Cultural Sensitivity and Responsiveness in Neurorehabilitation

A Personalized Approach for Speech-Language Pathologists

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Dr. Wallace obtained a BS from Miami University in Oxford, Ohio; an MA from the University of Colorado, Boulder; a PhD from Northwestern University in Evanston, Illinois; and postdoctoral training at the University of Arizona, Tucson and the Boston V.A. Dr. Wallace has had an illustrious career that spans 40 plus years, during which time she has served as Professor, Endowed Professor, Department Chairperson and Graduate Program Director, Medical SLP and Neurorehabilitation Coach and Advocate for people with neurogenic disorders, and Mentor to junior faculty and students (with a desire to help fill the speech-language pathology pipeline with the best and brightest future leaders).

Dr. Wallace specializes in neurogenics, with a focus on adult aphasia, and a special interest in people from underserved communities. This is her third neurogenics book. Dr. Wallace's current research includes the development of an assessment *system*, the Reliable Assessment Inventory of Neuro-Behavioral Organization

(RAINBO), designed for people from diverse backgrounds who have communication, cognitive, and swallowing impairments. It is her vision that the RAINBO will support the selection of evidence-based treatments and prediction of life participation outcomes.

Dr. Wallace is an ASHA Fellow, Board Certified by the Academy of Neurologic Communication Disorders and Sciences (ANCDS), and licensed to practice in North Carolina, California, Ohio, and Hawai'i. She is a recipient of the ANCDS Special Recognition for Leadership and Contributions to Neurogenics Award, and the National Black Association for Speech-Language-Hearing Association (NBASLH) Scholar Mentor Award. Dr. Wallace, is ordained as both an Interfaith and a Christian Minister, with extensive Chaplaincy training in medical contexts.

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1 Finding Our North Star: Introduction to Multicultural Neurogenics and Personalized Speech-Language Neurorehabilitation Care for People From Diverse Communities

Gloriajean L. Wallace

Definition of Multicultural Neurogenics

This compendium is a follow-up to a book edited 27 years ago on the topic of *multicultural neurogenics* (Wallace, 1997). Multicultural neurogenics refers to the study of many cultures and the impact those cultures may have on the design, implementation, and life participation outcomes for people with neurogenic communication, cognitive, and swallowing disorders. As the term "multicultural" (many cultures) implies, there are a myriad of possible cultural group memberships, including race, ethnicity, culture, language use, preferred communication style (e.g., oral communication or sign language), gender orientation, age, ability, religious preference, country of origin, immigration status, and consideration of intersectionality across these categories and more. The term multicultural neurogenics is grounded firmly in the World Health Organization's International Classification of Functioning, Disability and Health model (WHO ICF), a psychosocial model where environmental support is valued and case-centered care is at the heart of all that is considered (WHO, 2001; Threats, 2012). Attentiveness to intragroup contrasts and idiosyncratic differences—unique to each person—are equally important to identify, recognize, and consider. Although some of the terminology used to discuss multicultural neurogenics has changed over the years, the essential points remain the same. For example, concepts such as cultural sensitivity and responsiveness (title of this book); diversity, equity, and inclusion (DEI);

intersectionality; and implicit bias are discussed in nearly every chapter, beginning with indepth coverage of these topics by Davis and Anderson in Chapter 2 of this book. All groups recognized by the United States Census Bureau are considered, with attention to the influence of multiple identities (intersectionality) on the design and implementation of neurorehabilitation care. Becoming aware of how to personalize care for people from minoritized communities provides a framework that can enhance care for all cases. In the face of limited available research to guide neurorehabilitation care of people from diverse communities, diversity matters warrant our attention—"*Diversity Matters*."

The Current Volume Leading to Our North Star

This current volume has truly been a labor of love, with the assistance of over 100 contributors. The final book manuscript presented here is different in breadth and scope from what was originally intended. This was by necessity, given the need for content expansions over the course of several years as we forged through an international pandemic, quickly changing advances in technology, national and international sociopolitical crises, and ramifications these factors have had on the speech-language pathology neurorehabilitation care that providers were and continue to be faced with today. With these things in mind, this book has been developed, revised, expanded, and then revised again, culminating in the most comprehensive presentation of multicultural neurogenics information that is available at this time. It is my vision that in 10 years or so, the next generation of neurogenics leaders will have expanded upon information presented here to support even more equitable neurorehabilitation care for people with neurogenic disorders who are from diverse communities. For now, this volume is intended to serve as an "A to Z" compendium for the reader.

For now, you are invited to embrace and allow material here to serve as your neurorehabilitation diversity North Star.

North Star Vision for the Book

The North Star (also known as Polaris) marks the location of the sky's northernmost pole around which the entire northern sky rotates. Because of its constant presence, the North Star can always be counted on to help locate the direction of true North.

- In ancient Egypt, the North Star was associated with the god Thoth, who was believed to represent wisdom and guidance.
- In Norse mythology, the North Star was a "jewel on the end of a stake"; a jewel that the gods had stuck through the universe for the entire sky to revolve around.
- According to people from the Mongolian Empire, the North Star was a peg that held the world together.
- Across time, both navigators by sea and travelers by land—in many demographic groups all over the world—used the North Star to determine location; especially helpful when away from the comfort and familiarity of home. The word for Polaris (meaning *steadfast*

star), for example, is Hōkūpa`a in the Hawaiian language.
- For African slaves in the United States, the North Star represented the map to freedom.

Metaphorically, a North Star is what inspires and influences us.

From a speech-language pathology (SLP) perspective, it is our ethos; the spirit of our professional culture that drives us with relentless passion to be the best that we can be as we serve the diverse clientele that we are graced to serve. It is with this spirit that the more than 100 contributors to this book and I invite you to join in on the journey where neurorehabilitation specialists and people with neurogenic disorders navigate alongside you with the hope that you will achieve greater knowledge, understanding, cultural sensitivity, responsiveness, and empowerment to provide stellar, personalized, and therefore equitable care for all.

Who We Are: A Snapshot of the ASHA Membership

Race and Ethnicity 1972–1984, 2013–2022

In 1972, 1% of the ASHA membership reported that they were from a minoritized group (Cole, 1985). Out of a total ASHA membership of 15,554 persons at that time, 176 reported as Black, 11 as Asian or Pacific Islander, 13 as Hispanic, and two as American Indian or Native Alaskan (Cole, 1985). Those are shocking figures. The overall percentage for minority ASHA membership increased to 2% in 1978 and then again in 1983 to 3.6%, when 650 reported race as Black, 345 reported race as Asian or Pacific Islander, 312 reported race as Hispanic, and 171 reported race as American Indian or Alaska Native (Cole, 1985; refer to Table 1–1).

Table 1–1. Data Page: Racial/Ethnic Demography of the ASHA Membership (Cole, 1985)

Year	*1972*	*1976*	*1978*	*1980*	*1982*	*1984*
Whites	15,554	24,180	32,019	35,327	37,022	39,828
Blacks	176	164	271	442	475	650
Asians (or Pacific Islanders)	11	74	86	161	204	345
Hispanics	13	40	71	135	194	312
American Indians (or Alaskan Natives)	2	8	17	31	49	171
Total ASHA Members	15,756	24,466	32,464	36,096	37,944	41,306
Total and	202	286	445	769	922	1,478
Percent Minority	1%	1%	2%	2%	2%	3.6%

Source: Data from 1978 to 1984 are from the ASHA Membership Update Survey and Annual Count Report. Data from 1972 to 1976 are from the ASHA Voluntary Ethnicity/Sex Questionnaire.
Note: Includes nonresponses to race/ethnicity items. For 1976, it also includes responses to the survey items "mixed ethnicity" and "other."

The number of racially and ethnically diverse ASHA members has continued to increase, although only to a small extent from 2013 to 2022 (ASHA, 2022). This is evidenced by demographic data self-reported for race (refer to Table 1–2) and ethnicity (refer to Table 1–3) provided by ASHA members and nonmembers who were certified in speech-language pathology only during this time (ASHA, 2012–2023).

Race and Ethnicity Reported by ASHA Special Interest Group 2 Members (Neurogenics SIG)

It was of great interest to explore the racial and ethnic makeup of speech-language pathologists (SLPs) who specialize in neurogenics, the focus of this book. However, at present, there is no direct link between the area of speech-language pathology specialization and racial/ethnic identity. Many neurogenics specialists are members of ASHA SIG 2, which is the neurogenics-designated Special Interest Group. However, not all neurogenics specialists are members of ASHA SIG 2, and it is not a requirement to be a member of ASHA SIG 2 to specialize in neurogenics. It was judged that information about the racial and ethnic composition of ASHA SIG 2 would, at minimum, provide a general sense of diversity representation in neurogenics. Membership data presented in Table 1–4 highlights that a low percentage of persons from minoritized groups are members of ASHA SIG 2 (ASHA, 2023). This is despite a slight increase over the past 11 years (2012–2023) in the number of SIG 2 members who recorded their race as non-White as compared to the number who identified as White. It is important to note that the observed slight increase is for the total number of non-White SIG 2 members (Black, Hispanic/Latino, Asian, and Native people groups), and therefore is not likely to represent a substantial increase for any one subgroup. For confidentiality reasons, it was not possible for ASHA to retrieve and send data for specific racial subgroups, which would have provided information to clarify whether number increases occurred in specific groups or simply in the overall number of persons (because of small subgroup changes).

Information about the small number of ASHA SIG 2 members who self-identified as Hispanic/Latino ethnicity as compared to non-Hispanic/Latino ethnicity from 2012–2023 is presented in Table 1–5 (ASHA, 2023).

Also of interest is a small—but not dramatic—increase in the number of ASHA SIG 2 members who identified as having Hispanic/Latino ethnicity during this time.

As noted earlier, not all neurogenics specialists join a special interest group, so there may in fact be people with racially and ethnically diverse identities who are not members of ASHA SIG 2. However, the low number of ASHA 2 SIG members who identify as being from a racially minoritized group and the low number of ASHA SIG 2 members who identify as being of Hispanic/Latino ethnicity suggest that efforts are needed to attract, recruit, and support neurogenics specialists of color (Black, Hispanic/Latino, Asian, and Native people groups). This includes expanded opportunities to serve in leadership roles.

Given the small number of racially and ethnically diverse persons who likely specialize in neurogenics, it is imperative that all clinicians, regardless of race or ethnicity, view their role as an important one that is critical for establishing personalized, equitable care for all neurogenics cases seen.

Table 1–2. Demographic Profiles for Race, as Self-Reported by ASHA Members and Nonmembers Certified in Speech-Language Pathology Only, 2013–2022

Year	*2013*	*2014*	*2015*	*2016*	*2017*	*2018*	*2019*	*2020*	*2021*	*2022*
Total Reporting =	138,433	144,253	150,468	156,254	162,473	168,604	175,025	181,628	188,143	193,799
Total Reporting for Race =	110,688	111,845	112,753	113,282	143,291	147,474	150,633	181,628	166,466	168,359
American Indian or Alaska Native	.3%	.3%	.3%	.3%	.3%	.3%	.3%	.3%	.3%	.3%
Asian	2.1%	2.2%	2.2%	2.3%	2.5%	2.5%	2.6%	2.8%	2.9%	3.0%
Black or African American	3.4%	3.5%	3.6%	3.6%	3.5%	3.5%	3.6%	3.6%	3.6%	3.7%
Native Hawaiian or Other Pacific Islander	.2%	.2%	.2%	.2%	.2%	.2%	.2%	.2%	.2%	.2%
White	92.6%	92.5%	92.4%	92.3%	92.2%	92.1%	91.9%	91.8%	91.6%	91.4%
Multiracial	1.4%	1.4%	1.3%	1.3%	1.3%	1.3%	1.4%	1.4%	1.4%	1.5%
Total % Minoritized	7.4%	7.6%	7.6%	7.7%	7.8%	7.8%	8.1%	8.3%	8.4%	8.7%

Table 1–3. Demographic Profiles for Ethnicity, as Self-Reported by ASHA Members and Nonmembers Certified in Speech-Language Pathology Only, 2013–2022

Year	*2013*	*2014*	*2015*	*2016*	*2017*	*2018*	*2019*	*2020*	*2021*	*2022*
Total Reporting =	138,433	144,253	150,468	156,254	162,473	168,604	175,025	181,628	188,143	193,799
Total Reporting for Ethnicity =	116,235	115,789	115,168	114,813	145,750	149,822	153,016	166,264	169,311	171,310
Hispanic or Latino	4.6%	4.7%	4,7%	4.8%	5.1%	5.3%	5.5%	5.9%	6.2%	6.3%
Non-Hispanic/ Non-Latino	95.4%	95.3%	95.3%	95.2%	94.9%	94.7%	94.5%	94.1%	93.8%	93.7%

Table 1–4. Race as Reported by ASHA SIG 2 (Neurogenics) Members 2012–2023

Membership Year	*Total SIG 2 Members*	*Total SIG 2 Members Declaring Race*	*% White*	*% Non-White*
2012	3,980	3,583	91.49%	8.51%
2013	4,419	3,946	90.93%	9.07%
2014	4,643	4,168	91.03%	8.97%
2015	4,809	4,370	90.69%	9.31%
2016	4,988	4,489	90.18%	9.82%
2017	4,797	4,365	90.47%	9.53%
2018	4,523	4,074	90.28%	9.72%
2019	3,853	3,494	90.35%	9.65%
2020	3,389	3,055	89.00%	11.00%
2021	3,179	2,794	89.23%	10.77%
2022	2,928	2,608	87.81%	12.19%
2023	2,643	2,377	87.13%	12.87%

Table 1–5. Ethnicity as Reported by ASHA SIG 2 (Neurogenics) Members, 2012–2023

Membership Year	*Total SIG 2 Members*	*Total SIG 2 Members Declaring Ethnicity*	*% Hispanic/ Latino*	*% Not Hispanic/ Latino*
2012	3,980	3,714	3.90%	96.10%
2013	4,419	4,106	4.82%	95.18%
2014	4,643	4,339	4.31%	95.69%
2015	4,809	4,538	4.43%	95.57%
2016	4,988	4,687	4.89%	95.11%
2017	4,797	4,550	4.97%	95.03%
2018	4,523	4,257	5.40%	94.60%
2019	3,853	3,643	5.52%	94.48%
2020	3,389	3,188	5.49%	94.51%
2021	3,179	2,928	6.18%	93.82%
2022	2,928	2,713	6.23%	93.77%
2023	2,643	2,468	5.92%	94.08%

Diversity Focus to Date

To date, the prevailing clinical interest in diversity within the professions of speech-language pathology and audiology has focused on pediatric populations, most notably the issue of whether to treat phonological and syntactical language and dialect differences. While these are important matters, the need to personalize care cuts across all disorder areas and is of importance to cases seen across the full age spectrum of care. This is especially true for areas in the realm of neurogenics, given the prevalence and incidence of medically based communication, cognitive, and swallowing disorders due to, for example, stroke (Acosta et al., 2021; Caughey et al., 2014), traumatic brain injury (Johnson & Diaz, 2003), Alzheimer's disease (Chin et al., 2011), multiple sclerosis (Langer-Gould et. al., 2022), Parkinson's disease (Bailey et al., 2020), and other etiologies among people from diverse communities. This is significant for the continuing growth of diverse (and diverse aging) populations in the United States (Vespa et al., 2020) and of international aging populations migrating to the United States (Feigin et al., 2020). Attention is sorely needed when one considers that speech-language pathology neurogenics specialists are expected to provide quality care in the absence of evidence-based research to guide best practices assessments and interventions for people from diverse communities (Wallace et al., manuscript in progress).

Neurorehabilitation Needs Assessment for People of Color

Given the prevalence of risk factors associated with neurological impairment among people of color (see Mullen and Wallace, Chapter 30 of this book), one would suspect that many cases on the typical neurogenics caseload include people of color. Research is needed to explore this. Health disparities, social determinants of health factors, and reduced knowledge about the availability and benefits of rehabilitation services are but a few of the reasons why caseloads may not include as many people from diverse communities as expected.

Research is needed to explore the SLP neurogenics caseload racial/ethnic composition, barriers to service these patients sometimes face, and the range of other issues confronting SLPs who work with neurogenics cases from diverse communities. To date, only one study has investigated these issues in a formal and comprehensive manner exploring matters of relevance to a wide array of cases from diverse communities (Wallace & Bridges, 1991). It would be interesting to replicate this study to obtain insights into current preferred practices and patterns of SLP care for cases from diverse communities. Two studies—one focusing on the perceived adequacy of diversity training provided by educational programs (Stockman et al., 2008) and another focusing on neurorehabilitation services delivered to bilingual neurogenics patients (Centeno, 2000)—provide useful information about preparedness for providing services to people from diverse communities and about the provision of services specifically for bilingual patients needing neurorehabilitation. Replication of these studies would also be of interest to gauge and compare perceptions and judgements about strides made in diversity training and preparedness.

We now turn our attention more directly to clinical issues. It will be helpful at this point to pause briefly, reflect, and examine our own level of preparedness for work with diverse populations.