

**TITLE**

Stuttering Identity's Contribution to Well-Being Among Adults who Stutter

**PRIMARY RESEARCHER**

Christopher Constantino, Ph.D., CCC-SLP

This project will measure the effects of stuttering identity on quality of life and well-being. Stuttering is a disorder of speech fluency where the forward flow of speech is involuntarily disrupted (Manning & DiLollo, 2018). This is often described as experiencing a momentary loss of control (Perkins, 1990). This loss of control results in speech disfluencies, the most common of which are part-word repetitions (li-li-li-like this), prolongations (lllllllllike this), and silent or strained blocks (\_\_\_\_like this) (Bloodstein & Bernstein Ratner, 2008). This experience can be frustrating on its own, as it can be a barrier to personal expression and communion with others (Bobrick, 2011; Carlisle, 1986; Corcoran & Stewart, 1998; Craig, Blumgart, & Tran, 2009; Hood, 1998). However, in the context of modern society, stuttering is especially troublesome. People who stutter experience active prejudice, from teasing and bullying as children, to job, financial, and social discrimination as adults (Blumgart, Tran, & Craig, 2010; Caruso & Linn, 1998; Gabel, Blood, Tellis, & Althouse, 2004; Hurst & Cooper, 1983; Silverman & Paynter, 1990).

People have many identities that impact how they perceive themselves and how others perceive them. The most salient of these are often sex, gender, race, sexual orientation, and ethnicity. However, researchers are increasingly aware of a disabled identity distinct from the normative able-bodied identity (Corker & French, 1999; Galvin, 2003; Galvin, 2005; Gosling, 2002). Often, disability is conceptualized as a subtraction from the able-bodied ideal. To society in general, disability represents a lessening and devaluing of the self (Campbell, 2009). The notion that disability represents a reduction in functioning due to pathology is typically called the medical model (Goodley, 2011). It is not the only way to make meaning of disability. New models of disability, such as the social (Shakespeare & Watson, 2002) and political/relational (Kafer, 2013) models, have opened up new ways of thinking about impairment that challenge the notion that disability represents a detraction from the ideal. These new ways of thinking can be seen in the progress of the neurodiversity movement, which sees autism as not simply an impairment but a variation in human functioning that comes with both benefits and challenges (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). The experience of stuttering has only recently been interrogated by researchers interested in social and cultural critiques of disability (Constantino, 2018; Constantino, Manning, & Nordstrom, 2017; Eagle, 2014; St. Pierre, 2012). However, it is clear that the experience of stuttering is nuanced, containing both positive and negative components (Constantino, 2016). The lived reality of stuttering is very different from the one-dimensional negative expectations of an ableist society.

The subtlety of the stuttered experience suggests that the disabled identity of people who stutter may function much like racial and ethnic identity. Rather than a basic increase or decrease in self-value and self-esteem, racial and ethnic identity are composed of a myriad of global beliefs and attitudes (Sellers, Smith, Shelton, Rowley, & Chavous, 1998). These include centrality, private regard, and salience. Centrality is the relative importance of a specific group identity in the construction of overall social identity.

Private regard is the way one feels about being a member of a specific group. Salience is a dynamic measure of the psychological prominence of a specific group identity at any particular point in time. These are formed by the collective experiences of understanding oneself as a member of a specific group, whether racial, ethnic, or disabled, as well as observing others understanding of you as such (Yip, 2005).

Mainstream approaches to racial identity saw the experience of African Americans as necessarily negative due to a racist environment (Allport, 1954). Therefore, in order to cope, African Americans were forced to make a choice. They either devalued aspects of themselves that reminded them of the stigma against them or they devalued broader society for its prejudice (Sellers et al., 1998). Alternative approaches to African American racial identity took a slightly different approach. They did not view African American identity as obviously damaged (Du Bois, 1903). Although, prejudice and oppression played a significant role in the development of the African American self-concept, this self-concept was complex, with both positive and negative components.

People who stutter are, perhaps unwittingly, following in the footsteps of African American theorists. Most mainstream conceptions of stuttering position it as an inferior way of speaking. This view is also held by many people who stutter. They seek fluency therapy to speak more like their able-bodied peers. This process of internalizing public stigma is known as self-stigma and is well documented (Boyle, 2013, 2015, 2018; Boyle & Blood, 2015; Boyle & Fearon, 2018). However, recently there have also been theorists pointing the finger at society, not people who stutter themselves, for the negative experiences they have.

Listeners have been implicated for lacking patience, and neoliberalism has been blamed for valuing efficiency and economy over human communication (St. Pierre, 2012). This self-blaming and society blaming both uphold a view similar to Allport's (1954) negative conception of the African American experience. That is, due to societal prejudice, people who stutter must choose to reject themselves or reject society. However, recent reflections by people who stutter suggest that, as with racial identity, the disabled identity of people who stutter is more complicated (Constantino, 2016; Constantino, 2018). There are positive aspects to stuttering and the stuttered identity is not necessarily damaged.

To date, there have been no studies explicitly documenting stuttering identity and its effects on the lived experiences of people who stutter. By employing an experience sampling method, this study will measure stuttering identity in different contexts. The experience sampling method is the distribution of short surveys that are completed outside of the lab while the participant is going about their daily life. The surveys are given several times a day over the course of a week. By using the experience sampling method, rather than static survey instruments, this study can investigate the dynamic properties of stuttering identity and its environmental and individual correlates. This study will also investigate the quality of life and mental health consequences of stuttered identity.