

Chapter 1

Introduction

Kathleen I. Dyer
Anna M. Linnehan
Mary Jane Weiss
Lisa Tereshko

INTRODUCTION

This book offers a comprehensive exploration of the role of behavior analysts in promoting community, social inclusion, and belonging for neurodiverse individuals. This introductory chapter sets this aim in the broader context of current concerns about ABA raised by some in the neurodiversity movement and provides some initial perspectives and responses to those concerns with potential areas of improvement. This introduction also sets the stage for subsequent chapters that provide perspectives on how behavior analysts can work with neurodiverse populations through genuine assent, individualized intervention, and collaborative efforts with families and communities. It underscores the importance of staying true to the principles of applied behavior analysis (ABA) while evolving to meet the needs of a diverse and dynamic world.

CHAPTER AND OVERALL BOOK OBJECTIVES

- Understand the evolution of the concept of neurodiversity and its significance in recognizing and respecting neurological differences in individuals.
- Explore the advocacy efforts of neurodivergent voices in promoting acceptance, inclusion, and support for individuals with neurological differences.
- Analyze the criticisms and concerns raised by the neurodiversity movement regarding applied behavior analysis (ABA) and consider potential areas for improvement.
- Explore and emphasize the foundational principles of ABA for behavior analysts serving neurodiverse individuals.
- Examine the role of behavior analysts in promoting social inclusion and belonging for neurodiverse individuals, emphasizing the importance of genuine assent and individualized intervention.
- Discuss the ethical dilemmas and challenges in goal selection for ABA interventions, and explore strategies to strike a balance between addressing challenging behaviors and respecting individual preferences and needs.

There was energy and excitement at the start of the school year. We were the “ABA faculty” in a small, private New England college. The convocation was filled with the fanfare of faculty wearing regalia, cheering students, and speeches about inclusion, diversity, and belonging. Following the ceremony, the entire campus flocked to the noisy dining hall. Students, in pairs and groups, hustled to tables with their trays. Our small department sat together, and we did what behavior analysts do: we observed. We saw one student sitting at an empty table, shoulders hunched, focused on his tray, alone amid the crowded dining hall. One of our faculty, upset with the sight, scooped up her tray and went over to join him. She learned about him, his housing situation, his major, and what brought him here. She found that he was living in a “forced triple dorm” situation with kind, yet busy roommates, who already knew each other. This residential hall arrangement was unfortunate as he had not connected with them. She reported her concerns to us, the faculty, and she reached out to a receptive and compassionate college administration.

This scene not only opens the book, but highlights the need for a societal shift toward partnering with neurodiverse individuals to promote a sense of community, social connection, and belonging. There is so much to cele-

brate in recent years, as many more neurodiverse individuals are entering higher education and employment contexts (Bakker et al., 2019; Hamilton & Petty, 2023; Krzeminska, et al., 2019). Yet, challenges persist, and the social realities sometimes overshadow the successes on other levels. Behavior analysts are uniquely positioned to assist with these challenges given the field's history and focus on individualized assessment, person-centered goal selection, and strength-based skill acquisition. Indeed, we aim to provide planful, effective ways to promote inclusion because, as Ilene Schwartz stated:

Being physically present, being in a room with people and not really belonging, that is not inclusion, that is loneliness. Inclusion is when someone helps you feel that you belong, when someone provides you the instruction that you need to participate meaningfully, where you get to choose what you are going to do and when you are going to do it... and we make that happen through the implementation of high quality, planful instruction that addresses issues that are important to and valued by individuals and families.... Instruction helps all of us be better, be able to achieve our own goals, and to be able to help our friends and neighbors achieve their goals. (Ted,x, 2015, :56)

This book aims to answer the following questions: What is the role of behavior analysts in fostering community, social inclusion, and belonging? Where are the guidebooks and roadmaps? How can behavior analysts help? What are the elements of experience that are most important to attend to? How can environments be altered to be maximally welcoming and supportive?

The Neurodiversity Movement

The term *neurodiversity* was originally coined by Judith Singer, an Australian sociologist, in 1998. She framed the idea that autistic people have brains that function differently and that the neurodivergent person has unique strengths and approaches to life that should be respected and valued. The neurodiversity movement emerged with the recognition that neurodivergent people were marginalized, and aimed to accept and include all people while embracing neurological differences. *Neurodiversity* is now more broadly used as a nonmedical term to describe the wide range of brain functioning and includes individuals with neurological differences, such as attention deficit hyperactivity disorder (ADHD), bipolar disorder, post-traumatic stress disorder (PTSD), anxiety disorder, and learning disabilities, among others.

Neurodivergent voices assert that those individuals whose brains function differently than most people are natural variations that fall out of the

parameters of “normality.” That is, neurological differences, rather than being viewed as a mental illness or pathology to be “fixed” within a dualistic frame of “normal” and “abnormal,” should be viewed as a spectrum of diversity that recognizes that each brain develops uniquely. Further, rather than being marginalized from society and forced to conform, neurodiverse persons should be accepted, included, and supported, and have the same access to resources, rights, and opportunities afforded to neurotypical people (Chapman, 2020; Singer, 1998).

Back to Our Roots

The field of applied behavior analysis (ABA) is getting lambasted by individuals unhappy with the science and practice of ABA, calling ABA unethical and misguided. Another perspective is offered by Michele Dawson, in her article *The Misbehavior of Behaviorists*. She concedes that “ABA is hard to argue against” (Dawson, 2004, para. 71) as children can learn many basic skills with behavioral principles, and has the additional benefit of having the adults in their lives behave consistently toward them, rather than in an arbitrary and emotional fashion (Dawson, 2004). With that said, she raises concerns about goal selection. For example, behavior analysts aim to reduce and eliminate behaviors, such as repetitive (self-stimulatory) behavior that the autistic person finds useful and necessary, and increase behaviors that the autistic person may find useless and painful, such as eye contact and appropriate gaze (Cunningham & Schreibman, 2008; Silva, & Fiske, 2021).

It is not just ABA that is being called into question regarding the treatment of those with special needs. For example, the troubled teen industry seems to also be under fire for their practices. This industry treats young people who are experiencing behavior, mental health, and substance abuse challenges. Many of the programs are residential, and some emphasize the health benefits of the outdoors. Wilderness programs are a variant of this approach. The industry is largely unregulated, and accusations of abuse have been made regarding a number of these providers. Specifically, there have been exposés of the harsh and inhumane treatment endured by program participants. Most recently, residential service providers for those with developmental disabilities have been exposed as utilizing arbitrary punishers, allowing abuse to occur and continue, and failing to keep clients safe (Kowalczyk, 2023). There appears to be widespread concern for the care of the vulnerable. It is reminiscent of the exposure of horrific practices at institutions such as Willowbrook in the 1970s (Addessi, 2017; Anekwe, 2014). It may be that the care of autistic individuals has been highlighted in these movements to ensure humane care for vulnerable populations.

In any case, the amplification of these voices has been intense. In a short few years, the movement has been galvanized and has leveraged social media to increase awareness and garner support. In fact, it is not uncommon for such concerns to reach mainstream audiences; the younger generation, in particular, seems to be contacting information from social media platforms such as TikTok and Instagram. Such critiques are usually offered as first-person accounts/opinions and are generally not grounded in science or other reputable referenced information sources.

There is controversy about these criticisms, and there is confusion about how to best address them. Many of the claims are questionable, and the published research cited by these individuals is largely lacking in experimental controls that would allow more confidence in the findings. Indeed, from a scientific evaluation perspective, these claims seem to present a narrow view/interpretation of the science's impact on autism. The distribution of these slanted appraisals of ABA has extreme consequences. In a real-world potential scenario, funding for ABA services could be disrupted. Many critics identify the dismantling of ABA intervention as their goal. This is potentially catastrophic for the large numbers of individuals receiving such services who are gaining meaningfully from them, who require them, and whose families also value and need them. It is also disproportionately concerned with those who are less impacted by autism; the Profound Autism Alliance (<https://profoundautism.org>) has noted the skew of this criticism and has voiced that those they serve are not represented in the debate.

Although behavior analysts must respond with claims of positive, scientific, evidenced-based results, along with positive testimonials of treatments from families as efforts to represent those who cannot speak out for themselves, the words of individuals from this growing movement should give pause. It is always the case that services can drift and that services can be improved. Indeed, the state of the field provides an opportunity for behavior analysts to consider that current practices of ABA may have drifted from the original aims of the science, and to seize the opportunity for the field to revisit its original values and traditions. This potential drift corresponds with the rapid expansion of ABA services to meet the growth in the number of persons diagnosed with ASD. With such accelerated growth, there is a risk of dilution of the quality and integrity of our treatments. This concern will be addressed directly in Chapter 3 of this book "The Truth about Autism and ABA" In that chapter, the authors further outline issues raised in the 2015 article, "Applied behavior analysis is a science and, therefore, progressive" (Leaf et al., 2015). These leaders in the field of ABA collectively caution the field that "we could be drifting toward an unsophisticated recipe approach to intervention," and that "there may

be a trend toward incomplete manualization of procedures, rigid adherence to decontextualized protocols, and potential of lack of understanding, or even worse, misunderstanding of the basic principles behind the procedures and interventions. Losing the “analysis” in applied behavior analysis may be a danger” (Leaf et al., 2015, para. 4). It may also be that the explosion of growth in ABA has led to quick solutions to training practitioners; it may be easier to train individuals to follow protocols than it is to exercise clinical judgment.

The “analysis” aspect of the science of ABA is firmly rooted in the origins of the field. This is highlighted with the launch of the flagship *Journal of Applied Behavior Analysis (JABA)*, in 1968. At the journal’s beginning, Montrose Wolf, asked the central question: “What is the purpose of the *JABA*?” (Wolf, 1978, p. 203). Don Baer responded, “It is for the publication of applications of the analysis of behavior to problems of social importance” (Wolf, 1978, p. 3). Wolf dug deeper: “What is ‘social importance?’” he asked. His queries led to the publication of the 1978 seminal article, “Social validity: The case for subjective measurement or how applied behavior analysis is finding its heart.” He urged us to consider the social appropriateness of our treatment goal, procedures, and effects, posing such penetrating questions as “Are the specific behavioral goals really what society wants?” “Do the ends justify the means?” “Do participants, caregivers, and other consumers consider the treatment procedures acceptable?” “Are consumers satisfied with the results?” (Wolf, 1978, p. 207).

We, the editors of this book, propose that these questions provide a foundation of principles for behavior analysts serving neurodiverse individuals, and we recommend a revisitation of the seminal article, “Current dimensions of applied behavior analysis.” Baer, Wolf, and Risley (1968, 1987) recommended that applied behavior analysis should be: 1) applied; 2) behavioral; 3) analytic; 4) conceptually systematic; 5) technological; 6) effective; and 7) capable of appropriately generalized outcomes. These principles hold true today and can provide us with a framework for assessment, treatment planning, and evaluation of our treatment effectiveness.

This book will be using this framework in 18 chapters with contributions from the neurodiverse population, practitioners, and researchers who have been closely committed to serving the neurodiverse population. These authors will address our aim of promoting community, social inclusion, and belonging for neurodiverse individuals while staying true to the following principles of applied behavior analysis:

Applied. *Applied* means that behaviors selected for intervention are socially significant, in that the goals, procedures, and outcomes improve lives in the sense that the person’s selected goal leads to more happi-

ness, self-sufficiency, and access to a higher quality of life (Bahry, et al., 2022). To improve a sense of belonging and connection to one's community, multiple domains in the areas of communication, social skills, self-regulation, leisure, and vocational skills can be addressed. While the importance of addressing these applied skills in our education programs is widely recognized, there are currently troubling outcomes for many persons with ASD, with the persistent problems of gaining and maintaining employment, continuing school, living independently, socializing, participating in the community, and staying healthy and safe (Howlin & Iliana, 2017; Lai et al., 2019). Along these lines, Gerhardt (2007) asserts that these troubles are less due to the challenges associated with being on the spectrum and more due to the failure of our systems to prepare individuals to become employed and engaged adults. On a positive note, he outlines programmatic solutions, including providing instruction on relevant skills related to social and employment engagement. While many autistic persons are not receiving this type of instruction, he recommends that in addition to being provided with academic instruction, it is useful to provide instruction to prepare for the transition. Skills that serve as barriers can include high rates of severe challenging behavior, poor hygiene, age-appropriate clothing, peer eating skills, inappropriate sexual behavior, and not being bowel- or urine-trained. These should all be addressed early on to prepare persons to succeed across environments. Skill building to promote this success should include requesting assistance, self-management, following schedules, and independent completion of self-care and hygiene routines. The selection of goals should be focused on meaningfulness to the person and for their current and future life. Several tools exist that can assist practitioners in achieving this goal; involving the individual served and the caregivers is important to developing value-based goals (Gerhardt & Bahry, 2024). These authors have emphasized the importance of an applied curriculum; indeed, goals should reflect a focus on next environments, and the skills selected should matter.

Social difficulties experienced by neurodiverse individuals can perhaps be the most painful and defining challenge, with difficulties in navigating complex social situations resulting in loneliness, peer rejection, peer victimization, poor social support, and isolation. Thus, the importance of providing instruction on social skills cannot be underestimated and an applied curriculum would especially address these areas to provide skills that the neurodiverse person would find useful in improving their happiness, community inclusion, and sense of belonging. These issues are specifically addressed in this book in Section 2: *Person-Centered Goal Selection*.

Behavioral. Behavior analysis focuses on what people do, and this orientation on day-to-day behavior begs us to answer the question: What behaviors result in more of a sense of belonging and community connection, fewer disappointments, and more happiness? As such, rather than focusing on indirect behaviors—such as improving a person’s subjective responses to a survey on loneliness and belonging—the behavior analyst might consider the value and importance of being an ally to the neurodiverse person to address socially significant behaviors in natural settings. For example, skills such as talking to peers, negotiating problems, sharing a meal, and going out for a night on the town with a group might be areas where the neurodiverse person might select to receive consultation to maximize success.

Analytic and conceptually systematic. There is a growing body of literature on identifying effective treatments that are based on strong empirical evidence, and this is part of a broader movement focused on accountability (Odom et al., 2010; Wilczynski, 2010; Wong et al., 2015). Using the scientific method to increase the believability of our selected treatments, rather than providing those based on current fads, or worse on valueless and fraudulent remedies, is the core premise of the *analytic and conceptually systematic* dimension of applied behavior analysis. The *Ethical Code for Behavior Analysts* states that:

Behavior analysts prioritize clients’ rights and needs in service delivery. They provide services that are conceptually consistent with behavioral principles, based on scientific evidence, and designed to maximize desired outcomes for and protect all clients, stakeholders, supervisees, trainees, and research participants from harm. Behavior analysts implement nonbehavioral services with clients only if they have the required education, formal training, and professional credentials to deliver such services. (Behavior Analyst Certification Board 2020, 2.01, p. 10)

The analytic tools used to assess the believability of the treatment involve collecting ongoing objective data on behavior, and analysis of treatment effectiveness through single-subject experimental designs (Kazdin, 2021). Objective data collection and procedures to control for threats to internal validity increase the probability that observations and ensuing data-based treatment decisions are based on observed behavior and demonstrations of experimental control. This lies in contrast to subjective impressions and biases offered by case studies, and claims of effectiveness based on anecdotal reports that are vulnerable to misrepresentation of the impacts of treatments.

With its emphasis on the individual, single-subject research is also uniquely suited to the neurodiverse community, given that *neurodivergent* means having a brain that works differently from the average or neurotypical person. As such, information about the mean performance of groups provided by more traditional group studies may have less relevance to neurodiverse individuals.

Finally, because of the commitment to providing socially significant behavior change, behavior analytic research efforts involve arranging environmental variables to demonstrate functional relationships between optimal contexts for promoting success, as well as identifying contexts that would be less conducive for the functioning of the individual. Thus, these analytic methods are well-suited to serve the neurodiverse individual by examining and empirically validating ways in which peers, families, and the community can support the person being served in a way that reduces harm and promotes well-being. The involvement of caregivers has been a historic value, and behavior analysis continues to be committed to the integration of stakeholders into the treatment team.

Technological. Consistency is key to successful treatment, and inconsistent treatment can jeopardize treatment gains (DiGennaro Reed & Reed, 2014). This is important whether we are teaching useful skills or changing the environment to provide support, as in the case of persons benefiting from augmentative or alternative communication. Finally, many neurodiverse individuals are finding that social demands can be exhausting, and sensory demands, such as loudness and discomfort, can be debilitating when the social environment requires exposure to aversive noises (Williams et al., 2021). Further, self-injurious behaviors can be impacted by what is occurring in the person's social environment. Thus, the provision of support that improves the quality of life relies on an interconnected relationship between the neurodiverse person and the social community, with the community providing consistent, respectful, and compassionate education and support.

To meet these essential aspects of intervention and support, applied behavioral analytic procedures are *technological*, such that procedures are defined clearly and objectively. This will guard the individual against variable and inconsistent expectations, which could lead to confusion. Interventions that are written with sufficient detail and clarity so that they are replicable across stakeholders and community members, including family members and teachers. Such information helps to enable the collaborative community to provide clear and consistent intervention and support.

Along these lines, behavior analysts must provide treatments that have integrity. *Treatment integrity* involves answering the question, "Is this

intervention implemented as planned?” As such, to ensure that decisions made about the effectiveness of interventions are valid, it is good practice to collect, analyze, and evaluate treatment integrity data, along with client outcome data (Sanetti & Collier-Meek, 2019). When the treatments are provided with clear descriptions of their implementation and how results are measured, there is more confidence that any changes in the behavior are the result of the treatment. These safeguard measures also reduce the chance that the treatment provider views improvements in the client through the lens of their own subjective bias.

Effective. Simply put: “If the application of behavioral techniques does not produce large enough effects for practical value, then the application has failed” (Baer et al., 1968, p. 96). This brings us back to our original question of what makes a socially valid outcome. The outcome of *effective* interventions ultimately has to result in a change in the individuals’ quality of life, concerning their interactions with the environment. As such, the behavior analyst is cautioned from considering that effective behavior change has occurred because there has simply been an increase in discrete targeted behaviors or a decrease in behaviors that are problematic for the person served. Rather, effectiveness can be measured by examining the degree the behavior has changed in the person’s daily life functioning. For example, if social skills are targeted, we cannot claim that the behavior change project was effective simply because the neurodiverse person has shown the skill of asking and answering a list of social questions with a small number of trained interventionists in a clinical setting. Rather, a successful outcome would be that the person is now able to engage in small talk in their daily life situations, such as when confronted with a police officer who is trying to help them navigate their situation if lost.

Generality. *Generality* refers to the aspect of behavior change occurring across people and situations and spreading to situations where intervention did not occur, or across behaviors not directly targeted, and maintained over time after formal intervention has ceased. Thus, effective gains are also generalized gains. The person, who has learned to engage in small talk in the clinic can now flexibly carry on light conversations across a range of topics that were not directly trained, be able to change from formal to informal speech according to the conversational partner, and use these skills consistently across their lifespan. Indeed, a behavioral intervention program should only be considered “mastered” when these criteria have been met. Ultimately, there must be a focus on long-term outcomes as well as on short-term goals. Indeed, the team needs to continually assess the meaningfulness of the selected goals and whether they are related to functional long-term outcomes (Gerhardt & Bahry, 2024). Generality, in other

words, is an essential outcome of instruction. Behavior analysts need to program for and assess generality as an outcome and ensure that any failure to generalize leads to additional training and troubleshooting.

OVERVIEW OF CHAPTERS

“I cannot emphasize enough the importance of a good teacher”

— Temple Grandin

The field of behavior analysis is at a crossroads. With the rapid expansion of ABA services to meet the unprecedented demand for services along with an increasing number of new Board Certified Behavior Analyst (BCBA) graduates entering the field, our science is at risk of diluting the quality and integrity of our treatments. The field is also under attack in the arena of social media and is also more widely affecting our societal distortion of reality and misinformation. Much of the anti-ABA movement is based on the provision of twisted information, a bias which is extreme in this space. There is real difficulty in finding the balance between listening to legitimate concerns and battling a movement that redefines autism, distorts our history, and seeks to annihilate our profession.

Thus, this book aims to provide our readers with guidelines for how to provide individualized, compassionate, assent-based, and comprehensive strength-based intervention. Our goals are to foster community, social connection, and belonging for the neurodiverse persons who we serve. We offer that the “good teacher” aims to reduce the suffering of the individuals brought about by loneliness, disconnection, and exclusion by starting at the place where the learner is and providing teaching to help them get to where they want to go. Indeed, this is an area where compassion and genuine assent are key, as the forming of friendships and deeper relationships is intricately connected to the desires, preferences, and enjoyment of the persons served. All of these elements are quintessentially behavior analytic; all of these strategies and values are foundational and current within the science of ABA. As such, this text provides our readers with guidance on how to use the tools of behavior analysis to meet this aim, through the selection of interventions that are applied, behavioral, analytic, conceptually systematic, technological, and capable of producing appropriately generalized outcomes.

This book is organized into five sections. The book begins with *Section 1: Current Perspectives* with interviews with individuals and families on their perspectives of neurodiversity and treatment. This is followed by a chapter in this section that responds to concerns with ABA-based interventions expressed by some autism rights and neurodiversity activists. The chapter will review, analyze, and discuss these recent criticisms and recom-

mend pathways forward for behavior analysts. *Section 2: Person-Centered Goal Selection* provides in-depth analysis and guidance on how to obtain and discriminate between genuine and apparent assent, and to ensure our treatments are continually aligned to, and result in, the creation of constructional programs for the persons whom we serve. This is followed by a chapter on specific steps to select goals that align with desired and meaningful outcomes that benefit the persons whom we serve. *Section 3: Strength-Based Treatment* provides intervention strategies for strength-based treatment for working with families, children, and young adults in a continuum of individual and group contexts ranging from early intervention to higher education. *Section 4: Promoting Well-Being and Quality of Life* continues to provide the reader with specific guidelines for assessment and intervention in the community, with a specific focus on person-centered leisure skills, safety skills to reduce risk and harm, and guidelines to support the person served in areas of sexuality and intimate relationships. Finally, *Section 5: Fostering Community and Belonging* addresses steps to prepare the community for acceptance and belonging, and finishes with continued considerations for the field of behavior analysis.

SUMMARY

In summary, we aim to provide our behavior-analytic readers with the tools and strategies they need to effectively partner with neurodiverse individuals and their caregivers and other appropriate stakeholders to select goals and achieve individually relevant outcomes. Ultimately, the goal is to provide the persons we serve with more connection, a higher degree of acceptance, and a deeper sense of belonging in the communities where they live. We offer that this aim can only be achieved through programming that is meaningful, established on genuine assent, consistently compassionate, individualized, and fosters relationship building among the persons served, BCBAAs, families, and community members. As a science and as a profession, we remain committed to providing compassionate and humane intervention, practicing ethically, using empirically validated and evidence-based interventions, and meaningfully partnering with those we serve and with other stakeholders.

CHAPTER ACTIVITY

- Design a behavior-analytic intervention that promotes social inclusion and community connection for neurodiverse individuals.
- Emphasize the principles of applied, behavioral, analytic, conceptually systematic, and technological interventions.
- Use creativity in developing strategies that go beyond traditional ABA practices to address the unique needs of neurodiverse individuals.

STUDY QUESTIONS

- What is the concept of neurodiversity, and how has it evolved over the years?
- What are some of the concerns about ABA interventions that have been raised, and how do these voiced concerns highlight controversy and criticisms surrounding not only ABA but also the troubled teen industry and residential service providers for individuals with developmental disabilities? What common themes and concerns emerge in these criticisms?
- According to Justin Leaf and others, what concerns do they raise about the potential drift in the field of ABA and how does this drift relate to issues such as manualization of procedures and a potential lack of understanding of basic principles?
- In what way does the chapter advocate for a revisitation of the principles outlined by Baer, Wolf, and Risley in 1968 and 1987, and how are these principles viewed as a foundation for behavior analysts serving neurodiverse individuals? How might these principles guide assessment, treatment planning, and the evaluation of treatment effectiveness in the field of ABA?

DISCUSSION QUESTIONS

- Why is it important to recognize and respect neurological differences in individuals?
- How do you see the role of behavior analysts in promoting social inclusion and belonging for neurodiverse individuals?

- In what ways can ABA interventions be more aligned with the principles of neurodiversity and individualized support?
- How can the field of applied behavior analysis ensure that its practices remain rooted in ethical principles and a commitment to improving the quality of life for neurodiverse individuals?