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Viewpoint

Ethically Responsible Participant Selection in Research: A Viewpoint

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ABSTRACT

Purpose: The American Speech-Language-Hearing Association (ASHA) has committed to advancing diversity, equity, and inclusion (DEI) in the profession of speech and hearing sciences. However, there exist significant discrepancies between the demographics of our members and the populations served. These discrepancies extend to the participants included within our research publications. This article addresses participant selection when conducting research investigations. First, we draw attention to standards of conduct that are present within and outside the field. Second, we highlight inequities that exist. We explore a case study as an example. Finally, we offer suggestions to help rectify the problem.

Conclusions: Inequities at the level of participants' selection result in discrepant access to clinical services and evidence-based research for multilingual individuals; neurodiverse individuals; and Black, Indigenous, and people of color communities. ASHA and researchers alike can show commitment to DEI by addressing this problem from multiple approaches.

The American Speech-Language-Hearing Association (ASHA) has made a pledge to support diversity, equity, and inclusion (DEI) initiatives (ASHA, n.d.). More recently, Ellis and Kendall (2021) proposed disrupting the institutional, symbolic, and individual powers that support inequity within our field. These power institutions extend support to White, neurotypical, monolingual research and the profession. Highly focused research comes at the exclusion of more diverse participant populations due to the logistical complexity required of inclusivity. This exclusion hurts both clinicians and clients alike. In this article, we focus on participant selection and the ramifications of exclusion in this profession. Specifically, we focus on intervention research for bilingual children with communication disorders.

We propose that (a) speech-language pathologists (SLPs) have an ethical responsibility to serve all populations equally well, (b) this ethical responsibility also applies to researchers, and (c) these mandates do not match participant demographics in intervention research. In the same sense that clinicians should not refuse to serve an entire segment of the population, so should researchers not be able to exclude an entire segment of the population from their empirical inquiries.

The standard practice of excluding multilingual individuals from research is demonstrably racist, as this results in the disproportionate exclusion of Black, Indigenous, and people of color (BIPOC; Millager et al., 2023). Simply mandating the inclusion of more BIPOC individuals in research is made difficult by the use of "standard psycholinguistic" exclusionary criteria. It also fails to address the underlying problem. We propose several recommendations that researchers may use to expand the population base their research is applicable to and simultaneously dismantle the power structures that promote inequity.

Standards of Clinical Competency

SLPs are routinely asked to work with children from cultural and communication backgrounds different than

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their own. The needs of these children may not always fit within the knowledge and skill set of the SLP. However, federal laws specifically prohibit discrimination on the basis of race, color, national origin, sex, disability, and age (U.S. Department of Education, n.d.). According to Fabiano (2023), racially and ethnically minoritized children make up the majority of American children (Children's Defense Fund, 2023). Of those racially and ethnically minoritized children, 73.5% speak a heritage language other than English at home (Federal Interagency Forum on Child and Family Statistics, 2023). This means the intersection of race and language comes to bear on U.S. bilingual children. Thus, while inclusivity of different languages can be challenging for monolingual SLPs, they are expected to utilize resources and increase their knowledge base to serve these children.

Preparation for working with diverse clientele is also consistent with ASHA's Principle of Ethics I, Rule C from the ASHA Code of Ethics (ASHA, 2016), which states: "Individuals shall not discriminate in the delivery of professional services or in the conduct of research and scholarly activities on the basis of race, ethnicity, sex, gender identity/gender expression, sexual orientation, age, religion, national origin, disability, culture, language, or dialect." Clinical instructors often assert these same expectations to their students, who will later graduate, serve our communities, and become our professional colleagues.

Two important conclusions that we draw from existing standards are the following: (a) Clinicians have an ethical responsibility to serve their clients' (or students') needs, and (b) clinicians need evidence-based resources to do so. These evidence-based resources include peer-reviewed publications that address the needs of minoritized client populations. Thus, clinical researchers have an ethical responsibility to conduct research that addresses inclusivity for clinical practice.

Standards of Clinical Research

Standards for clinical research are different than those for clinical practice, as we researchers actively choose who to include and who to exclude from our studies. For example, our research questions may be focused on a subset of the general population. As researchers in the realm of speech sound disorders, the authors of this article have focused specifically on phonological disorders using linguistically based intervention techniques. When recruiting and screening, we may choose children as participants who do not present primarily with signs of a motor planning deficit, commonly associated with childhood apraxia of speech (CAS). Children with CAS may be a better match for an approach targeting intelligibility that focuses on speech movement gestures. For the purposes of this article, we will focus on children with developmental disorders of phonology with no known etiology.

If a child presents with a phonological disorder, the child may be excluded from study samples if they do not present with sufficient levels of production knowledge in Spanish. Enrolling a monolingual child when answering a bilingual theoretical question in many cases would not provide the data needed to test our hypotheses. Another possible research question that would require bilingual participants, and not monolinguals in either English or Spanish, is the possible benefit of receiving intervention in a child's home language. Only a sample of bilingual participants could illuminate this effect. Selecting appropriate cases for intervention is crucial to answering experimental questions and addressing client needs.

The focus on a subset of the population, in this case, bilingual children, still requires ethical standards be maintained. In fact, a close read of ASHA Principle of Ethics I, Rule C indicates these ethical standards should be employed "in the conduct of research and scholarly activities." State and federal guidelines dictate policies regarding the provision of clinical services and provide checks and balances for when they fall out of compliance (e.g., file reviews from the Office of Civil Rights). However, research journals and professional organizations (e.g., ASHA) create and enforce their own ethical guidelines and practices. When conducting experimental research projects, it is important to ask, "How does ASHA Principle of Ethics I, Rule C apply to the conduct of research and scholarly activities?"

This question of ethics is particularly relevant to a study's participant selection. Practices of inclusion and exclusion when selecting participants may lead to over- and underrepresentation of specific populations. In school settings, SLPs run the risk of being negligent if they do not serve or refer children who do not fall within their clinical skill set. The same risks that our colleagues run with being ethically negligent, we argue are applicable to researchers. Oluo (2019) suggests movement for social change should consider all intersections of identity, power, and oppression. We consider how these elements impact BIPOC bilingual children below.

Underrepresentation in Participant Selection

In the United States, English monolingualism defines the standard by which language ability is measured (Cioè-Peña, 2017). This monolingual standard is reflected in what participants are selected to participate in research studies. Kohnert and Medina (2009) called attention to this selection bias specifically in intervention research. In a 30-year review of the literature in communication disorders, the authors identified only 46 publications that included bilingual children with language impairment in their study samples, 12 articles that included bilingual children with speech sound disorders, two case studies of acquired neuropathology, two with autism, and none with stuttering. Over a decade later, this lack of representation continues to be a problem. In the area of speech sound disorders, Irizarry-Pérez et al. (2023) document 11 bilingual participants across 13 studies that have been included in intervention research. That is, over the past 40 years, a notable absence of diversity exists in published research within the field of pediatric communication disorders. While the lack of bilingual participants included in research is a problem for children of bilingual backgrounds, Fabiano (2023) drew specific attention to the intersection of bilingualism and race in publication bias. The term *intersectionality* (Crenshaw, 1989) is used here to consider the unique impact of race/ethnicity, bilingualism, and other marginalized statuses on the lived experiences of children with communication disorders. In considering this impact, we must account for the social dimension of silencing, as described by Tripp (2023). We must consider which experiences have been obscured from publication by oppression.

The exclusion of bilingual, BIPOC children as research participants is an example of the racialization of bilingual children with disabilities described by Cioè-Peña (2021). Bilingual children are less likely to be valued for their linguistic variation in the way they communicate based on an English monolingual, White standard and thus less valued in the context of communication disorders when selecting participants for intervention research. This marginalization is not only unique to bilingual children but also directed toward bidialectal children who speak English differently from mainstream American English (MAE), including children from Black communities who use Black language (Baker-Bell, 2020).

Experiences of bilingualism and race likewise co-occur with other marginalized experiences that significantly shape children's communication. We are unaware of any speech intervention study that has included bilingual children with speech sound disorders that has also described those participants with diagnoses such as autism or attention-deficit/hyperactivity disorder. These two research paths rarely cross if at all, effectively erasing these individuals from the discussion. However, research environments should be prioritized for children with communication disorders regardless of ability or diagnosis, acknowledging also how these labels are socially constructed and the privilege attained in receiving one. The ramifications of the absence of diversity are important: (a) Despite best intentions to help others, socially constructed exclusion perpetuates systems of power and oppression within the profession, and (b) there are greater evidence-based intervention resources for monolingual, White children who speak MAE with otherwise typically developing abilities than for any other pediatric population with a speech or language disorder. The quantity and quality of intervention resources simply cannot be considered the same among populations.

The Role of Researchers

Fabiano (2023) raised the question, "Who is deciding what participants are included in our research?" ASHA demographics (ASHA, 2023) offer an answer: 91.1% of SLPs report being White, and approximately 8.3% of providers identify as being multilingual (ASHA, 2023). Additionally, of those providers who identify as being multilingual, only 46.2% identified as also being Latino (ASHA, 2023), which makes multilingual providers predominantly White as well. Finally, only 4.6% of those multilingual providers work in university settings (ASHA, 2023). If only a small fraction of the professional community represents minoritized populations, then White, monolingual researchers are designing intervention studies that include White, monolingual children (Fabiano, 2023). This effect is compounded by the fact that this research is then likely to be perceived as more favorable by other researchers who share a connection to the topic (Altenmüller et al., 2021). In essence, White, monolingual researchers may also be more likely to view research with White, monolingual children more positively.

A variety of studies have drawn attention to similar barriers present for researchers of color. Specifically, researchers of color may experience imposter syndrome; microaggressions at their place of work; ineffective mentoring; lack of institutional support; and, importantly, discrimination during the peer-review process (Girolamo et al., 2022; Horton, 2021; Mishra et al., 2021; Muñoz et al., 2023). These challenges may also include being accused of "me-search" when including populations that have been made invisible. Me-search can be defined as pursuing a scientific question when the answer is personally relevant for the individual (Altenmüller et al., 2021). While only pursuing personally relevant questions is at the ethical crux of this discussion, the same conversation has not occurred historically when only including White, monolingual children.

When participant qualities become normalized, exclusionary practices can be used as justification for research of a presumed higher quality. Furthermore, as Tripp (2023) identifies, when inclusion does occur, it may be used to support existing (White, monolingual) epistemologies toward diverse populations, and importantly, there is neither mandate nor incentive to avoid such research practices. These practices can be described as forms of cognitive imperialism (Battiste, 2005).

Case Study

As an example and to address this lack of diversity among bilingual participants, we present portions of a case study for a bilingual child with a speech sound disorder who presented with a profile that went beyond speech and language impairments. We evaluated a boy, Edgar (pseudonym), age 5;4 (years;months), whose mother expressed interest in participating in our research study. However, she expressed fear of sharing personal information due to being undocumented and had no means of transportation. We reassured her through a mutual contact of trust and evaluated Edgar via telehealth.

Edgar presented with a phonological and articulation disorder based on our initial assessments. He also had a previous diagnosis of a language disorder. He came from a home where he was reported to be exposed to primarily Spanish based on parent interview and attended a school where his instruction and speech therapy were delivered in English. He was reported by his mother to have difficulty in attending to activities and would become distracted quite easily both at home and at school, which was an additional area of concern for her. This was consistent with behavioral observations during our initial assessment and subsequent intervention sessions: Our students and the clinical supervisor had an incredibly difficult time completing intervention activities.

Although we overcame some behavioral barriers and we adjusted his targets, reduced the length of our tasks, provided increased physical breaks, and identified topics of high interest with his mother, Edgar still struggled to follow our research protocol. We were left with a limited data set that did not meet the needs of our experimental design. However, the value of this work is not in the data. Children such as Edgar are simply not visible in bilingual research because of our struggles as researchers to be inclusive enough to meet their needs. An important lesson was learned: Our research designs and treatment approaches for speech sound disorders need to be created for children such as Edgar.

Addressing Participant Selection in Research

This conversation leads to an important question: Where do we draw the line between inclusion and exclusion of individuals as potential participants? On one end, if we narrow down our participant pool to the skill set of the 92% of members who are monolingual, it is not surprising that we would have so few studies that include bilingual participants, for example. If we narrow down our participant pool further to those with neurotypical behavior, directly or indirectly through design, it is not surprising that we would be left with practically nothing.

On the other hand, it is clearly important to maintain high-quality research, implement evidence-based intervention approaches, and maintain experimental rigor as much as possible. This is a complex problem that will require a process in which we begin to dismantle a system of power. However, there are several areas where we can begin to start, which include abandoning the notion of objectivity in place of reflexivity and awareness of positionality, actively selecting and valuing diversity in study design, seeking collaboration, updating the peer-review process, and increasing access to the profession.

Abandon the Notion of Objectivity

Within the field, there is a strong value placed on data as being inherently objective. Indeed, data are incredibly helpful in identifying the effects of our interventions. Large group data offer powerful quantitative support. Contrastively, single-case experimental designs and visual analysis help identify trends among outcome measures. However, we must also acknowledge that all data are inherently biased along with our interpretation of it. This is exemplified in Reinisch's (2016) perception task in which perception of German tokens was influenced by the participants' belief of who the speaker was, using knowledge about the individual to discriminate between German words.

Tripp and Munson (2023) highlight how narrowing participant pools in search of objectivity fails to acknowledge how reflexivity and positionality influence research outcomes. Specifically, researchers must be aware of their subjective experiences and capacity to decide how knowledge is valued through their positions of power. In addition, this acknowledgment should be embraced. Only then can we begin to discuss different ways of knowing. The same is true for speech-language intervention, our views of speech and language difficulties, and our ways of classifying differences, which then inherently affect how we select participants and interpret the knowledge from the outcomes of our intervention.

When selecting project team members and participants, researchers can ask, "How might race, gender, sexuality, ability, class, and sex impact this topic?" (Oluo, 2019). Garivaldo and Fabiano-Smith (2023) stress the importance of including community insiders as members of the research team, which may help to answer these questions. Tripp (2023) suggests asking similar questions when approaching a research topic by considering power dynamics. That is, an alternative way to frame this is, "Who has been included/excluded from participating in this category, and how?" (Tripp, 2023). Rather than design our participant criteria based on socially constructed categories, or representational demographics, we can ask, "How has relative power affected outcomes in this area of study?" For many bilingual children in this country, like with Edgar, the legal status of their caregivers is an example of low power. If we, researchers, do not consider power, then we run the risk of only addressing the needs of the most powerful members of the class, even if they might be oppressed as well. Specifically, bilingual speech intervention can end up being designed for otherwise nondisabled, bilingual individuals with citizenship.

Actively Select Multiple Study Designs

Much of the research value can fall on design, with group design trumping many other factors including smaller, single-case experimental designs, which allow for individualization. However, scientific diversity is also incredibly important (Elman, 2022). Single-case designs, often used during early research, or those studying unique populations, are no less valuable. Since there is such a small knowledge pool, these studies may fail at times as researchers learn how to do research differently. And these experiences must be available to other researchers and have a home in ASHA journals. This research must be supported and valued for publication (Tincani & Travers, 2018) the same as neurotypical, monolingual, and group studies.

Extend qualitative research. Equitable research extends beyond typical quantitative research designs. Included in this discussion should be qualitative research, which can capture the experiences of our participants that quantitative data cannot account for. For example, outcome measures may identify that mass production trials during intervention have a greater effect on production accuracy for children with articulation disorders than production trials with fewer practice opportunities. However, if our client experiences our intervention as negative or fatiguing, what true value is gained? How does this affect the social validity of our findings?

In fact, qualitative research has the potential to avoid many pitfalls in our interventions. Qualitative research shows that bilingual caregivers strongly prefer bilingual speech intervention (Irizarry-Pérez et al., in press), yet this profession often provides ("high quality") monolingual intervention to bilingual families. These bilingual families may experience any monolingual protocol as insufficient despite the best empirical data supporting the approach.

Seek Collaboration

Interprofessional collaboration challenges disciplinary models that see knowledge as separated constructs that are not interconnected. Researchers of speech sound intervention cannot be separated from researchers of bilingualism, autism, or other developmental areas. Furthermore, the intention to expand intervention research cannot be placed solely on the shoulders of researchers of underrepresented or marginalized communities. Researchers must choose to have budgets for specialized staff, interpreters, or collaboration with expert colleagues in areas outside of our own. "I don't do [fill-in-the-blank] area or I am not [fill-in-the-blank]" can no longer be acceptable responses. Researchers must begin designs by considering children like Edgar and collaborating with each other from the start.

Update the Peer-Review Process

We are currently unaware of actionable policies by ASHA journals to address the challenges outlined here in participant selection. However, Girolamo et al. (2022) highlight that some ways in which biases can be mitigated or reduced are through diversifying reviewers, prioritizing underrepresented communities, and building in equity standards. Journals can begin to address equity standards in participant selection by requiring authors to describe how they have considered power and equity in participant selection. Requiring attention to the decisions made in participant selection can help to identify when this has not occurred and provide accountability as suggested by Tripp (2023).

Increase Access to the Profession

Finally, this profession must also fix the pipeline producing intervention researchers, which starts early in the educational process. However, as Ellis and Kendall (2021) describe, demographics are only the tip of the iceberg in academia. Structural and institutional policies of higher education are based on White, dominant culture. Do we not have enough students who represent minoritized groups in the United States, or are committees choosing not to recruit and accept those students to support their success (making narrow definitions of educational preparation and excluding them from this space)? Few SLPs report having bilingual skills (ASHA, 2023), and in general, SLPs report feeling uncomfortable working with bilingual populations (Santhanam & Parveen, 2018). However, this profession graduates students who are only prepared to work with monolingual populations while denying access to other students who could potentially enter our programs with those linguistic skills already present. By placing the value on bilingualism only if English skills are strong, this profession perpetuates elite multilingualism (Barakos & Selleck, 2019) while simultaneously perpetuating a deficit view of our bilingual students, many of which can (and do) begin as undergraduate researchers.

Bilingual skills do not represent "bonus" skills on a graduate application but rather essential skills for the profession.

Summary

This article argues for eliminating barriers to research studies that will result in greater participant representation and equity of clinical intervention resources. We argue for adherence to ASHA's Principles of Ethics by researchers alike. We must take advantage of opportunities to select designs that fall out of our comfort zone and our expertise. This might still require focusing on our participant pool. There can be legitimate reasons for doing so. However, we see a greater rationale for shifting our policies toward implementing inclusionary practices as described in this article.

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