formal training effort, at least Penny got someone to interact with her every day, perhaps touring the grounds in her wheelchair or sitting in the sun.

In 1974, a physical therapist examined Penny, who was now 15 years old. She had never learned to walk, and it would have been difficult because both feet were severely turned down and inward at the ankle. Instead, she had learned to scoot—sitting upright and pulling herself forward with her feet while pushing with her hands. She was admitted to the hospital for corrective surgery and returned physically capable of walking, but there was no one to teach her.

A year later, she fractured her left leg and was placed in the hospital for several months so it could heal. During this time, her rumination increased dramatically. When she returned to her cottage at the developmental center, she had lost 26 pounds and, at 56 inches tall, weighed only 49 pounds. She was not toilet trained and was unable to walk, communicate, or care for herself in even the most basic ways. During her more than 15 years in the state center, her only accomplishments seemed to be learning a few maladaptive or problem behaviors, one of which (rumination) was likely to end her life due to malnutrition from repeatedly bringing up and reswallowing her food.

CHANGING FORTUNES

In late 1975, Penny's world changed. A federal grant sponsored a new training program at the state center, and the funds were used to hire 17 staff members to work on an individual basis with up to 35 "profoundly retarded" individuals under the age of 22. The on-site team was directed by a graduate student working on his doctorate in the field of behavior analysis at a large state university in town. He was also a part-time employee of the developmental center, and most other members of the team also had at least some training in behavior analysis. It was no accident that applied behavior analysis, or ABA, was the basis for the federal grant funding and the team's approach to training. ABA had been developing as an increasingly distinct treatment model for some years, based on a well-established basic science literature that had already identified the fundamental processes of learning. Because intellectual disabilities are the result of problems in brain development that made it difficult for affected individuals to learn, a therapeutic approach rooted in an understanding of learning was a perfect match of problem and solution.

The grant called for training to focus on motor, self-care, and social skills. Penny's cottage (the common name for residences within an institution) was selected as the training site because its boys and girls wings had the highest proportion of "untrainables"—people with multiple handicaps, aggression, and self-abusive

behavior who historically were considered incapable of learning, and individuals who needed intense training that other units could not offer.

Penny's selection to participate in this program was easy. Her staff immediately pointed her out as most in need of whatever was being offered. The team's first observations were not encouraging. She was lying on her back on the floor with her knees tucked under her chest. She was so malnourished that her bones showed through everywhere. She had about six inches of diaper in her mouth and periodically made a small gagging noise, after which some vomitus appeared in her mouth and ran down her chin. After chewing on it briefly, she reswallowed it and began again. There was no evidence that she was even aware of her visitors.

In planning their approach to working with Penny, it was clear that addressing her ruminating was the highest priority. They learned that her diet was a pureed mix of vegetables, meat, and a nutrient-rich liquid prescribed to combat her weight loss resulting from ruminating. The cottage staff fed it to her in whatever position

Box 1.2

What We Later Learned About Rumination

The kind of rumination observed in the intellectually disabled population is not a medical condition (though it can have medical consequences), but a learned behavior whose sensory consequences are highly reinforcing, much in the way that chewing gum is enjoyable for many people. It is usually found only in individuals who are severely or profoundly intellectually disabled, especially those living in settings in which there is little focus on training and other activities. It is not clear why regurgitating and then reswallowing food immediately after a meal results in weight loss, but this is one of its most serious effects. Severely malnourished individuals are especially susceptible to infections or diseases that may then result in their death.

The approach to treating rumination used by Penny's team was the best that was known at the time. They simply followed each regurgitation with a consequence thought to be mildly unpleasant (lemon juice) in the hope that this consequence would override rumination's usual

reinforcing effects. They also engaged her in activities after meals, though they did not try to learn which procedure contributed to the decrease in ruminating they observed.

Some years later, a program of research on this problem identified some of the factors that contribute to ruminating and ways of using this knowledge to fashion treatment protocols (Johnston, 1993). Over a period of ten years, this research learned that the amount of food consumed at meals has a substantial effect on the rate of ruminating after eating—the more food consumed, the less ruminating, although it is not quite this simple. The researchers also identified three specific factors that play a role in this effect of meal size: the amount of chewing and swallowing, the extent of stomach distension, and the number of calories in the meal. The researchers then focused on the ways that these factors could be combined to serve as treatment protocols. In the years since, this research has been widely used and shown to be reliably effective.

they found her, one spoonful every few seconds, and the “meal” was over in less than five minutes. Immediately after eating, Penny began ruminating.

It was obvious that food was a powerful reward. (The technical term for reward is reinforcer—a consequence that will strengthen responding.) When the meal cart arrived, she looked toward the door, balled up her hands and rubbed her eyes and nose, and made excited gurgling noises. She scooted over to the cart and looked up at it until her turn came. The team also observed the same reaction when Penny’s foster grandmother arrived. Once in her wheelchair and out the door, however, she began ruminating. In looking for activities that might interrupt her ruminating, they discovered that she loved to play with a ball, bouncing it and trying to keep other clients from grabbing it. Unfortunately, she did this while continuing to ruminate.

The team started by counting the number of times she ruminated after meals. These bouts lasted for about an hour, when the initial frequency of three times per minute right after eating gradually decreased to near zero for three to four hours—a typical rumination pattern. Some preliminary manipulations in what she was fed at meals had only modest effects.

In 1975, there were no studies analyzing the causes of rumination behavior to offer the team any guidance, so they began by standardizing the mealtime routine, including where feeding occurred, her seating position, and the pace at which she was fed. They also changed her diet by substituting a calorie-rich peanut butter and jelly mixture for the liquid supplement and ensuring adequate fluid intake by giving her water mixed with Jell-O before the meal. They knew these changes would not stop the behavior, so they turned to modifying the consequences of ruminating, which was clearly a highly reinforcing activity. With the necessary permissions, and based on a recently published research study, they squirted a small amount of lemon juice onto Penny’s tongue each time she attempted to ruminate, accompanied by a firm “No!”

The effects of this procedure were dramatic. By the next day, her rate of ruminating had dropped to about one every seven minutes, and a day later it remained low. By the third day, it was down to one in 20 minutes and one in 50 minutes by the fourth day. Within a week, Penny had gained five pounds. The team soon replaced her mealtime blend with regular meals, still supplemented by peanut butter and jelly sandwiches. As she continued to gain weight, they dropped this extra nutrition and eventually had to put her on a diet by removing fattening desserts!

Despite this progress, the team would learn that Penny’s ruminating did not entirely disappear. At one point, they discovered that her ruminating picked up in the evening when they were not present, for example. They also learned that exactly how they delivered the lemon juice made a difference. It would take more than two and a half years of work, including daily data collection after meals, before her ruminations were truly few and far between.

TRAINING A BASIC REPERTOIRE

Making Eye Contact

As the rumination intervention got underway, the team turned to building Penny's basic skills. She had many needs, but some were more basic than others. The team reasoned that teaching Penny to respond to make eye contact on request would help future training efforts and chose this objective as a place to start. They combined this initiative with an effort to teach her to respond to her name—a behavior she had never acquired.

They first collected baseline data for five weeks to see how often she would respond to the instruction, "Penny, look at me" prior to initiating training. (Collecting baseline data is a standard ABA procedure for determining what procedures might help and for evaluating whatever procedures are carried out.) She rarely responded in any way. Over a period of four months, they then systematically varied different parts of their training procedures in an effort to find the most effective arrangement. They began training by using the fact that Penny would visually follow a spoon during feeding to prompt her to look at the trainer's eyes on request. (Prompting is an ABA procedure that involves providing systematic assistance to help someone perform a desired behavior.) Her correct responses were followed by the trainer giving her the food in the spoon.

After more than four months of conducting training sessions before meals, they had made decent progress, although her performance was still not what they wanted. At one point, the team tried conducting training sessions between meals using marshmallows and raisins but discovered that these were not reinforcers for her. They also gradually varied the position and distance of the trainer relative to Penny and delivered food reinforcers variably, instead of after each correct response. Eventually Penny consistently raised her eyes when asked, though it was not quite the direct eye contact they wanted.

This first training project had taught the team some things as well. Not surprisingly, it was clear that progress was going to require many, many training sessions using careful procedures and powerful reinforcers, and that improvement was still going to be slow. Nevertheless, they had shown that Penny could learn new behaviors. Much later, after incorporating her name and the eye contact requirement across many thousands of trials in other training projects, they would see her learn to make good eye contact and respond to her name at least some of the time.

Playing Ball

Although playing ball could hardly be called a basic skill, the team had plenty of evidence that a ball was a powerful reinforcer—one that might be useful in future training initiatives. As well, this was the only meaningful way of interacting with

Penny outside of training sessions, and learning how to catch and return a ball created the possibility of social interactions with other people. Because the team had plenty of time for training—and Penny certainly had plenty of needs—they began this training project at about the same time they started the eye contact training.

Baseline data showed that when sitting on the floor she returned a thrown ball about half the time, but their first training procedure only seemed to make things worse. In analyzing what they might be doing wrong, they realized that what they were doing when she failed to throw the ball back or threw it in the wrong direction could be the problem. Instead of waiting 10 seconds and then starting a new trial, they stopped playing the game for two minutes. If she threw it in the wrong direction twice in a row, they ended the session entirely. After 11 weeks, she had gotten so good that she would play ball as long as there was a willing trainer.

Eating Independently

One of Penny's most obvious training needs was to learn to eat by herself. It turned out to be much more challenging than the team expected. The first step—learning to scoop food into a spoon and get most of its contents into her mouth—seemed to go well. Sitting upright in her feeding chair, she had no trouble holding a spoon with an adaptive handle in a fist-like grip. The trainer manually guided her movements as necessary, and within a few weeks Penny had worked up to eight scoops per minute. At the age of 17, she was finally eating by herself.

Meals were still a pretty big mess, however. She increasingly tended to roll her wrist, which had the effect of dumping the food before it got to her mouth and leading her to scoop the food wherever it landed. She was also learning to take larger and larger spoonfuls. After unsuccessfully modifying their procedures, the trainers tried building a new scooping movement to get rid of wrist-rolling. They were successful, but Penny then started scooping backhanded, pushing most of the food off the backside of the plate. Nothing they tried seemed to get rid of this tendency entirely. Over a period of months, however, the amount of trainer assistance in blocking backhanded scooping dropped to only a few times per meal. They called this a success, though they continued to work on her eating skills for a long time. Consistent with ABA procedures, the team kept graphs of daily progress for all of their training initiatives, and the independent eating project graphs eventually showed 500 daily sessions.

Learning to Walk

From the beginning, the team knew that teaching Penny to walk was of paramount importance. The earlier surgery had made this behavior physically possible, although bringing her rumination under control was initially a more important priority. Early on, they learned that she could be persuaded to walk for a minute or

two at a time if someone held her hands tightly. She managed 50 to 80 small steps per minute, though she sat down every 15 to 20 seconds. Her gait was jerky, and she swayed from side to side.

To help her gain strength, the team prompted Penny to push an empty wheelchair, with her trainers walking behind her and keeping her hands on the grips. This was awkward, however, and they abandoned it after a couple of weeks. Next, they focused on getting her to ride a tricycle, which would get her about 10 minutes of leg-strengthening exercise at a time. Of course, this required its own training effort. The first challenge was finding a way to keep her feet on the pedals. After much trial and error, they figured out a way to use several shoelaces to keep her feet in place. Then there was the need to teach her to actually pedal. After some weeks of simply pushing her, the rotating pedals flexed her legs and they noticed that she was doing some of the work. After more than three months, the number of trainer assists to move or steer dropped somewhat, and they discovered that she was learning to keep her feet on the pedals on her own. Tricycle sessions continued as formal walking training began, and a year and a half later she graduated to a bicycle with training wheels—a meaningful recreational skill.

The effort to teach Penny to walk began two months after the rumination intervention began and while training her to eat by herself was in progress. The initial procedure was simple. The trainers took her into a long hall and let her sit on the floor. One trainer showed her a cup with juice in it and then walked back about eight feet. The other trainer lifted Penny to a standing position and walked her forward, letting go after about four feet. Penny then staggered to the trainer holding the juice and got her reward. They repeated the trial and got the same result. Excited by this breakthrough, they then pushed too far to see how far she would walk by backing away as Penny approached. After 20 feet, she sat down, and future trials were a complete failure.

They resolved this dilemma by moving to the kitchen and putting the cup at the edge of a counter. When lifted to her feet and started on her way, Penny managed the last three feet on her own. After a week of 10 to 20 daily trials, she was ready to move back to the longer hall. By now, after standing her up it was no longer necessary to start her walking. Progress continued as the team increased the required distance, even entering other rooms and turning corners. They added extra practice under different circumstances when opportunities arose. She occasionally sat down, but they did no more than stand her up again. Her steps were still small, and more work remained, but Penny was walking alone.

Getting Better at It

On the other hand, Penny's newly learned ability to walk was hardly serving all of her needs. The team now needed to make this rudimentary skill functional. They began by moving the training outside on the sidewalk, placing two chairs 30 feet

apart, and using the same prompting and reinforcement procedure to encourage her to make 10 to 15 one-way trips prior to each meal. A crack in the sidewalk proved troublesome—she would simply sit down—but they were able to overcome this challenge fairly easily. Her step size had increased to about one foot, and her rate was about 100 steps per minute. This pace remained constant on level surfaces over time, while her step size eventually increased to a foot and a half.

It was now time to teach Penny to get in and out of a chair on her own, to climb stairs, and to walk over rough terrain. The team addressed these needs using shaping procedures, which are described further in a later section. In the case of getting out of a chair, this involved initially placing her chair a foot and a half in front of a clothes dryer with a spoon of food on top of it. By stretching out her arms and rocking forward, she would gain enough momentum to stand and brace herself against the machine and get her food. As her balance improved, they moved the chair back further, which also delayed her access to the food reinforcer. Teaching her to sit down was a bit more complicated but worked well.

Teaching Penny to stand from a sitting position on the floor also went well. They began by prompting her to use their hand to pull herself to a standing position, always reinforcing successful performances. They then substituted objects in her environment as a support, placing the spoon of food on the objects as a prompt. Her initial frequency of standing using the clothes dryer was two times per minute, but in three and a half weeks, it had increased to seven times per minute. As they used other objects such as a clothes chest, ledges, and walls, she got better at making the most of each circumstance. Eventually, the team required her to stand without any form of assistance, which she learned to do by rocking forward with arms outstretched until her momentum enabled her to balance upright. They extended the requirement to earn her food reward to standing and walking, and then changed the procedure by delivering the food after variable numbers of trials to make the behavior stronger. In all, teaching her to stand took about a year of daily training sessions, each including a number of trials.

Early on in the effort to teach Penny to walk, the team realized that she would need a lot of practice to build her physical capabilities and refine her skill. They focused on walking to different sites on the large campus of the developmental center, eventually using not just sidewalks but unpaved areas. The team's programming was very systematic, involving gradual changes in both physical circumstances and prompting and reinforcement procedures. It took three months of training for her to get pretty good at walking from her cottage to the training building, which was about 1300 of her small steps. Penny's attempts to sit down gradually decreased from once for every 25 steps to once in 250 steps. They finally began to let Penny choose the route, as long as she was walking for at least a half hour.

Teaching Penny to go up and down stairs required the same careful arrangement of prompting and reinforcement adapted to physical features of the training

situation and her slowly developing skills. As always, the details were critical. It took almost four months to master going up and down the three shallow steps to her cottage. The team ordered a set of playground stairs, and it took another four months to get reasonably good and going up and down them. They then branched out to other stairs on the campus, and her new skill broadened her options for navigating the grounds.

The team even initiated a training protocol to teach Penny to cross obstacles in her path. They placed a board (three and a half inches wide) between two chairs on either side of a sidewalk, initially locating it only one and a half inches above the sidewalk. It was not too difficult to teach her to step over the board. They then similarly placed another board 11 feet away from the first, and she again learned to cross it with the usual training procedures. With ongoing training, they were able to raise the height of one and then both boards to three inches. The team then added a platform a foot and a half wide that she had to step onto to cross it. With further training, she mastered this obstacle as well. This obstacle training lasted for nine months. Penny could now truly walk by herself.

Eating in the Cafeteria

Although Penny had learned how to walk to the cafeteria and could scoop her food with a spoon, someone had to help her with everything else. The team reasoned that learning how to use a fork to spear some foods would be useful but after two months of training without success, they gave up. Teaching her to handle a cup was not as difficult, although the project still took a couple of months. They already assisted her to avoid her tendency to pick up the cup, take a drink, and then drop it. With persistent physical guidance and careful reinforcement, they were able to teach her to place the cup back on the table almost all of the time. As her cup handling skills improved, they noted that she also spilled less liquid while she drank.

Teaching Penny to carry a tray of food from the cafeteria line to her seat required a more sophisticated training effort over a period of seven months. The team conducted some training sessions in her cottage, where there was less interference compared to the busy cafeteria. The training procedures mostly involved countless trials of shaping, although they got creative in the use of training materials. For example, instead of conducting early sessions with actual food, they place graduated weights in bowls to create the desired level of sensitivity to Penny's tendency to tilt the tray. Much of the early training occurred in her cottage. In 15 daily trials, they focused on teaching her to slide the tray as if in a serving line, pick it up, and carry it to a designated point. The trainers gradually found it necessary to assist her less often. Their efforts to teach Penny to go through the serving line independently were not successful, however. She eventually learned to pick up flatware but never discriminated among knives, forks, and spoons. She also continued to need help to take the food dishes.

Box 1.3**An Operating Assumption About Capabilities**

The apparent limits of Penny's progress in this program cannot be clearly apportioned to her capabilities or those of her trainers. It is traditional in this field to assume that any limitations experienced in training can be overcome with improved procedures. This assumption may or may not be true in each instance, especially for individuals with profound intellectual disabilities, but the argument is that if limitations are taken as inherent in the learner, it only encourages the trainers to blame the individual for training problems and give up at the first sign of failure. The idea is to instead use training failures to motivate trainers to identify more effective procedures.

This approach means that trainers must acknowledge from the outset

that they do not know what someone is capable of learning. Unless skilled trainers have tried, failed, and tried and failed yet again to teach a behavior, they should be reluctant to conclude that the individual is incapable of learning it. The proper conclusion is only that it remains possible that better training procedures might still be fashioned that would be effective. Repeated failures to achieve training objectives does not mean that turning to different objectives is inappropriate; there is always the question of how to best allocate training hours for the most benefit. However, applied behavior analysts always resist drawing conclusions about what an individual can achieve, even when the going gets tough.

Incidental Training

The team's efforts to develop Penny's repertoire had a growing impact that was not directly trained, although they certainly took advantage of unplanned training opportunities. As Penny grew more capable of walking independently, her world began to expand considerably. Her experiences on off-campus field trips brought her into contact with more people, noises, music, and objects. She had always loved motion, and riding in a van or car or experiencing a playground or carnival ride was a delight. All of these circumstances presented her with opportunities to react in some way and to experience the consequences of these reactions—the core of learning procedures, whether planned or incidental. The team observed that she laughed more often and even began to respond occasionally to her name. She learned to follow trainers and others, instead of having to be guided. She learned to enjoy physical contact and even seek out contact with trainers by sitting down beside them and taking their hand. She was learning a more social repertoire.

SOME LIMITATIONS OF TRAINING

Penny participated in the federally funded training program for two and a half years. During this period, she received formal, intensive training services for approximately 12 hours a day, seven days a week—an extraordinary circumstance both then and now. Her lead trainers were experts in applied behavior analysis as

it was defined in the mid-1970s. Over the succeeding decades, this technology has become far more sophisticated, although the core of the technology remains rooted in the basic principles of what is technically referred to as operant learning.

It was clear from the outset that Penny's ability to learn was profoundly deficient. She was certainly among the most challenging intellectually disabled individuals in the state facility. As is typical of individuals with profound intellectual disabilities, she initially presented both an extremely limited repertoire and an assortment of challenging behaviors that placed her at health and safety risks.

The core training procedure the team most often used is called shaping. This involves carefully designing the training setting, prompting a small piece of the desired target behavior, and providing a positive reinforcer for correct responding. Many such trials are usually conducted in each training session, with frequent, small adjustments of the setting, prompts, and requirements for correct responding. In this manner, the target behavior is gradually shaped to a desired final form in a way that is roughly similar to an artist shaping an object in modeling clay. This summary fails to convey the complexity of sophisticated shaping procedures, however, nor does it do justice to the team's training efforts.

With these considerations in mind, it is important to summarize the limitations in Penny's training that the team acknowledged. The most obvious feature of her progress was that it was painfully slow, a finding documented in other efforts with similar individuals (Reid, Phillips, & Greene, 1991). Teaching even the most basic components of a skill invariably required seemingly endless trials, and newly learned performances were fragile and easily disrupted. Most training targets took at least months to achieve, and a number of initiatives lasted throughout the entire program.

Even the team's successes were limited in some ways compared to their early hopes. For example, after two and a half years, Penny could independently eat her entire meal and drink her juice. However, she still needed a bib to contain spills, and her handling of a spoon still resulted in food being pushed off of the plate. She never learned to use a fork. She also failed to progress to the point that she could go through the serving line in the cafeteria entirely on her own. Although she learned to walk reasonably well, running was out of the question. It was clear that climbing stairs would always require support by a bannister. The team did not focus on self-care and hygiene programs, if only because early efforts made it clear that progress would be extremely challenging. Five months of effort to teach Penny to put on a T-shirt was not fully successful and discouraged further efforts to train other dressing skills, although this may have been unfair to Penny. There is no reason to believe that a sufficiently intensive effort would not have eventually have made useful progress.

The team never tried to accomplish some objectives. For a number of reasons they chose not to attempt systematic toilet training with Penny, for example, although they were successful with other individuals in the special program. They

also decided not to give communication skills any priority—a decision that would probably be approached differently today. It was not as if there was any chance of teaching her to talk, but even teaching other forms of communication were deemed less important than her other needs.

The limitations the team faced should not detract from the pervasive transformation of Penny's daily life that they engineered. There was every reason to believe that her severe ruminating would have led to an early death from an inopportune infection or illness. Her life before the program started was as environmentally impoverished and behaviorally constrained as one could imagine, in part a tragic testimony to the quality of services too often typical of state developmental centers in that period.

The training program, which gave her first place among equals, did more than stop her ruminating and establish some rudimentary skills. It gave her a new way to experience and react to her world. It increased her options and preferences. It dramatically changed how others responded to her, which in turn further changed her behavior. Each training success was like hitting the cue ball in pool—it hits one ball, which hits other balls, which might then hit still others. Each single change in her repertoire resulted in unprogrammed changes that could then lead to many others.

Of course, the most fundamental limitation the team faced was that Penny had been given no systematic training of this sort during the first 17 years of her life. We can only wonder what she might have learned had she had access to skilled intervention services from the outset. The team's efforts spanned only two and a half years; what would 17 years of no less sophisticated, though perhaps less intensive, efforts have accomplished?

POSTSCRIPT

All good things must come to and end, as did the federal funding that made Penny's extraordinary experience possible. Her progress was sufficient, however, that she was moved to a cottage with more-skilled peers, where she seemed to do well, although the extensive measurement of her various training targets was discontinued. Her days were no longer filled with training activities, but her "grandmother" continued to make daily visits to take Penny out on the grounds. Her walks were not as long, however, and she received less social contact than she did when the trainers were always around. For a period of time, other funding supported her attending an on-campus school, where training focused on unstructured gross motor tasks. The team's main concern was whether her ruminating would increase over time, and there was some evidence that it did not entirely go away. Although her new cottage staff implemented planned intervention procedures some of the time, they were not consistent. On the other hand, Penny did not ruminate so much that she lost weight, and she remained healthy.

I visited Penny at the developmental center in 1992, and her lead trainer and two other team members visited her in 1996—20 years after this story began. Our observations were that although she occasionally ruminated, it was not a problem. She continued to eat by herself well but required monitoring to prevent eating too fast. She still walked with a swaying gait, but otherwise capably, and she continued to get up from the ground unassisted. She still required considerable assistance for dressing, bathing, and oral hygiene. She had learned to go to the toilet on her own, though only with scheduled prompting. She enjoyed daily activities and participated in simple workshop tasks each day that earned her some money. She got along well with her peers and staff but still did not consistently respond to her name.

PENNY'S PROMISE

Our everyday conception of what it means to be human is predicated on fairly “normal” levels of intellectual functioning, which implies all of the usual age appropriate skills, a full-fledged verbal capability, and skilled responsiveness to the world around us. Someone like Penny lacks these characteristics, so it is not unusual for others to view such individuals in terms of these deficiencies and as somehow less than fully human and without hope of redemption. It is a cruel assessment and a self-fulfilling prophecy. If individuals with intellectual disabilities are incapable of learning to be “normal,” especially when these disabilities are severe or profound, then why try? And if we do not try....

Penny's promise is the same as anyone else's, however, and her story answers this question. Her promise is not one of some particular level of achievement, any more than each of us can achieve equally. (Why give children piano lessons when very few will go on to become concert pianists? Why provide access to a college education for students who earned less than As and Bs in high school, given that many will fail to earn a college degree?) Penny's promise is her ability to achieve the possibilities that her world can offer her. In her case, this meant the possibilities offered by what was, in the mid-1970s, state-of-the-art applied behavior analysis services all day every day for two and a half years. This experience transformed her life from a pathetic struggle for survival to one of varied daily experiences and pleasures that are meaningful to her and to her family and caregivers.

For others with intellectual disabilities, equivalent access to today's ABA services would accomplish different outcomes. Most individuals would bring a good deal more potential than Penny offered, and their progress would be much more rapid and lead to considerably more capabilities. In this sense, Penny's story might be seen as a discouraging example of what is possible. What Penny's story should make us ask, however, is what could be achieved for individuals with varied levels of intellectual disabilities if each had unfettered access to expert ABA services throughout each day throughout their childhood, adolescence, and beyond.

The “state of the art” today—almost 40 years later—is a sophisticated, powerful, and long established science-based technology for addressing the needs of these individuals. The question is no longer what can be accomplished—the achievements of this technology have been demonstrated in a substantial body of applied research and with countless individuals over the years since Penny’s experience. The only remaining question is how to insure the needed level of access to these services. This book is a road map for families and professionals who are responsible for fulfilling their promise to these individuals.

RECOMMENDED READING

Maurice, C. (1993). *Let me hear your voice: A family’s triumph over autism*. New York: Random House. Although this book tells the story of a family’s search for effective treatment for autism, it will otherwise ring true for parents and caregivers of all forms of developmental disabilities. This book had a powerful impact on the autism parent community and led to today’s demand for ABA services.