Considering Disability Culture for Culturally Competent Interactions With Individuals Who Stutter

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ABSTRACT: Purpose: This article focuses primarily on disability culture for individuals who stutter. A firm understanding of disability culture related to stuttering among professionals in communication sciences and disorders could reduce misunderstandings and culturally insensitive statements or behaviors during interactions with individuals who stutter.

Method: This article reviews (a) the importance of cultural competence during interactions with individuals with disabilities, (b) the culture of disability and its relevance to individuals who stutter, (c) examples of interactions that could be perceived as inappropriate by individuals who stutter, (d) the importance of increasing understanding of stuttering, (e) recommendations for interactions with individuals who stutter, and (f) ways of integrating education in disability culture to course work in fluency disorders.

Conclusion: Disability culture should be considered as part of the cultural competence curriculum in order to prepare graduate students for best interactions with individuals who stutter.

KEY WORDS: cultural and linguistic diversity, fluency, fluency disorders, psychosocial issues, stuttering
stutters. When Nick introduces himself to Tammy, he tells her that he is looking forward to working with her, and that he has always considered people who stutter (PWS, this acronym will also stand for "person who stutters") to be very smart and courageous. Tammy rolls her eyes and walks away from the interaction. Nick is perplexed at Tammy’s disapproval of his comments.

What is happening in these two situations? Interactions between individuals with and without disabilities can be challenging because of misunderstandings regarding appropriate behavior. Both Sandra and Nick were apparently going out of their way to give compliments, demonstrate a positive attitude, and be supportive of David and Tammy. However, it was not received that way by David or Tammy. In these cases, the very meaning of what constitutes a positive attitude toward stuttering was not shared between the individuals in the interactions, and this misunderstanding caused stress and frustration. What the helpers in these two scenarios interpreted as positive may have been interpreted as condescending, patronizing, or infantilizing by the PWS. Even worse, the PWS may have mistakenly attributed the words of the communication partner to negative intent, and the actions and responses of the PWS may have been mistakenly attributed to rudeness, rather than each person in the interaction attributing the communication difficulty to different perspectives on what a positive attitude actually means. In the end, each person walked away from the experience feeling upset, making it less likely that they will have a positive interaction in the future.

The potential for strained interactions due to discrepancies in expectations between individuals with and without disabilities has been documented in cases of blindness and other physical disabilities (Makas, 1988) as well as in cases of cognitive impairments (Eddey & Robey, 2005). According to Conyers (2003), taking into account the disability culture model in the rehabilitation curriculum is vital for broadening the perspectives of students and increasing their critical thinking skills about the very nature of disability. Eddey and Robey (2005) echoed this sentiment and stated the importance of including education in disability culture to enhance cultural competence in students and professionals in health care fields, including physicians.

In communication sciences and disorders (CSD), Dollaghan (2007) emphasized that it is critical for speech-language pathologists (SLPs) to understand the values and beliefs of individuals with communication disorders in order to maximize the effectiveness of treatment and provide true evidence-based practice to clients. In addition, several articles have been written in recent years describing the importance of professional and preservice SLPs demonstrating cultural competence (e.g., Dixon, 2014; Griffer & Perlis, 2007; Torres, 2015).

It should be noted that all of the authors of this article are PWS and also professional SLPs, clinicians, or researchers in the area of stuttering. We have all experienced situations and circumstances similar to those described in this article. From our combined personal and professional experience, we have also interacted with hundreds of individuals who stutter across many age groups in a variety of clinical, self-help, and informal settings throughout the course of our lives. We have had the chance to observe many interactions between SLPs and individuals who stutter, as well as having conversations with PWS and social activists about how certain interactions with members of the public and professionals can be frustrating. This frustration seems to hinge on the perception of many PWS that individuals who do not stutter perceive stuttering and disability differently than do individuals who are living with the condition.

From our accumulated experiences, we believe that the discussion about disability culture should be initiated in the field of CSD in order to improve students’ and professionals’ cultural competence when interacting with PWS and therefore improve communication with these individuals. Before discussing the disability culture model, it is important to review the definition of culture itself, the meaning of cultural competence, and its relevance to ethical service provision in the field of CSD.

**Cultural Competence in CSD**

A common definition of culture from the field of anthropology is “a system of shared beliefs, values, customs, behaviors, and artifacts that the members of a society use to cope with their world and one another, and that are transmitted from generation to generation through learning” (Bates & Plog, 1991, p. 4). The American Speech-Language-Hearing Association (ASHA) describes key issues related to cultural competence on their practice portal. ASHA states that cultural competence involves understanding and responding to unique combinations of cultural variables that both the professional and client bring to interactions (e.g., ability, beliefs, ethnicity, gender, national origin, race, religion, sexual orientation, and others) (ASHA, n.d.). Cultural competence and the ability of professionals to provide culturally appropriate services are also discussed in ASHA’s scope of practice as one of the major priorities and responsibilities of SLPs (ASHA, 2007).
According to ASHA, important steps for developing cultural competence related to service delivery include (a) being aware of cultural dynamics (e.g., values, beliefs, traditions) during interaction with a client or family; (b) being able to adapt to diversity and address cultural differences; (c) understanding and reflecting on the impact, however subtle, of one’s own culture and how it may impact service delivery; (d) viewing cultural competence as an ongoing process requiring self-assessment and continual acquisition of cultural knowledge; and (e) valuing diversity (ASHA, n.d.). ASHA uses the term cultural humility to communicate the notion that professionals must continue to critically evaluate their own level of cultural competence. ASHA states that SLPs and audiologists must recognize cultural variables that they do not understand, actively seek to gain relevant knowledge and experience with the culture of the individuals they are serving, and adjust their attitudes and behaviors accordingly (ASHA, n.d.).

What is the real importance of professionals in CSD demonstrating cultural competence in their interactions with individuals from other cultures? According to ASHA, “crucial miscommunications” can result from cultural variations between communication partners. These miscommunications can have negative effects on interactions between communication partners and harmful implications for clinical service, including assessment and treatment (ASHA, n.d.). Examples of cultural mismatches, or miscommunications, were demonstrated in the two opening scenarios in this article. In those examples, communication broke down because of a difference in shared meaning about what constitutes a positive or helpful attitude about stuttering.

Eddey and Robey (2005) stated that professionals in health-related fields tend to be more familiar with cultural competence related to beliefs and values associated with age, gender, or racial, ethnic, or religious backgrounds, and not as familiar with cultural competence related to disability culture. These authors stated that disability culture should be emphasized as a type of culture that could have significant implications for interactions and service delivery for clients. We agree, and we believe that the notion of disability culture should be included in cultural competence education in fluency disorders. The following section describes disability culture and its relevance for PWS.

Disability Culture for Individuals Who Stutter

Disability culture originated in the 1960s with the Disability Rights Movement because societies and institutions were not always sensitive or accommodating to the needs of people with disabilities (Reid-Cunningham, 2009). As a result, laws were created to address these concerns, such as the American Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990. Disability culture has been defined in a number of ways (Reid-Cunningham, 2009). According to one description by Brown (2002, p. 48),

People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives and our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity.

This definition of disability culture contains three important components that must be emphasized in order to engage in a meaningful discussion about disability culture and its application to PWS: (a) shared history, (b) expression of identity and meaning, and (c) pride.

First, people with disabilities share common histories of oppression and resilience. Due to differences in how they experience the world (e.g., hearing, visual, motor difficulties), many have experienced a lack of access to important parts of society, such as public transportation and wheelchair ramps for individuals with ambulatory difficulties, or Braille signs for individuals with visual difficulties or blindness. In addition, people with disabilities have experienced discrimination in terms of employment, housing, and negative societal attitudes. As a result of these collective histories, many people with disabilities have formed bonds of support.

Second, people with disabilities have expressed meaning about their identity and experiences through various forms of art. Books, artwork, poetry, YouTube videos, and blogs are a few examples of the ways in which individuals have redefined what it means to live with a disability. And third, disability culture emphasizes pride, rather than shame, of the disability. Individuals in a culture of disability see disability as a cultural characteristic rather than as something that needs to be changed. There are cultural traditions associated with the disability, such as ways of talking or behaving. For example, individuals who identify with Deaf culture use sign language to communicate. In addition, there are schools and universities that have been created for individuals who identify as Deaf. These cultural practices are viewed as different ways of expressing the richness of what it means to be human (McDermott & Varenne, 1995).

Given that disability culture involves a community of people who navigate life differently because of a difference in ability, one might ask, is there a
culture of stuttering? We contend that, yes, there is a culture of stuttering. PWS have common histories of oppression and resilience. For example, many PWS have experienced employment discrimination, unjust school experiences, conversational partners completing their sentences, and overall negative public opinions. As a result, they have developed shared beliefs, behaviors, customs, and artifacts that they use to navigate a world that prioritizes fluency. For example, PWS have developed self-help groups, websites, creative writing, social networking groups, music, podcasts, bracelets, and t-shirts that embrace stuttering.

Common stories told by PWS include difficulty with introducing oneself, using the telephone, word-substituting, disclosing that one stutters, and reaching acceptance of stuttering. Furthermore, although it is acknowledged that some PWS choose to use techniques to modify or reduce the frequency of stuttering, others choose to embrace their stuttering and not make volitional changes to their speech. In this article, we highlight the idea that for some people, stuttering is not a source of shame but rather is a source of pride. PWS are a diverse group, and one should not assume that all PWS desire the outcome of being perceived as a fluent speaker. A relevant example of this perspective can be seen from the following quote:

I stutter more because I do not want to live in (nor help create) a world that normalizes bodies and discriminates against those who do not fit in. I take pride in my stutter as a way of resisting communicative expectations that are supposed to make me feel ashamed and are supposed to silence me. Stuttering more and stuttering proudly turns the tables on all those people who assume that, given a choice, I would rather talk just like them.

I wouldn’t. These are our voices. Deal with it. (St. Pierre, 2014)

Because there are PWS who choose to embrace stuttering as part of their identity, it is important to discuss problematic interactions that assume that fluency is the gold-standard way of communicating. By bringing these interactions to the forefront, we hope to minimize misunderstandings such as the ones presented in the opening scenarios in this article.

Inappropriate Interactions With PWS

Misunderstandings happen frequently in communication exchanges. As you read this, you can probably recall multiple misunderstandings you have experienced during the course of a day. When one reflects on the factors involved in communicating a message effectively, it is easy to see how messages can be misinterpreted. As professionals in the field of speech-language pathology, the help we offer usually comes with the best of intentions; however, as mentioned earlier, there may be a mismatch between these intentions and the expectations of our listeners. In this section, we discuss interactions that could be perceived as inappropriate when communicating with a PWS.

Minimizing the experience of stuttering. One example of an inappropriate interaction is when individuals minimize the impact that stuttering has on a person’s life. For instance, when an individual discloses stuttering and communicates the negative experiences endured as a result of stuttering, a person might respond with, “Yeah, but you don’t stutter that badly.” Or, a person may state another expression that diminishes the person’s experience with stuttering by saying, “Well, I never hear you stutter, so it can’t be that bad.”

Although likely not the intention of the listener, a PWS might interpret this response to mean that his or her problems may not be important to the other person. The assumption revealed in this statement suggests that because someone does not stutter “bad,” it must mean that the person is not impacted by stuttering in any other way. Making a statement such as this may lead a PWS to feel guilty for sharing his or her stuttering or disclosing information about it. Just as dangerous is the possibility that the PWS was avoiding or hiding stuttering during the interaction. The listener’s minimization of the problem may reinforce the decision of the PWS to avoid or hide stuttering. In essence, what the PWS may hear is, “Keep hiding it, you sound good like this.” Feedback like this might make it even harder for PWS to disclose and be open about their stuttering.

Unsolicited observations and advice. Another illustration of an inappropriate interaction with PWS is when unsolicited observations or advice are given related to stuttering. We have often observed parents, members of the public, and SLPs offer unsolicited suggestions to a PWS regarding his or her speech. Often, these observations are overly simplistic in the form of advice for how to better manage stuttering. For example, after communicating with a PWS, an SLP might make a statement such as, “That person could really use some easy onsets in his speech,” or “You really need to focus on your respiratory support and improve your eye contact when in stuttering moments.” Such statements can be problematic for many reasons. First, suggestions like these (a) put PWS in a position of presumed need, (b) assume that PWS are victims, and (c) attack POS’s sense of normalcy. In other words, just because a person is stuttering does not mean that the person needs or wants advice on how to manage his or her stuttering. This is
especially true for individuals who have entered a culture of stuttering in which they do not value fluent speech as a priority, do not believe that they are impaired, and have no desire to be “fixed.” There does in fact appear to be a growing culture of acceptance, empowerment, and pride among PWS that does not value or desire fluent speech (Meredith & Harrison, 2015; Rentschler, 2007).

Certain unsolicited observations can also be perceived as patronizing, as the person providing the advice can be viewed as conveying a sense of superiority over the PWS. Other examples of simplistic advice that might be considered patronizing include recommendations of slowing down, relaxing, or thinking about what to say before talking. Such statements are not only patronizing, they also minimize the complexity of the disorder and the person’s experience with stuttering. Infantilizing statements toward PWS should also be avoided. One of the authors of this article has heard members of the lay public, and even professional SLPs, make comments in a somewhat surprised manner about how smart PWS are. While presenting his research at a poster presentation at a state conference, one of the authors of this article was approached by an unfamiliar SLP claiming to specialize in stuttering. This professional asked the presenter if he stuttered, and when this was confirmed, the SLP stated in an infantilizing manner that perhaps one day he would be presenting an oral presentation. This faulty assumption on the part of the SLP that the author likely had little public speaking experience was in conflict with the fact that at the time, he had lectured to hundreds of students in a week and had already given several oral research presentations to large groups. Statements like these that sound patronizing or infantilizing can attack PWS’s sense of being normal, competent, or ordinary.

Another example of an unsolicited observation is making the assumption that any stuttering would prevent an individual from communicating well. For instance, this observation is often described as occurring during a speech and language screening of individuals who wish to enter the field of speech-language pathology. For a PWS, there may be concerns in an academic program that because a person stutters, he or she may not be able to pass the screening. This perspective can be problematic because it limits a PWS’s employment choices and assumes that the person cannot be an effective communicator and SLP (Quesal, 2012). Furthermore, the PWS may internalize these comments, and feelings of inferiority may emerge.

It is perhaps important to remind current and future professionals in the field of speech-language pathology that PWS have a rich history in the development of the field as a serious scientific enterprise. In fact, Charles Van Riper and Wendell Johnson, two of the pioneers in speech-language pathology, were PWS. It is fortunate that Van Riper and Johnson did not let the negative or limiting attitudes of others deter them from entering the field and excelling in it. How many other clinicians in our field may have been discouraged from entering the field when confronted with these types of negative attitudes? PWS can be successful in many vocations that require frequent oral communication in addition to speech-language pathology. For example, we have seen individuals who stutter succeed in vocations such as trial lawyer, emergency room physician, intelligence analyst for the Federal Bureau of Investigation, police officer, chief executive officer of a large corporation, and many others (Wen, Neufville, Almeida, & Anderson, 2014). It seems clear that stuttering does not need to prevent a person from pursuing a career that requires oral communication skills.

**Focusing all attention on fluency.** Another example of an inappropriate interaction when communicating with a PWS who is in a supportive disability culture is commenting only on their speech fluency. Examples of this might be professionals telling a PWS that he or she sounds great when the person happened to be producing fluent speech at that particular time. By making such comments and not understanding the person’s experience with his or her stuttering, the listener is making the assumption that speech fluency is important for the PWS. In interactions such as these, a PWS may be led to believe that stuttering is unacceptable and he or she should be focusing only on speech fluency. If the person is stuttering, then he or she must not be doing a good job and does not sound great.

Interactions that focus all attention on fluency minimize the complexity of effective communication and reinforce the false dichotomy of either being fluent (success) or stuttering (failure). Speech fluency is not synonymous with effective communication. There are many individuals who are extremely fluent who may be categorized as ineffective communicators. Although these individuals may be very fluent, they might also talk over their communication partners, constantly interrupt others when they are talking, make poor eye contact, demonstrate a lack of turn-taking in a conversation, show ineffective listening skills, be unable to clearly state to their communication partners their wants and needs, and be unable to summarize their ideas and convey these thoughts concisely to others. On the other hand, a person with disfluent speech can also be passionate and persuasive, have appropriate pragmatic skills, convey information effectively, and make an emotional connection with communication partners.
In addition to the preceding problems with focusing purely on fluency, if the PWS is in a disability culture, praising the person for fluency may actually be perceived as offensive. In essence, praising or rewarding fluent speech assumes that the PWS highly values being a fluent speaker and considers it an important part of his or her self-concept, which not every person who stutters does (Boyle, 2013; Venkata-giri, 2009). In addition, making stuttering salient and defining can have the effect of making the PWS feel as if speech fluency is the only thing that the listener cares about, and that other important aspects of the person are being neglected. One of the authors was at a research conference and ran into an SLP acquaintance that he had not seen in several years. Since they had last seen each other, the author had shifted into an acceptance and empowerment focus and no longer viewed fluency as a prime indicator of success. Rather than focusing on the content of the author’s research, the fact that he had become an ASHA-certified SLP and obtained a doctoral degree and tenure-track faculty position, or any other important developments in his life since their latest interaction, the acquaintance focused on speech fluency and commented on how great the author sounded. Focusing purely on speech fluency in situations like this put the author in a position of presumed need and attacked his sense of normality and competence. It also seemed to overshadow other, more important aspects of himself.

It is important to reiterate our understanding that professionals are not intending to be offensive or inappropriate in situations like these, and most act out of genuine care and compassion. It appears to be the case, however, that most professionals in CSD have adopted a perspective on disability that falls in line with the biomedical model, which is the most well known in our society, with the longest history and deepest roots (Smart & Smart, 2006). The biomedical model emphasizes the notion that an objective pathology resides within the individual. The normative aspect of this model is the notion that one day, it may be possible to eliminate the disability so that the individual can become “normal” (Fine & Asch, 1988; Smart & Smart, 2006). For example, the medical community often contrasts an impaired body before treatment (signifying failure) with a repaired or cured body after treatment (signifying achievement; Harrison & Kahn, 2004). This would be similar to before and after videos of PWS in which the person stuttered severely before treatment and was very fluent after treatment. But again, it is important for professionals to be aware of other models and perspectives of disability that do not conform to the biomedical model, such as the cultural model of disability (Conyers, 2003) being described in this article. There is also a social model of disability that has recently been discussed as it pertains to individuals who stutter (Simpson & Everard, 2015). This model views a disability as being socially constructed rather than existing intrinsically within the individual. Individuals who view disability from the cultural or social model may feel pride and empowerment, not shame, in their identity and view stuttering as a unique and important aspect of who they are. Therefore, in order to prevent misunderstandings and improve interactions with PWS, we offer important suggestions for understanding and interacting with PWS in the next sections of this article.

**Increasing Understanding About the Nature of Stuttering**

For many people, interacting with a person with a disability might bring about feelings of discomfort. Perhaps the reason for this is that people are unsure how they should act, or are afraid of offending the person with the disability. Many people might believe that it is simply easier to avoid talking to a person with a disability altogether than to attempt to figure out how to interact appropriately. However, this is not a viable long-term option, as effective communication between these disabled and nondisabled individuals is crucial.

Many PWS might feel as if they have a disability, not only because speaking can be difficult, but also because of how listeners respond to their speech. One’s first reaction while talking with a PWS might be one of surprise. Most people in the general public are probably not prepared to communicate with a person who has difficulty speaking when this is a skill that most people take for granted. A person might be taken aback by the secondary behaviors exhibited by the PWS, such as excessive muscle tension or sudden head movements. It could be countered that although members of the lay public are uncomfortable interacting with PWS, SLPs would not have this problem because they are the primary professionals responsible for the proper assessment and treatment of stuttering. Although SLPs should demonstrate knowledge of the nature of stuttering and skills in interacting with PWS, unfortunately, this is not always the case (Kelly et al., 1997; Tellis, Bressler, & Emerick, 2008). In addition, sometimes SLPs can be perceived by clients who stutter as being judgmental, annoyed, and not understanding when interacting with them, much to the detriment of their relationship (Plexico, Manning, & DiLollo, 2010). Therefore, the following discussion of recommendations for interacting with PWS can be applied to professional SLPs as well as to members of the general public.
When considering what to do when first engaged with a PWS, it is important to acknowledge that it is very human to react with surprise at something that is unexpected. We might often feel ourselves reacting to events before we have had time to consider what our response is, or whether our response is appropriate. Even PWS might find themselves reacting to listeners before having had time to think (e.g., applying too negative of an interpretation to a listener’s response). However, it is important to recognize that when one’s initial response is inappropriate, one should take steps to change the inappropriate behavior. For example, if one’s initial facial expression conveys surprise, the surprise can then give way to listening.

A unique aspect of stuttering is that the origin of the disorder is often poorly understood by society. For many people with more visible disabilities, such as those who depend on assistive devices to communicate, listeners are likely aware of the physical etiology of the condition. It is perhaps easier to feel empathy for such individuals because of the perception that the limitation is beyond the individual’s control. In contrast, the chronic feeling of loss of control over speech production that is a hallmark of stuttering might not be easy for a person who does not stutter to empathize with. This might be because people who do not stutter imagine that stuttered speech is the outcome of being nervous or anxious, or struggling to think of what one wants to say. These individuals may be reflective of their own moments of disfluent speech (i.e., moments where they were nervous, anxious, or did not know what to say) and infer this as the ultimate cause of stuttering in PWS (MacKinnon, Hall, & MacIntyre, 2007). Not realizing that stuttering is a neurodevelopmental and chronic communication disorder that is present in the absence of anxiety or uncertainty about what to say, members of the lay public may give simplistic suggestions to PWS such as think before speaking, slow down speech, or take deep breaths.

The tendency to use one’s own experiences to understand the actions of others can be described by a well-researched psychological principle known as the fundamental attribution error (Ross, 1977). This effect is the tendency for people to overestimate how much a person’s behavior can be explained by internal characteristics (e.g., personality traits) and to underestimate contextual factors. For example, someone may perceive the speaking difficulty demonstrated by a PWS as representative of a lack of hard work or weakness rather than attributing it to genetic predisposition. If this is the case, it is not difficult to see how negative stereotypes can emerge regarding PWS, for example, that they are more nervous, anxious, weak, or less competent than fluent speakers. It is vitally important for people to understand that people do not stutter because of a failure to put forth enough effort. Because many people who do not stutter lack meaningful experience with PWS, it is important for individuals who do not stutter to be educated about stuttering. To this end, several recommendations are important to consider.

**Interacting With Individuals Who Stutter in a Culturally Sensitive Manner**

**Avoid assumptions.** When interacting with PWS, it is important to avoid making assumptions about PWS and to realize that each person is unique. It is very easy for people to develop stereotypes about other people within a social group (Greenwald & Banaji, 1995). This can be thought of as an evolutionary survival skill, one that enables people to predict others’ behavior while having limited information about them (Schaller & Latané, 1996). However, it is important to be aware that stereotypes often need to be questioned, particularly if the information that one uses to form the stereotype is biased. For example, even though many people have limited experience with PWS, many people possess stereotypes about individuals who stutter, including the belief that they are shy, anxious, self-conscious, and lacking in self-confidence (Craig, Tran, & Craig, 2003).

Another stereotype placed on people with disabilities is that their disability defines who they are, or that it consumes their lives. However, this does not have to be the case (Watson, 2002). As mentioned previously, for many PWS, stuttering itself might not even be a major concern in their lives. In fact, for any particular communicative exchange, stuttering could be more of an issue for the person who does not stutter. Some PWS might even choose to stutter as a way to manage their stuttering. As part of the personal journey of self-discovery, the experience of stuttering in front of other people can be illuminating and perhaps necessary. The process by which a person is able to stutter more fluently almost certainly involves a willingness to stutter.

One could ask if an individual has the right to stutter. A person who has dealt with stuttering for a lifetime might come to see their own stuttering as an essential part of who they are. This is to say that one has achieved a change in perspective. By embracing stuttering, the fear and shame about stuttering can diminish or disappear, and the tendencies to avoid stuttering can fade away. What remains is merely a behavior that one need not look upon negatively; instead, these PWS may recognize that the struggle with stuttering has made them who they are.
However, one might ask if people have the right to expect others to speak according to fluent standards, such as a minimum speaking rate or absence of secondary behaviors. Does a listener have the right to become impatient or give up on the communicative interaction? The answer must be no. Rather, one can argue that society has a social responsibility to accommodate individuals with disabilities, and that individuals with disabilities such as stuttering can offer unique perspectives and contribute new ideas to the world. When interacting with PWS, such accommodations might include being patient and taking more time to listen to the person’s message.

**Make eye contact.** When communicating with a PWS, you should maintain eye contact. Maintaining appropriate eye contact is an important means of facilitating communication itself. For example, Baron-Cohen, Wheelwright, and Jolliffe (1997) reported evidence of a nonverbal communication channel during speech, referred to as a “language of the eyes,” to convey extralinguistic information to a listener (p. 314). Some evidence suggests that eye contact functions to activate parts of the brain that specialize in analyzing social interactions (Senju & Johnson, 2009), which can provide important information regarding the speaker’s intentions (Emery, 2000). Eye contact among communication partners provides important cues for cooperative social behavior in mammals (Tomasello, Hare, Lehmann, & Call, 2007), and more specifically, turn-taking for humans (Bavelas, Coates, & Johnson, 2002). Averting one’s gaze can thus contribute to a breakdown in communication. Interestingly, listeners have been reported to avert their eye gaze when viewing stuttered compared to fluent speech, even when they are not aware they are doing so (Bowers, Crawcour, Saltuklaroglu, & Kalinowski, 2010).

For a PWS, maintaining eye contact is important for additional reasons. Eye contact helps important aspects of the self develop as a consequence of social feedback. A prominent perspective on the emergence and development of the self, by both social psychologists and cognitive neuroscientists, is that the self is in large part socially constructed (e.g., Hood, 2011). Important aspects of self-identity develop from social feedback. As a PWS attempts to break off the negative aspect of self that stuttering often brings, positive or empathetic social feedback can be a critical factor for positive change.

**Use person-first language.** It is also important to use person-first language when interacting with PWS. This would involve using terms like person who stutters or client who stutters rather than stutterer or stuttering client. The semantic difference between these terms represents differences in empowerment. Group designations or labels that highlight a diagnosis such as stutters are often said to be inappropriate because they define people with one trait and fail to reflect the equality, individuality, and dignity of PWS (U.S. Department of Labor, n.d.). These labels can also perpetuate negative stereotypes, devaluation, and marginalization of people with disabilities, particularly when the language is used by individuals without the condition (Hudock, Altieri, O’Donnell, & Knudson, 2014). In some instances, however, a PWS may actually prefer to be referred to as a stutterer instead of a person who stutters in an effort to transform the label into a display of pride.

It has been pointed out by disability rights activists in a variety of areas (e.g., blindness, deafness, autism, stuttering) that person-first language, by attempting to separate the condition from the person, can be interpreted as reinforcing the condition as an undesirable trait or defect (Collier, 2012). St. Louis (1999) reported that using person-first language made no difference in minimizing negative reactions to PWS compared to nonperson-first language. It should also be noted that use of the acronym PWS can be perceived by some individuals as marginalizing and dehumanizing (Schick, 2015). Despite the fact that this topic is debated among PWS, because person-first language is the current standard in professional organizations (e.g., ASHA), scientific publications, and government documents and policy, we do recommend that people who do not stutter use person-first language when referring to PWS unless an individual who stutters has a preference for nonperson-first language.

Furthermore, using words like normal, normals, or normal speaker when referring to a person who does not stutter implies that the PWS is abnormal. The term person who does not stutter is more descriptive and neutral, rather than pejorative. As Folkins (1992) pointed out, everyone likes to think of him- or herself as normal, including individuals with disabilities. Folkins also discussed that it is desirable to avoid projecting unnecessary negative connotations on people with disabilities (e.g., this person struggles with stuttering or this person suffers from a terrible stutter). Statements like these assume struggle, pain, and suffering when in reality, this may not be the case. Several of the authors of this article have observed students (undergraduate and graduate) in CSD write terms like these in papers describing someone with a communication disorder. Instead, it is preferable to state more neutral terms like the person stutters.

**Demonstrate patience.** When interacting with PWS, it is also important to be patient and take as much time as necessary for the PWS to communicate his or her message. PWS often have increased speech difficulty under time pressure or with listeners who
appear to lack patience. Again, it is our responsibility as sensitive human beings to allow as much time as is needed for speech. We would hopefully not be impatient with an individual with a physical/mobility disability needing more time to cross the street before going on our way, and this should be the case for speaking with PWS also. Being patient conveys to a speaker that (a) you are comfortable with how they are speaking and (b) you are genuinely interested in what they have to say.

**Let the person speak.** You should also refrain from speaking for the PWS or attempting to finish his or her words or sentences. First of all, a PWS might require much more time to complete an utterance. Not only might additional time be required to work through stuttering events, but stuttering on purpose or trying to stutter in a different way might be part of the person’s approach to modifying stuttering. In order to become more skillful with new speaking behaviors, it might be necessary to use them with a variety of people in a variety of situations. For such an approach to succeed, PWS need patience from communication partners rather than attempts to finish words or sentences for them. Receiving unsolicited help can contribute to the sense that one is incapable or is dependent on other people. It should be noted as a caveat, however, that we have heard a few examples of individuals who stutter saying that occasionally they appreciate when someone completes a word or sentence for them, particularly in stressful situations in which there is time pressure. We recommend that during everyday interactions, you follow the preferences of the individual, even if it is in conflict with the principles and recommendations that we are discussing, but that these recommendations serve as the default mode for interactions with PWS. In the context of treatment, however, it would not be advised to complete words or sentences for a client as this would contribute to avoidance patterns.

**Focus on content.** When interacting with PWS, it is important to focus on the content of what the individual is saying rather than being preoccupied with how the person is saying it. Focusing on content makes the person feel normal and valued, like what they are saying matters, as opposed to being defined in the interaction by their stuttering. Using facial expressions and body language to indicate that you are listening to the actual words and content of the PWS can be very helpful. As discussed previously, maintaining eye contact is very important, as well as things such as head nodding, smiling, and so on.

To summarize recommendations for interacting with PWS, particularly those who embrace a culture of stuttering, it is important to remember to refrain from giving unsolicited advice, speaking for the individual or completing words or sentences (unless the PWS expresses preference for that), assuming that the person needs help or that fluency is valued, and saying things that could be construed as patronizing or infantilizing. Instead, appropriate and successful interaction will occur by valuing the uniqueness of the individual, making and keeping eye contact during communication, being patient, using person-first language, and concentrating on the content of what the individual is saying rather than focusing on only the stuttering itself or the fluency of speech.

**Integrating Disability Culture Into Education in CSD**

It is critically important that students in CSD understand the perspective of individuals within disability culture; therefore, course work in academic programs should include opportunities for students to become familiar with these perspectives. There are many potential ways for instructors to integrate lessons in the culture of disability into course work in fluency disorders, and this section will review some options that instructors may consider to achieve this goal (see Table 1 for a review).

Although there are many options, the common thread between these different possibilities is that students could have exposure to the thoughts, feelings, values, and beliefs of PWS. Having students read materials and websites with authors discussing diverse opinions about stuttering could be useful. For example, the podcast StutterTalk (www.stuttertalk.com) seeks to discuss an array of stuttering-related issues and presents multiple perspectives on the disorder of stuttering (Reitzes & Snyder, 2009). The host, and

<table>
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<th>Possible student assignments</th>
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<tr>
<td>Listen to podcasts such as stutt	talk.com, stutteringiscool.com, or istuttersowhat.com and write a reaction paper.</td>
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<tr>
<td>Access the International Stuttering Awareness Day online conference, read presentations, and interact with presenters.</td>
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<tr>
<td>Listen to several audio presentations by people who stutter (PWS) on the Stuttering Homepage and compare perspectives about stuttering.</td>
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<tr>
<td>Read the writings of PWS, including books, newsletters, and blogs, to gain a wider perspective of what it means to stutter.</td>
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<tr>
<td>Attend a self-help group meeting or an annual conference for PWS.</td>
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<tr>
<td>Attend conference sessions by PWS discussing their personal perspective and experiences with stuttering.</td>
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many of the guests interviewed, are themselves PWS. Other podcasts hosted by PWS that may represent a view of stuttering that differs from the norm of clinical training are stutteringscool.com, stutterrockstar.com, and istuttersowhat.com. Listening to these podcasts could provide students and professionals with an insider’s view of the culture of PWS.

Assignments could be given that require students to listen to a podcast with a potentially controversial issue that is being debated among the guests and then write a reaction paper discussing what they agreed with and why, or whether any of the ideas presented challenged their perspectives. Many of these websites also contain written material such as blogs, which could also be a helpful way to learn about the thoughts or perspectives of PWS. The Stuttering Homepage (Kuster, 2015) also contains various audio clips and speeches from PWS, most of whom are professionals who stutter, representing differing viewpoints about the nature of stuttering and the nature of recovery. Students could listen to several of these speeches and compare and contrast differing perspectives from the speakers.

Written content, websites, books, or articles in which PWS describe their experiences with stuttering could be valuable for students to read. Each October for International Stuttering Awareness Day, an online conference arranged by the International Stuttering Association (ISA) can be accessed for free (ISA, 2015). In this conference, both professionals and PWS share their thoughts and stories related to stuttering through written essays and brief audio/video presentations (Osborne, 2006). Guests can read these essays or listen to presentations and then ask questions and interact with authors from across the world. Students could then write reflection papers about the experience, highlighting any perspectives that they did not have before. These online forums are particularly useful at highlighting perspectives of stuttering from individuals from other cultures. Additionally, presentations from previous years dating back to 1998 can be accessed on the ISA website.

In addition, books such as Stuttering: Inspiring Stories and Professional Wisdom (Reitzes & Reitzes, 2012) contain several chapters written by PWS describing their experiences and perspectives. One common thread that runs throughout these chapters is the notion of acceptance of stuttering and putting less emphasis on fluent speech. For many graduate students, these ideas might seem strange; however, the assignment could potentially expose them to perspectives that they have not considered before. Newsletters such as “Letting Go,” a publication from the National Stuttering Association, are another source of written perspectives on being a PWS. Websites such as didistutter.com also provide examples of alternative ways of looking at stuttering. It is important to note that not all readers will necessarily agree personally with the perspectives presented. However, it is important for students to know that such attitudes do exist and that they could have an impact on interactions with PWS who embrace disability culture.

Other options for students and professionals to gain knowledge of disability culture in stuttering include actually interacting with PWS outside of treatment settings. Having students attend a self-help group session for PWS or a convention for PWS (such as the annual conference of the National Stuttering Association), or inviting a guest speaker who stutters to class could all be options to increase contact between students and PWS. Rentschler (2007) noted that many students learned valuable lessons at these groups when they realized that not all PWS wanted to be helped or assisted. Many group participants did not think they had a problem and so they did not need to be “fixed” (p. 22). These are eye-opening experiences for students and professionals alike, and are very useful in expanding cultural awareness and competence.

In addition, professional conferences such as the ASHA annual conference should continue to enhance cultural competence education to SLPs and audiologists by inviting individuals with disabilities to share their stories and perspectives. For example, individuals in Deaf culture and individuals with autism spectrum disorder have presented at professional conferences recently, and this should continue in the future. We recently presented on the culture of disability and stuttering at ASHA’s annual convention (Boyle, Daniels, Hughes, & Buhr, 2014), and it was apparent that many people in the audience were hearing ideas that they had not considered previously. Based on comments and feedback during and after the presentation, many people seemed to show signs of expanding their perspective of stuttering and disability in general. Including individuals with a broad range of perspectives on disability and communication disorders will help to improve the cultural competence of students and professionals in the field of CSD.

Conclusion

The culture of disability related to stuttering offers a variety of beliefs, values, and perspectives related to the very nature of the condition and its impact on everyday life. It is important that CSD professionals have an understanding of this aspect of culture, just as they would for cultural issues related to race, religion, ethnicity, and other social factors. A lack of
understanding in this area could result in a cultural mismatch between the professional and the PWS. This mismatch in expectations and perceptions could lead to inappropriate interactions with individuals who stutter in which their values and beliefs are dismissed or ignored altogether. If a PWS has entered into a culture of disability related to stuttering but also wishes to receive intervention, the SLP should be able to develop an individualized treatment plan that supports the person within that culture of disability. PWS also need to be aware of the prevalent perceptions about them and learn how to respond to any misperceptions patiently but assertively. To conclude, a sharing of information needs to occur in order for well-intentioned professionals to interact in ways that will be perceived as positive by PWS. It was the goal of this article to initiate this discussion in the field of CSD.

REFERENCES


Watson, N. (2002). Well, I know this is going to sound very strange to you, but I don’t see myself as a disabled person: Identity and disability. Disability & Society, 17(5), 509–527.


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