Behavior Analysis in Practice (2019) 12:879–886
https://doi.org/10.1007/s40617-019-00377-y

SPECIAL SECTION: DIVERSITY AND INCLUSION

The Diversity Is in the Details: Unintentional Language Discrimination in the Practice of Applied Behavior Analysis

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Published online: 9 August 2019

Abstract

Individuals with limited English proficiency face more challenges accessing applied behavior analysis (ABA) than their English-speaking counterparts. Many federal and state laws have been enacted to ensure the civil rights of protected classes, and Section 1557 of the Affordable Care Act (ACA, 2010) builds on those laws and explicitly establishes a cause of action (i.e., a basis to sue) against health care providers, including ABA providers, who discriminate against patients on the basis of race, color, national origin, sex, age, or disability. A patient's language falls under the scope of national origin, and most health care providers, including behavior analysts who deliver ABA as medically necessary treatment, have a duty to ensure that patients who are Limited English Proficient (LEP) have the same access to the provider's services as English-speaking patients. Knowledge of this provision of the ACA is critical to its compliance and, more importantly, to ensuring that behavior analysts rise to the challenge that the goal of true diversity represents. Note: Many terms are used interchangeably to describe insurance carriers, insurance issuers, health plans, and managed care organizations, as well as practitioners of applied behavior analysis. In this article, insurance carriers, insurance issuers, health plans, and managed care organizations are referred to as payors, and practitioners of applied behavior analysis are referred to as behavior analysts or ABA providers.

Keywords Applied behavior analysis, ABA · Autism, ASD · Affordable Care Act, ACA · Obamacare, Section 1557, diversity, interpreter, health care, discrimination · LEP, Limited English Proficient

How we define diversity likely informs how we manifest it in our lives and in the practice of behavior analysis. If diversity is defined too narrowly or contemplated too briefly, unintentional discrimination may adversely impact access to health care for patients with limited English proficiency, including individuals seeking access to applied behavior analysis (ABA). Simply put, if an English-speaking patient can access ABA services more easily than a non-English-speaking patient, then a discriminatory practice is likely in place. Ensuring diversity in the practice of health care, including ABA, is especially complex, replete with ethical and practical implications for patient access to care, best practices, and provider sustainability.

The field of ABA and the population it serves have historically endured discrimination to such an extent that nonprofit organizations, advocacy groups, bodies of law, and even research exist purely to ensure that people who need ABA have access to it (Unumb & Unumb, 2011). With a focus on individualized, data-driven treatment, goals, and priorities to address each patient's unique challenges and deficits, behavior analysis would seem inherently diverse; yet, data show that individuals who are limited English proficient (LEP) access ABA later, less often, and for shorter durations than their English-speaking counterparts (Zuckerman et al., 2017).

LEP is defined to include "individuals who do not speak English as a primary language and who have a limited ability to read, speak, write, or understand English" (LEP.gov, n.d.). The percentage of LEP families varies broadly from state to state and from one community to the next. Yu and Singh (2009) report that nearly 14% of children come from households where the primary language is not English. Patients and

This manuscript has not been previously published and has not been or will not be submitted elsewhere during the review process.

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their families who speak English are likely to encounter fewer barriers to accessing ABA. This more challenging access for LEP families raises important questions about which practices currently in place may be discriminatory and draws attention to potential legal and ethical issues for ABA providers.

Given that patients who receive ABA earlier, at greater intensity, and for a longer duration are more likely to have better outcomes (Eikeseth, Smith, Jahr, & Eldevik, 2007; Granpeesheh, Dixon, Tarbox, Kaplan, & Wilke, 2009; Linstead et al., 2017; Virues-Ortega, Rodríguez, & Yu, 2013), equal access to ABA across all demographics is not only a requirement under federal law (Affordable Care Act [ACA], 2010) but also an important goal in the effort to advance diversity in ABA among providers and patients alike. The next frontier, in other words, is to ensure that access to ABA is the same for both English-speaking and LEP populations.

Although ABA is used to treat a variety of diagnoses, a majority of behavior analysts treat the behaviors and deficits associated with the core diagnostic criteria of autism spectrum disorder (ASD), and predictions for growth in the field of ABA rely on the preservation and expansion of autism insurance reform laws and on data regarding autism prevalence rates (Deochand & Fuqua, 2016). As such, this discussion about ABA providers in the context of a benefit covered by health insurance and Medicaid is primarily—and necessarily—focused on access to ABA by individuals diagnosed with ASD and their families.

Disparity in Access to ABA

Autism insurance reform, the ACA, and clarification that ASD treatment is a covered benefit for Medicaid's pediatric population have collectively increased access to ABA (ACA, 2010; Cernius, 2016; Mann, 2014;). Yet, families frequently face practical barriers to accessing ABA therapy programs for their children despite their legal right to coverage. Many of the barriers experienced by patients (e.g., lack of insurance, excessive cost sharing, difficulty understanding and navigating the health care system, provider shortages) are not typically within the control of an ABA provider. Once a patient contacts an ABA provider, though, federal law mandates that the patient must be able to communicate with the behavior analyst and his or her staff regardless of the patient's language (ACA, 2010).

Indeed, Yu and Singh (2009) cited "linguistically concordant providers" and access to interpreters as two potential variables that may increase access to medically necessary treatment for children from LEP homes. Zuckerman et al. (2017) identified English proficiency as a significant variable in access to autism treatment in Spanish-speaking families, meaning that LEP families encounter more barriers to treatment than their English-speaking counterparts. In a retrospective review of 152 children with ASD, St. Amant, Schrager, Pena-Ricardo, Williams, and Vanderbilt (2018) identified language as a potential barrier to health care for children in the study whose parents' primary language was not English.

Role of Behavior Analysts in Ensuring Equitable Access to ABA

With increasing recognition of the effectiveness of ABA and the growing prevalence rate of ASD (Baio et al., 2018), behavior analysts may find themselves with an abundance of prospective patients. Indeed, behavior analysts qualified to treat ASD are in short supply (Behavior Analyst Certification Board, 2018). That abundance of patients may make it less likely for a behavior analyst to have a practice that reflects his or her community demographics. For example, if a behavior analyst only speaks English, then she or he may be inclined to treat only those patients who speak English and may very well build a successful practice serving only English-speaking patients. That is, ASD's high prevalence rate may contribute to a process in which ABA providers have the option to be selective about the patients they treat. Yet, what may be viewed by an ABA provider as an efficient business practice or professional focus may, in fact, be discrimination, both in the eyes of the federal government and in the experience of the LEP community.

Quite possibly, in an effort to comply with the Behavior Analyst Certification Board's *Professional and Ethical Compliance Code for Behavior Analysts* (2017, Code 1.05[b–c]), a behavior analyst who encounters an LEP patient may determine that she or he is unable to "use language that is fully understandable to the recipient of those services while remaining conceptually systematic with the profession of behavior analysis" or obtain the appropriate "training, experience, consultation, and/or supervision necessary to ensure the competence of their services" and will refer the patient to another provider. An ABA provider may view this practice as an effort to honor the compliance code, but Section 1.05(d) of the compliance code clearly states that behavior analysts may not "engage in discrimination against individuals or groups based on . . . national origin . . . or any basis proscribed by law." Behavior analysts should take necessary steps to understand their responsibility to ensure that patients who seek medically necessary ABA have equitable access to treatment, irrespective of their primary language. In addition to the clear ethical duty to provide such access, most behavior analysts are required by law to take proactive steps to ensure equitable access to the services they provide.

Overview of the ACA and Section 1557

In 2010, Congress passed the Patient Protection and Affordable Care Act and, shortly after, the Health Care and Education Reconciliation Act of 2010. Together, these acts became known as the Affordable Care Act (ACA), commonly known as Obamacare, setting in motion a major overhaul of the health insurance system in America, with many implications for health care and insurance coverage (Unumb & Unumb, 2011). Section 1557 is the nondiscrimination provision of the ACA that extends nondiscrimination protections to individuals in accessing health care by building upon long-standing and well-known federal civil rights laws, such as Title VI of the Civil Rights Act of 1964, which prohibits discrimination on the basis of race, color, and national origin; Title IX of the Education Amendments of 1972, which prohibits discrimination on the basis of sex; Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination on the basis of disability; and the Age Discrimination Act of 1975, which prohibits discrimination on the basis of age (Department of Health and Human Services [HHS] Office for Civil Rights, 2016). Section 1557 is meant to advance and protect the ACA's goals of widening access to health care and coverage, eliminating barriers, and reducing health disparities (HHS Office for Civil Rights, 2016). By creating new obligations for covered health care providers and payors to ensure that people have equitable access to health care services and do not face discrimination, Section 1557 extends the protections of civil rights laws to the U.S. health care system (Seng, Jakubowski, & Compton-Brown, 2016).

In relevant part, Section 1557 provides that

> an individual shall not . . . be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity, any part of which is receiving Federal financial assistance, or under any program or activity that is administered by an Executive Agency or any entity established under Title I of the Act or its amendments.

(Nondiscrimination in Health Programs and Activities, Final Rule, 2016)

In simpler terms, under Section 1557, most health programs and activities, including most medically necessary ABA, are prohibited from discriminating on the basis of race, color, national origin, sex, age, or disability (HHS Office for Civil Rights, 2016).

Although Section 1557 has always existed as part of the ACA law that was passed in 2010, implementing regulations were not finalized until 2016, extending the principle of nondiscrimination to health care and health insurance. In May 2016, HHS issued a rule describing precisely what covered providers must do in order to comply with Section 1557 (Seng et al., 2016). These regulations, titled "Nondiscrimination in Health Programs and Activities, Final Rule" and found at 42 CFR Part 92, became effective on July 18, 2016, and offer guidance as to which populations are protected under Section 1557, which health care providers are required to comply and how they may do so, and the various remedies individuals may seek if they experience discrimination from covered entities.

Understanding Section 1557 and Its Relevance to ABA

The first step to understanding the impact of Section 1557 of the ACA is to understand which ABA providers are covered under its command. Section 1557 applies to all health programs and activities that receive federal financial assistance from HHS and that are administered by HHS or by entities created under Title I of the ACA (HHS Office for Civil Rights, 2016; Nondiscrimination in Health Programs and Activities, Final Rule, 2016). Essentially, ABA providers who participate to any extent in federally funded programs (e.g., TRICARE, Medicaid, managed care organizations administering Medicaid benefits, most commercial plans, etc.) are subject to Section 1557 and are required to comply with its nondiscriminatory mandate.

Although the autism community recognized early on that Section 1557's nondiscrimination provisions have great potential to eliminate age discrimination in the funding of ABA-based treatment, resources to increase awareness of provider responsibilities under Section 1557 have not been widely disseminated in the field of ABA (Lello, 2015). Compliance with Section 1557 requires thoughtful planning, development of new policies and procedures, employee education and training, and implementation of an ongoing compliance program. Additionally, the costs associated with compliance with Section 1557 should be contemplated when ABA providers contract with payors to provide services. As the population seeking ABA grows, ABA providers should be conscious of the linguistic diversity that exists within the patient base they serve and of any duties they may have to improve the accessibility of their services to LEP families, whom the law incorporates and protects under the category of national origin.

Compliance

The Section 1557 provision outlines clear guidance and specific steps to help covered providers deliver health care to the populations they serve in a way that is equitable and nondiscriminatory. Under Section 1557, a covered provider may not "segregate, delay or deny services or benefits based on an

individual's race, color or national origin, or delay or deny effective language assistance services to individuals with limited English proficiency (LEP)" (HHS Office for Civil Rights, 2016; Nondiscrimination in Health Programs and Activities, Final Rule, 2016). Covered providers, including ABA providers, have a duty to take reasonable steps to provide "meaningful access" to care and coverage for each individual with LEP who is eligible to be served or likely to be encountered in their health programs and activities (Nondiscrimination in Health Programs and Activities, Final Rule, 2016). Examples of reasonable steps include the provision of language assistance services, such as oral-language assistance or written translations (HHS Office for Civil Rights, 2016).

Given the importance of complying with Section 1557, both to serve the diverse population that comprises those seeking ABA therapy and to avoid triggering the legal ramifications of violating this nondiscrimination provision, it is critical for covered ABA providers to understand the steps that must be taken to comply with the law. To meet the language access requirements to communicate with families who are LEP, covered entities must:

- provide oral interpretation and written translation services at no cost to the individual and in a timely manner (Nondiscrimination in Health Programs and Activities, Final Rule, 2016; Schuh, 2017);
- adhere to certain quality standards in delivering language assistance services—for instance, a covered entity may not require an individual to provide his or her own interpreter; rely on a minor child to interpret, except in a life-threatening emergency where there is no qualified interpreter immediately available; rely on interpreters that the individual prefers when there are competency, confidentiality, or other concerns; rely on unqualified bilingual or multilingual staff; or use low-quality video remote interpreting services (HHS Office for Civil Rights, 2016; Nondiscrimination in Health Programs and Activities, Final Rule, 2016; Schuh, 2017);
- post notices of nondiscrimination in offices, on websites, and in any significant publications and communications (Center for Medicare and Medicaid Services, 2016; Nondiscrimination in Health Programs and Activities, Final Rule, 2016); and
- post translated taglines (short statements in non-English languages spoken in the state in which the entity is located or conducts business) in significant publications and post in prominent locations and on its website, indicating the availability of language support services (Center for Medicare and Medicaid Services, 2016; HHS Office for Civil Rights, 2016; Nondiscrimination in Health Programs and Activities, Final Rule, 2016; Schuh, 2017).

Additionally, covered providers who have 15 employees or more must:

- appoint or hire a Section 1557 compliance coordinator to carry out the provider's compliance efforts and responsibilities, including the investigation of any grievance communicated to it alleging noncompliance with Section 1557 (Nondiscrimination in Health Programs and Activities, Final Rule, 2016); and
- adopt grievance procedures that provide for the prompt and equitable resolution of grievances alleging violations of Section 1557 (Nondiscrimination in Health Programs and Activities, Final Rule, 2016).

Sample notices, taglines, and other materials drafted by the HHS Office of Civil Rights (OCR) are included in the appendices following the regulations 42 CFR Part 92.

If ever a question is raised about a covered provider's compliance with Section 1557, many factors are taken into consideration to determine whether the provider has met its obligations, such as the "nature and importance of the health program or activity and the particular communication at issue to the individual with [LEP]," whether the provider has "developed and implemented an effective written language access plan that is appropriate to its particular circumstances," and whether the provider has demonstrated an effort to meet its obligations to take reasonable steps to provide meaningful access to LEP families (Nondiscrimination in Health Programs and Activities, Final Rule, 2016). With this in mind, ABA providers should evaluate their compliance with Section 1557 and make adjustments as necessary.

Consequence of Noncompliance

Covered ABA providers should be aware of the consequences of noncompliance with Section 1557. Section 1557 explicitly establishes a cause of action (i.e., right to sue) against health care entities, including ABA providers, who discriminate against patients on the basis of race, color, national origin, sex, age, or disability (Rosenbaum, 2016). If an individual experiences discrimination in accessing health care services by a health care provider or insurer covered by Section 1557, the law affords him or her several remedies, including (a) pursuing a civil suit against the covered provider, (b) reporting instances of discrimination by a covered provider to the OCR for investigation, (c) having the OCR revise the policies and procedures of the covered provider, (d) requiring the covered provider to pay compensatory damages to the individual who experienced discrimination, (e) suspending or terminating federal financial assistance allotted to providers who refuse to take corrective action, and/or (f) referring the covered provider to the U.S. Department of Justice for further enforcement action (HHS

Office for Civil Rights, 2016; Nondiscrimination in Health Programs and Activities, Final Rule, 2016).

Costs Associated with Section 1557

In addition to administrative costs, the primary cost arising from the effort to ensure equal access to ABA for LEP families is the cost of the interpreter, but whether the provider or payor is responsible for that cost can depend on a number of variables, including the state where the services are delivered, the funding source, and the inclination of the payor to incentivize providers to make their services accessible to the payor's LEP population (Jacobs, Shepard, Suaya, & Stone, 2004; Nondiscrimination in Health Plans and Activities, Final Rule, 2016). Both the behavior analyst and the payor have a duty to ensure that patients can access treatment regardless of their primary language. In many instances, payors will provide access to an interpreter service when the health care provider requests it. Prior to identifying a patient's funding source, however, behavior analysts should be prepared to communicate with prospective LEP patients.

Therefore, employees who initially communicate with prospective patients or their families should be trained and equipped to communicate with and collect information from English-proficient and nonproficient patients alike at the ABA provider's expense. Once a patient's funding source is identified, the cost of the interpreter may shift to the payor. Importantly, though, the failure of a payor to provide an interpreter does not relieve the behavior analyst of the duty to ensure equal access to ABA by LEP patients and their families.

HHS makes clear that its preference is for the cost of the interpreter to be borne by the payors but stops well short of imposing any sort of requirement on the payors to bear that cost. In the Final Rule implementing Section 1557, HHS reminds payors that the ACA requires qualified health plans to incentivize providers for "the implementation of activities to reduce health and health care disparities, including through the use of language services" (Nondiscrimination in Health Programs and Activities, Final Rule, 2016). HHS goes on to encourage payors to "consider health care providers' expenses in providing language assistance services" when structuring reimbursement rates.

State Medicaid agencies have the option of securing matching federal funds for the cost of the interpreter, but the National Health Law Program (NHeLP) reports that only 14 states and the District of Columbia appear to have taken advantage of this resource, including Connecticut, Iowa, Idaho, Kansas, Maine, Minnesota, Montana, New Hampshire, New York, Texas (sign language interpreters only), Utah, Vermont, Washington, and Wyoming (Youdelman, 2017). Additionally, Arizona Medicaid explicitly requires the managed care organizations administering its Medicaid benefit to pay for the interpreter (Arizona Health Care Cost Containment System [AHCCCS], 2017). Anecdotally, providers report state Medicaid agencies, in addition to those identified by NHeLP, as providing access to interpreter services funded by the state or managed care organization contracting with the state to deliver the Medicaid benefit, including California, Colorado, Louisiana, Michigan, Minnesota, Oregon, and Washington.

Behavior analysts who contract with payors as in-network providers should address Section 1557 requirements in the contracting process to ensure that reimbursement rates reflect the projected cost of providing services to the payor's beneficiaries in compliance with Section 1557. Although all patients who require an interpreter must have access to an interpreter when contacting their payor, the process to sustain that access continues to evolve as health care providers seek guidance from the payors and become more familiar with their responsibilities under Section 1557.

Considerations

Section 1557 is replete with positive implications for ensuring equitable access to ABA across diverse populations. Compliance with Section 1557 requires providers to take specific steps (see Appendix Table 1). Even so, as the field of behavior analysis endeavors to comply with Section 1557, existing and new processes and procedures should be evaluated to ensure that best practices are not diluted.

Length of Visit with Interpreter Involvement

Several studies evaluate the increased duration of clinic visits associated with the use of an interpreter and report minimal to no increase in visit length (Fagan, Diaz, Reinert, Sciamanna, & Fagan, 2003; Jacobs, Ryan, Henrichs, & Weiss, 2018). Behavior analysts who use interpreters for assessment, parent/caregiver training, or one-to-one ABA may be in a position to collect and disseminate data specific to the use of interpreters in the delivery of ABA to help the field identify whether the use of an interpreter significantly extends the duration of a service. To ensure that LEP patients have access to the same intensity of treatment as their English-proficient counterparts, ABA providers may want to seek additional hours or flexibility from payors to avoid inadequate treatment authorizations. Additionally, the need for interpreters may be minimized if ABA providers undertake intentional efforts to hire and train individuals who reflect the cultural and linguistic diversity of the community in which they practice.

Separate Billing Codes and Modifiers

If the payor has agreed to pay for the interpreter, ABA providers should be cognizant of billing codes and modifiers associated with the interpreter activity to ensure proper claims

submissions and timely reimbursement. If the cost of the interpreter is borne by the provider, providers may want to ask their accountants to check for tax subsidies and/or tax credits that may be available for such expenditures.

Medically Unlikely Edits

Medically Unlikely Edits (MUEs), developed by CMS for most billing codes to reduce the number of erroneously paid claims, set the likely number of units for each billing code in a day (Center for Medicare and Medicaid Services, 2018). An MUE is the maximum number of units that a provider is likely to report for one patient in one day. Interpreter services should not be counted toward the MUEs for the billable service that requires the interpreter. If payors do not offer a separate billing code or modifier for the interpreter service, ABA providers should be alert to the possibility of rejected claims that require an appeal and the delay associated with such a process. MUEs should not be used to limit medically necessary treatment, regardless of the language status of the patient.

Rate Negotiations

Rate negotiations should be undertaken only with a full understanding of whether the payor or provider is financially responsible for the interpreter and translation of medical records and forms, where necessary. Staff training, interpreter, translator, and development of materials represent some of the costs that should be contemplated when negotiating rates. If the cost of the interpreter is not explicitly denoted in the contract, seek clarification and update the contract to reflect any clarification provided. Absent sufficient rates or clarification, providers should be wary of contracts that do not allow them to make informed decisions that ensure the sustainability of their ABA practice.

Conclusion

The realm of health care is an area where lack of diversity is particularly visible, often because the serious consequences that arise from inadequate access to quality health care services have measurable deleterious effects for years to come. As ABA providers increasingly comply with the requirements of Section 1557, access to ABA is likely to become more equitable and more likely to reflect the diversity of the communities in which services are provided.

Behavior analysts should continue to develop and disseminate resources to increase awareness of Section 1557 and should build on existing research that currently identifies LEP as a barrier to ABA. In states where Medicaid agencies have not pursued federal matching funds for the cost of interpreters for Medicaid enrollees, behavior analysts may want to ensure their state is aware of this funding source and of the impracticality of shifting such a cost to ABA providers. This task will require active and engaged participation from stakeholders, including families, providers, lawmakers, and advocates, to ensure equitable access to ABA that reflects best practices and optimizes outcomes.

The principle of nondiscrimination embodied in Section 1557 aligns with ongoing efforts in the field of behavior analysis to encourage and embrace diversity and is critical to ensuring equitable access to ABA. Given that significant barriers were overcome in order to create access to medically necessary ABA, the goal to eliminate discriminatory provider practices, both in compliance with Section 1557 and in keeping with the aspirations of the field, would seem well within reach. Laws and regulations that affect ABA providers are always subject to change, and behavior analysts should have a plan in place to stay informed about their legal obligations as health care providers.

Funding No funding was received for this study.

Compliance with Ethical Standards

Conflict of Interest Julie Kornack declares that she has no conflict of interest. Ariana Cernius declares that she has no conflict of interest. Angela Persicke declares that she has no conflict of interest.

Ethical Approval This article does not contain any studies with human participants or animals performed by any of the authors.

Appendix

Table 1 Language diversity and section 1557 compliance toolkit

Anticipate the language needs of your community.	• Identify the top 15 non-English languages in your state by going to https://www.cms.gov/CCIIO/Resources/Regulations-and-Guidance/Downloads/Appendix-A-Top-15.pdf. • Solicit information from health plans and insurers regarding primary languages of beneficiaries. • Ask other health care providers and schools to share data about dominant languages in the community where your practice is located.

Table 1 (continued)

	• Visit https://www.lep.gov/maps/ to get specific information about LEP in your community.
Identify compliance tools.	• Depending on the number of employees, appoint or hire a Section 1557 coordinator.
	• Customize and post the nondiscrimination notice and non-English taglines in your office and on your website and include them in significant publications.
	• Contract with an interpreter service.
	For providers with 15 employees or more:
	• Appoint or hire a Section 1557 compliance coordinator.
	• Adopt grievance procedures for incidents of noncompliance.
Increase awareness.	• Train all staff who communicate with patients, prospective patients, and their families to be aware of patient rights and provider responsibilities.
	• Familiarize employees with posted notices and interpreter resources.
	• Share your knowledge with colleagues.
Ensure sustainability.	• Collect data on the time and cost associated with compliance.
	• Ensure payors authorize sufficient hours for each element of treatment that requires an interpreter.
	• Negotiate rates with payors that contemplate the additional costs (e.g., interpreter, translator, staff training, personnel, materials).
	• Review payor contracts to identify whether the payor or provider bears the cost of the interpreter.

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