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Quality of Life for People with Disabilities: Why Applied Behavior Analysts Should Consider This a Primary Dependent Variable

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Abstract

Applied behavior analysis (ABA) is a natural science dedicated to using behavioral principles to address socially important problems. One area in which behavior analysts have made compelling gains in the last 50 years is in developing, evaluating, and disseminating effective interventions for people with significant intellectual and developmental disabilities. As the science of ABA has matured, many practitioners, researchers, and consumers have questioned how our field should define appropriate outcomes of behavioral interventions. In this article, we propose that improved quality of life should be the ultimate outcome for consumers receiving behavioral interventions. We explore definitions of quality of life and suggest some strategies that behavior analysts can apply to modify practices to more clearly center quality of life as an outcome variable.

Keywords

applied behavior analysis, quality of life, social validity

What does it mean for people with significant intellectual and developmental disabilities, across their lifespan, to have a good quality of life (QOL), and what is the responsibility of behavior analysts in helping their clients achieve this goal? In 1968, Baer and colleagues proposed that addressing socially important behaviors was a core dimension of applied behavior analysis (ABA). More than three decades later, Carr and colleagues suggested that improved QOL—not merely a decrease in discrete behaviors labeled challenging—should be a primary outcome variable when working with people with disabilities (e.g., Carr et al., 2002; Carr & Horner, 2007). Improving the QOL for adults and children with disabilities and their families has been recommended as the overall dependent measure for Positive Behavioral Interventions and Supports (PBIS) and related interventions. But what does it mean to have what Marsha Linehan, the renowned behavior therapist who developed Dialectical Behavior Therapy, calls "a life worth living" (Linehan, 2020)?

We are more than 50 years into the science and practice of ABA, and it is a good time to examine the direction and quality of behavioral services that people with disabilities—especially people with autism spectrum disorder (ASD) and intellectual and developmental disabilities (IDD)—receive from qualified behavior analysts. With the rise in insurance coverage for ABA services, treatment is often provided in clinical settings that offer little or no opportunity to interact with typically developing peers or to even participate in age-appropriate activities. This service provision is far from Baer et al.'s (1968) encouragement to

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study behavior in natural environments, rather than those that are convenient for the behavior analyst. While most recipients of these intensive services make gains on their insurance treatment plans and some make remarkable gains that maintain throughout their lives, it is less clear that they acquire skills that will help them make choices, make friends, and participate in a meaningful manner in their school and community—outcomes that define QOL.

The purpose of this article is to examine what has happened to the heart of ABA (cf., Wolf, 1978) and to explore what we need to do to ensure that the guiding principles of our science are not lost. We will illustrate some of the contributions that ABA has made to the knowledge base and state of intervention for people with severe disabilities and acknowledge areas in which behavior analysts may need to improve their practice. We will also discuss the role that QOL should play in developing and evaluating the effectiveness of behavioral services.

The Optimism of ABA

ABA is essentially an optimistic enterprise. Early practitioners and researchers, working with new populations of clients and new issues, sought creative ways to solve problems. A little boy with intellectual disability and a degenerative eye problem refuses to wear his glasses (Wolf et al., 1963); we can solve that. Preschoolers appear to be antisocial and will not interact with their classmates (Allen et al., 1964); we can solve that too. Children who are economically disadvantaged demonstrate delayed language development that is related to poor academic outcomes; let us develop incidental teaching to address that (Hart & Risley, 1968, 1995). Adjudicated youth have a high rate of recidivism after participating in traditional treatment programs; let us try the Achievement Place Teaching Family Model (Kirigin et al., 1982).

Although one of the primary goals of ABA is to address problems of social importance, this optimistic approach to intervention has been and must be tempered by humility and reliance on data to demonstrate effectiveness. Not all behavioral interventions are effective, can be implemented or maintained with fidelity, or meet the needs of all learners. When this happens, behavior analysts follow their data, both the quantitative, observable data demonstrating the rate of behavior and the qualitative, social validity data through which consumers share their perceptions of what interventions mean to them (e.g., in terms of acceptability, cost, relevance). This feedback allows behavior analysts to reimagine, redesign, and reevaluate their work.

Perhaps the most optimistic application of ABA has been in developing treatments for young children with ASD. In his seminal paper about early intensive behavioral intervention for young children with ASD, Lovaas (1987) reported that nine of the 19 children in the experimental groups who received at least 2 years of home-based intensive behavioral intervention were “indistinguishable from their normal friends” when they entered first grade (p. 8). This paper sparked a rise in home-based behavioral therapy and may be responsible for what has been an astonishing growth in the field of ABA since the early 1990s (Behavior Analyst Certification Board [BACB], 2020). Although many behavior analysts were impressed with the power of intensive behavioral interventions, others suggested caution about the experimental method used and attempted to remind the field that even with Lovaas’s remarkable outcomes, more than 50% of the children still needed substantial supports after 2 years of intensive intervention (e.g., Gresham & MacMillan, 1998).

Early intensive behavioral intervention programs are now readily available to most children with ASD through medical insurance or public schools. Although many programs are still primarily home- or clinic-based, some are accepting the challenge of blending best practices of ABA with the belief that children with ASD are children first and should be educated alongside their typically developing peers. The LEAP (Learning Experiences: An Alternative Program for Preschoolers and Parents) Model (Strain, 2017), Walden Early Childhood Programs (McGee et al., 2000), and Project DATA (Developmentally Appropriate Treatment for Autism) Model (Schwartz et al., 2017) are examples of early intensive behavioral intervention programs that are located in inclusive settings. These comprehensive treatment models demonstrate how ABA can provide services in the community, alongside typically developing children, addressing developmentally appropriate and socially important outcomes.

Behavior analysts are doing much good for people with ASD and related disabilities. As reported in the Project DATA archives, some people with ASD who have had ABA intervention learn to communicate, play, read, write music, run marathons, attend and graduate from college, and achieve many valued outcomes throughout their lives. Other people with ASD who have had ABA intervention make many meaningful gains but, despite high-quality early intensive behavioral intervention, continue to have significant support needs throughout their lives. And unfortunately, still others report that the ABA intervention they received did not improve their QOL but was, in fact, a barrier to achieving it. As a field, behavior analysts have been guilty of overselling the effectiveness of early intensive behavioral intervention and not listening to concerns that some people, including many adults with ASD, have about the practice of ABA.

Criticisms of ABA

Although ABA has made many important contributions, especially in the area of treatment for people with severe disabilities and ASD, there are also many criticisms that have been leveled at this discipline. As board-certified behavior analysts[1] (BCBAs), it is vital that we acknowledge these criticisms, analyze them, and use what we have learned to change our practices. ABA is the application of behavioral principles to address socially important problems. This definition affirms that ABA is not a collection of strategies, evidence-based practices, or cookie-cutter approaches to intervention. It is a natural science that requires behavior analysts to have a thorough understanding of behavioral principles and how to use them in different situations. Applied behavior analysts must communicate their practices in enough detail so that a reader or other consumer could implement them on their own. As a field, behavior analysts are committed to sharing knowledge so that others can learn to use behavioral principles, such as positive reinforcement, to address socially important issues, resulting in improvement in QOL for the consumers of behavioral interventions.

The number of behavior analysts trained every year is increasing dramatically (BACB, 2020). In a field in which more than half of its members have earned their certification in the past decade, it is difficult to maintain quality and rigor in training. A result of this problem may be that new trainees do not receive a deep dive into the core behavioral principles behind the practices that they are being taught to implement. To demonstrate disciplinary expertise, behavior analysts must have a thorough understanding of the behavioral principles that are fundamental to the science, but they must also understand why they are doing this work. They must have a clear understanding not just of behavioral concepts and principles, such as reinforcement, but also of the ethical principles that guide the heart of their work (Kelly et al., 2021).

Behavior analysts must pay careful attention to the interventions that they are implementing. Rather than thinking of scientifically validated interventions as preapproved packages that will work for all clients, behavior analysts should identify the underlying principles that are the active ingredients of the interventions. BCBAs must ask themselves what principle aligns with the behavioral change that they are trying to achieve? Finally, BCBAs must conduct the analysis. Is the intervention a good choice for a specific client? Is it working? What do the data say? What do the consumers say? How do the implementation and the outcome of this intervention impact the QOL of clients? Are they more independent, are they able to make more choices, and do they participate in their community in an authentic manner? The answers to these questions must be synthesized into an updated, data-based decision-making process that ensures behavior analysts are working with people with disabilities to help them make changes to behaviors that are socially important and related to their QOL.

Listening to and working with the consumers of behavioral interventions is a guiding tenet of ABA (e.g., Schwartz & Baer, 1991; Wolf, 1978). This is an area of practice that is challenging and one in which many current BCBAs need additional training and support. While many advocates for people with ASD and intellectual disability consider ABA to be a highly regarded treatment framework for reaching meaningful outcomes (Dillenburger et al., 2004), some have criticized ABA as a tool for exercising undue control over individuals who lack the ability to advocate for their own preferences (Ne'eman, 2010). A common criticism of ABA among autistic self-advocates with ASD is that its primary goal is to "cure" autism (Ne'eman, 2010; Ortega, 2009). For these advocates, ASD is not a pathology in need of a cure. Rather, it is a neurological difference to be accepted and celebrated (McGuire, 2011; Ortega, 2009).

While there are many valid counternarratives to criticisms about the effectiveness and appropriateness of behavioral intervention, we suggest that it is important to listen and learn. Rather than discounting criticism outright, we could view it as an authentic measure of social validity (e.g., Schwartz & Baer, 1991; Snodgrass et al., 2018; Wolf, 1978). Rather than ignoring the voices of critics, we can attempt to understand the bases for their opinions and address them as we work to improve the types of services that we offer to people with ASD.

The Evolution of ABA

In common with other helping professions that remain effective and relevant, ABA has undergone and continues to undergo changes. Not long ago, ABA was considered a mechanistic intervention for ensuring that outcomes for people with ASD centered on indistinguishability from neurotypical peers (Lovaas, 1987). This idea aligns with an outdated, medical model of disability that aims to cure individual pathology (Baker, 2011). The medical model of disability does not acknowledge how culture may define "normal ability," nor does it distinguish between conditions that result from neurological pathology and those that reflect a misalignment between an individual and their environment (Baker, 2011; Kapp et al., 2013; Wolfensberger, 1970).

The biopsychosocial model of disability reflects a newer understanding that neurological disabilities such as IDD and ASD are a result of both physiological differences within individuals and cultural variables that prevent an individual from being fully included in society (Gillespie-Lynch et al., 2017). ABA is well situated to align with this model because it is a treatment framework focused on building both individual skills and arranging contingencies that increase the frequency of reinforcement in social environments. Although the vast majority of members of the ABA community once operated under the medical model of disability, many now embrace the biopsychosocial model that recognizes neurodiversity but also emphasizes treatment outcomes that enhance QOL as individuals with disabilities and their caregivers define it. Listening to and working with advocates of the neurodiversity movement will help behavior analysts identify the socially important challenges in their lives. Not only will this approach improve the quality of interventions, but it is also an important step in building and sustaining effective partnerships.

These newer ideological assumptions about the nature of the disability and how ABA should operate are complicated by the political debate between ABA consumer groups and activists with their own ideologies (Ortega, 2009). Medical insurance companies and clinics confound the evolving ABA narrative when they promote the belief that ASD is a neurological pathology in need of medically necessary ABA treatment. Some self-advocates complicate the issue when they refer to controversial, fringe practices such as shock therapy to characterize ABA treatment as a whole (Nelson, 2004). Behavior analysts further complicate the issue when they avoid difficult conversations with critics, despite the potential benefits of reframing popular negative notions.

Rather than contributing to competing narratives, behavior analysts, parents of children with disabilities, self-advocates, and anyone else with a stake in ABA should work together to determine socially significant QOL outcomes and promote high-quality ethical ABA treatments. There are a small number of examples of strategies that may be useful to guide this process. Intergroup dialogue (e.g., Zúñiga et al., 2007) is a facilitated form of conversation used to promote interaction between groups of people with conflicting truths and strongly held beliefs about a common issue. Although it is not a research method, it is a strategy that holds promise for building bridges between behavior analysts and adults with severe disabilities, including ASD. Nicolaidis and her colleagues (Nicolaidis, 2012; Nicolaidis et al., 2011, 2019) have worked since 2006 to establish, sustain, and document the efforts of a collaboration of researchers and adults with ASD. The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) is a partnership that incorporates Community-Based Participatory Research to address issues that are important to adults with ASD including health care, employment, and autistic burnout. This Community-Based Participatory Research model allows researchers and people with ASD[2] to serve as equal partners in all phases of autism research with the shared goal of improving QOL for people with ASD. Community participation ensures that research is socially relevant, accessible, and respectful as well as credible, reliable, and academically relevant (Nicolaidis et al., 2011). ABA researchers might consider developing similar models in their research to build interventions that are enthusiastically accepted by people with ASD, families that have children with ASD, and the greater public.

Quality of Life

Although an enriched QOL should be an expectation for every person, we acknowledge that there are many people in the United States and around the world who, regardless of disability status, do not have access to an acceptable QOL. This situation is not tolerable for anyone and, as interventionists, we must ensure that we are not engaged in any practice that would diminish the QOL for a client. Our focus, however, is on QOL for individuals with significant disabilities. An enhanced QOL is unequivocally the most important outcome for people receiving ABA services. The World Health Organization (1997) defines QOL as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (p. 3). QOL is a set of multiple individual and environmental factors and relationships that are important to all people based on individual needs and choices. While it is a multidimensional social construct, influenced by both individual and environmental factors, it is experienced at the individual level when a person has an opportunity to engage in socially significant life experiences beyond basic needs (Schalock & Verdugo, 2002).

Little attention has been devoted to assessing QOL, specifically for adults significantly impacted by ASD and other adult populations with significant IDD (Van Heijst & Geurts, 2015), despite the need for clear indicators to guide appropriate behavior analytic services. Much of the research on QOL outcomes for adults with ASD and IDD is focused on one or a few domains (e.g., employment, social skills, and adaptive living skills) and assessed primarily through quantitative measures (Chiang & Wineman, 2014; Van Heijst & Geurts, 2015). While this research contributes to practitioner knowledge about building skill repertoires for individuals with severe disabilities focused on specific QOL domains, it may be more effective for practitioners to develop programming using the multiple domains of QOL as intervention targets. ABA services guided by a clear QOL framework ensure that practitioners use a multifaceted approach to program planning that facilitates outcomes across many different socially significant domains. Practitioners who do not use a QOL framework to guide service provision may miss critical domains that contribute to their clients’ overall QOL and instead design programming that is not as relevant or socially significant for the individuals they are serving.

In the past two decades, much attention has been given to identifying core domains and associated indicators that contribute to an enhanced QOL for individuals with significant ASD and other disabilities (Brown et al., 2013; Schalock, 2004). QOL domains refer to the areas of life that are critical to overall well-being. Researchers have identified eight critical domains that impact QOL: self-determination, emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, rights, and inclusion (Schalock, 2004; Schalock & Verdugo, 2002). Within each of these domains, the top three indicators of QOL have also been identified. An indicator refers to an aspect of a QOL domain that can be either objectively or subjectively measured. (See Table 1 for a summary of QOL domains and related indicators. Note that two domains, rights and inclusion, are combined here.)

Applying a QOL Framework to ABA Services

Although there have been many QOL frameworks proposed for individuals with significant disabilities (e.g., Ayres et al., 2018; Schalock, 2004), Schalock’s (2004) is the most commonly referenced in the literature. Schalock and colleagues based their QOL framework on a global analysis of relevant literature from 1985 to 1999. A team of researchers reviewed more than 2,400 articles, studying nearly 1,000 in-depth to develop their QOL conceptual framework (Schalock, 2004). Schalock’s QOL framework is relevant for individuals with significant ASD or IDD. It has been validated as both a conceptual and a measurement

Table 1. QOL Domains.

QOL domain	Definition
Self-determination	A person's right to make decisions about their own lives
Emotional well-being	A person, regardless of ability or background, has the right to access safe and predictable environments, experience contentment at home and at work, and be free from stress or anxiety
Interpersonal relations	A person has the right to a supportive social network and interpersonal relationships with family and friends
Material well-being	A person has the right to financial security, employment, and safe housing
Personal development	A person has the right to opportunities for life-long learning, authentic participation in meaningful activities, and overall productivity
Physical well-being	A person has a right to health care, a healthy diet, and opportunities to engage in physical activity and other healthy pursuits
Rights and inclusion	A person has the right to be respected, afforded dignity, and be included in society regardless of race, ethnicity, sex, gender, religion, sexual orientation, or ability

Note. QOL = quality of life.

framework across multiple populations (Jenaro et al., 2005; Morisse et al., 2013; Schalock, 2004). The framework is consistent with the World Health Organization's (1997) QOL framework that has identified parallel domains across world cultures. Some of Schalock's QOL indicators are already targeted by ABA practitioners serving adults with significant ASD and IDD in home and community settings. Predictability in expectations and routines, social interactions and social-emotional supports, supported employment, adaptive living and leisure activity skills, goal setting, and choice-making are all skills, behaviors, and routines that ABA practitioners have taught adults with IDD (Koyama & Wang, 2011; McVey et al., 2016; Palmen et al., 2012; Watanabe & Sturmey, 2003). Each skill, however, is often individually targeted for intervention without the consideration of QOL as the primary dependent variable. ABA practitioners, dedicated to enhancing the quality of lives of adults with IDD, should consider using a QOL framework to guide service delivery in addition to other common tools such as assessments and stakeholder consultation. The following QOL domains and indicators can be applied to guide person-centered, ABA service provision that may contribute to an enhanced QOL for adults with IDD.

Self-determination. Self-determination is the process by which individuals make decisions about their own lives (Wehmeyer & Garner, 2003). Self-determination is accepted as an inalienable right for most Americans without disabilities but has only recently been recognized as a right for Americans with significant disabilities (Algozzine et al., 2001). Self-determination requires both a demonstration of individual skill (e.g., choice-making) and others' acceptance and respect for the choices an individual has made, even if there is disagreement about that choice. After all, everyone deserves the right to choose to eat too many donuts and take too many naps, even if it is bad for them (Bannerman et al., 1990).

A prevalent and erroneous assumption about adults significantly impacted by their disability is that they cannot become self-determined (Wehmeyer, 1998). Research suggests, however, that regardless of cognitive functioning, the environment plays a significant role in an individual's ability to engage in self-determined behaviors (Wehmeyer & Bolding, 2001). Therefore, practitioners dedicated to applying behavior analytic interventions to increase QOL must not only consider strategies to teach adults with ASD behaviors to promote self-determination but also ensure that environments are arranged to provide opportunities for people to demonstrate that self-determination and ensure that the use of self-determination behaviors are reinforced. Individual skills associated with self-determination include choice-making, decision-making, self-efficacy, self-advocacy, and self-management (Algozzine et al., 2001). Practitioners who use ABA interventions to increase QOL for adults with IDD and ASD should consider identifying and teaching skills within the self-determination domain first. These skills can then be used across all other QOL domains to ensure that clients have a voice in determining other service goals for themselves.

Emotional well-being. Adults with disabilities deserve to be as happy as those without disabilities. Some indicators of emotional well-being include safe and predictable environments, contentment at home and at work, and an absence of stress or anxiety (Schalock & Verdugo, 2002). Adults with ASD experience anxiety at higher rates than adults with other disabilities (Gillott & Standen, 2007). Practitioners who work with adults having ASD or IDD should consider teaching skills related to these areas to promote opportunities for emotional well-being. Some skills associated with emotional well-being are building and following a schedule, safety-related skills (e.g., following safety directions, responding appropriately to toxin labels), and emotion regulation (Harriage et al., 2016). These are just a few ways that ABA practitioners could target individual skills to enhance emotional well-being in an individual's life.

Interpersonal relations. Interpersonal relations refer to relationships among family members and friends. This domain also includes social–emotional support as a QOL indicator (Schalock & Verdugo, 2002). Social and emotional skills are often delayed in adults who are highly impacted by their ASD. Adults with ASD tend to have fewer friendships overall than adults without ASD, and those friendships tend to be less reciprocal (Tobin et al., 2014). Social activities between friends also tend to be more commonly prearranged (Orsmond et al., 2013). Adults with ASD have reported a strong motivation for developing meaningful relationships, although their social relationships may have different goals and values than those of neurotypical adults (Brownlow et al., 2015; Robertson, 2010). Practitioners who teach social skills to adults with ASD should continue to use traditional assessments to identify appropriate social skills to target. They should also consider setting up social activities and opportunities that benefit the individual with disabilities in ways that are socially meaningful for them. Common social activities may include some form of parallel exercise (e.g., taking a walk) or engaging in shared, preferred activities (e.g., building models together; Orsmond et al., 2013). These activities may not require high rates of communication but still allow opportunities for meaningful social engagement. ABA practitioners who target meaningful social skills such as reciprocal communication on both nonpreferred and preferred conversational topics and arrange social opportunities that align with adults' interests are more likely to contribute to a greater QOL than those that only target discrete individual skills selected without input from the consumer or family.

Material well-being. Indicators of material well-being include financial security, access to employment, and safe housing (Schalock, 2004). Access to meaningful employment, a safe place to live, a reliable income, and the financial ability to pay for basic needs such as food and clothing contribute to greater material well-being for *all* adults (Schalock & Verdugo, 2002). Although all of these issues warrant serious discussion, we are going to focus on employment options and how they might contribute to QOL. Current estimates suggest that only 58% of adults with ASD are employed outside of the home (Hedley et al., 2017). This is less than employment estimates for individuals with learning disabilities (90%) and intellectual disabilities (74%; Gray et al., 2014). Even when adults with ASD are provided with employment opportunities, they are not always meaningful and they often are provided in the form of low-paying, part-time jobs that are not representative of individuals' education levels or preferences (Shattuck et al., 2012). Supported employment increases earning potential and enhances the likelihood of competitive employment for adults with ASD and IDD (Cimera et al., 2012; Lawer et al., 2009).

Personal development. Personal development refers to an individual's cognitive abilities, educational success, and overall productivity (Schalock & Verdugo, 2002). When working with children and adolescents, ABA practitioners spend a great deal of time on cognitive skills. Far less time may be spent increasing cognitive skills with adults with significant IDD. There may be several reasons for this. First, there is a public assumption that adults in general have less capacity for learning new, difficult skills. This assumption is refuted, however, by neurological research (Gage, 2004). The second assumption is intellectual development and education are lesser priorities for adults significantly impacted by their disabilities than are skills such as employment and adaptive living. Many adults without disabilities, however, consider life-long learning a significant factor in their overall QOL (Tuijnman & Boström, 2002). Therefore, practitioners who facilitate skill building should also consider the possibility for their clients of cognitive skill building and the pursuit of knowledge related to topics of interest.

Physical well-being. Physical well-being refers to a person's overall health, including nutrition, exercise, leisure activities, and daily living skills. ABA practitioners who want to encourage both self-determination and physical well-being need to consider teaching health-related skills to their clients with IDD and arrange the environment to reinforce those skills. In addition to teaching behaviors related to consuming healthy foods and physical activity engagement, ABA practitioners who wish to increase QOL for clients must consider teaching both daily living skills and leisure activities.

A life worth living is dependent on fulfilling basic needs and engaging in meaningful experiences (Linehan, 2020). The opportunity to enjoy personal leisure activities contributes significantly to an individual's QOL. What a person considers a leisure activity is unique to them. One person may consider sailing a boat a highly rated leisure activity, while another person may consider sailing aversive due to their fear of large bodies of water. ABA practitioners who focus on teaching leisure skills to adults with disabilities should provide opportunities for their clients to first choose their own leisure activities and then determine the skills necessary for their clients to meaningfully engage in their activities of choice. This QOL indicator, engagement in leisure activities, highlights the necessity of teaching self-determination first so that individuals significantly impacted by disabilities can first indicate in some way what their leisure preferences are to support socially significant ABA programming.

Rights and inclusion. An individual's right to be respected, afforded dignity, and be included in society must be an inalienable right regardless of race, ethnicity, gender, religion, sexual orientation, tribal affiliation, or ability. *Everyone deserves the right to be included.* Adults with disabilities, however, are less likely to be included in employment, living, and social communities when compared to adults without disabilities (Gerhardt & Lainer, 2011). Much of the literature on inclusion related to employment, independent living, and community is singularly focused on the abilities and behaviors of the individual with disabilities for determining the extent to which that individual can be included (Gray et al., 2014). While individual behaviors can be targeted to promote the self-advocacy skills necessary for adults to champion their own rights and inclusion, professionals who support them also have a social responsibility to arrange environments that acknowledge the value of disability rights and inclusion.

Organizations and individuals have a responsibility to include people with disabilities in school, work, and community settings. ABA practitioners who identify QOL as the primary outcome for their clients must consider not just the role that they play in building client skill repertoires; they must also engage in public behaviors that support disability rights and justice to bring about the social changes necessary for their clients' civil rights to be respected, to be afforded the dignity they deserve, and to be socially included in all aspects of society.

Suggestions for Behavior Analysts to Help Them Find Their Hearts

A lot has changed since Baer and colleagues (1968, 1987) introduced and then revisited the seven dimensions that are fundamental to ABA. On one hand, the field has grown larger than many could imagine, and behavioral principles have changed the lives of countless numbers of people. On the other hand, and perhaps related to this growth, some behavior analysts provide services in a manner that is not consistent with the initial seven dimensions. They have strayed from the goal of making ABA "a responsive consumer-oriented applied social science" (Wolf, 1978, p. 213). As behavior analysts, we need to find our way back to that goal. We suggest some bold strategies that might serve as guideposts along the way.

Develop Principles to Guide Practice

A principle is a value that helps guide behavior and beliefs. Until recently (BACB, 2020), the field of behavior analysis did not have ethical principles, a collective North Star, that practitioners could use to guide their practices. Kelly et al. (2021) worked with a group of colleagues to develop a set of principles to guide behavioral practice. They identified five key principles: (a) beneficence, (b) inclusion, (c) professional excellence, (d) self-determination, and (e) social justice. These principles do not replace professional codes of ethics or conduct or agency regulations. Rather, they help professionals communicate their priorities to consumers and colleagues. This set of principles may not be the right set for all behavior analysts (see the new Ethics Code for a set of principles for BCBAs; BACB, 2020), but they serve as an example. Their purpose is to assist behavior analysts in making decisions that help them to secure for their clients a life well-lived.

Listen to Consumers

The consumers of behavior services come to these services with strong, robust, interesting identities of which disability is just one feature. As behavior analysts, we must always remember that people with disabilities are people first and that they come from different cultures, have different values, possess varying strengths, and possess individuality when determining which issues are socially important to them. Listening to consumers and respecting the intersectionality of their identities is the optimal course for behavior analysts to do their work. Only consumers of our services can decide what matters are socially important to them. Respectful exchanges will build bridges between consumers and behavior analysts and may help make ABA more inclusive and effective.

Remember the Science

One important difference between ABA and other approaches to working with people with severe disabilities is our reliance on data to make decisions. As the field of ABA has matured, some subjective measurements (i.e., qualitative data) have become important components of our practice (Schwartz & Baer, 1991; Wolf, 1978). The cornerstone of ABA has, and will always be, reliance on data to make decisions about the effectiveness of interventions. This does not mean resistance to innovation. Behavior analysts rely on data to demonstrate the effectiveness (or lack thereof) of new interventions and use data daily to demonstrate that interventions are (or are not) effective for individual clients.

Practice Intellectual and Cultural Humility

We must recognize that input from people with different points of view and with different backgrounds can improve our ABA practice. By respecting constructive criticism from adults with disabilities, families of people with disabilities, and individuals from diverse racial and ethnic communities, behavior analysts can begin to understand how interventions may affect these consumers in a social sense. Although an intervention may effectively increase or decrease a target behavior, it is of no use and could be harmful if the target of the intervention or the procedure implemented does not correspond with the consumers' values, priorities, and social mores.

Until recently, people with severe disabilities have had little to no power in the development of educational and behavioral interventions that affect them directly. To increase acceptance of behavior analytic interventions by stakeholders and consumers, ABA researchers may need to consider developing nontraditional research partnerships that include a broad swath of the community of people with ASD and their families. Including community voices in future ABA research could lead to enhanced QOL outcomes for individuals with ASD who receive ABA interventions (Nicolaidis et al., 2011).

Behavior analysts also need to develop a more robust understanding of cultural humility and recognize that ASD or IDD is just one part of a person's identity. We need to acknowledge the multiple identities (e.g., culture, race, religion, and gender) that people bring to treatment and embrace issues of intersectionality as we work with them to develop instructional programming, services, and support to lead a life worth living.

Learn and Practice the "Soft Skills"

In the past few years, some behavior analysts have suggested that in addition to learning the conceptual and technical aspects of ABA, behavior analysts need to focus on compassionate care—the soft skills that will help them work more successfully with families, clients, and other consumers (e.g., Taylor et al., 2019). Core components of compassionate care include active listening, collaboration, understanding a family's culture, avoiding jargon, and asking open-ended questions (LeBlanc et al., 2019).

Conclusion

ABA is an optimistic approach to intervention that has been effective in helping many people with severe disabilities across the age range. Although ABA has made great strides in developing interventions for people with severe disabilities, including ASD, improvements in practice are clearly needed. Often in the rush to provide services, behavior analysts have not employed the more humane aspects of ABA, occasionally losing sight of the primary outcome: improved QOL.

Given that ABA is a "self-examining, self-evaluating, discovery-oriented research procedure for studying behavior" (Baer et al., 1968, p. 91), it is time for behavior analysts to reexamine how they interact with clients, especially those with severe disabilities, and what we focus on during those interactions. We need to evaluate how to move forward to bring individuals receiving services more fully into the process so that, in the words of many leaders in the disability movement including Ari Ne'man and James Charlton, there should be "nothing about us without us" (Charlton, 2000). And as we do so, we need to discover how ABA can become an essential component in creating structures for people to live a life worth living.

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Notes

1. To address our positionality, both of the authors identify as White women who are board-certified behavior analysts, committed to the field of applied behavior analysis, and are actively involved in training the next generation of behavior analysts.
2. In general, it is our practice to honor the preference of individuals with ASD regarding the use of people first versus identity first language. In this article, however, we are following the policy of RPSD and using people first language throughout.

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