

In-home services may be scarce, and overburdened aging parents may find it difficult to provide in-home care and accompany the individual to care services.

In sum, the current study has made an important contribution to the understanding of health service use by individuals with CP. Future studies should broaden the area by examining the topic in other types of disabilities. Given the complex needs of this population, studies should also examine their social needs (e.g. leisure activities, friendships, sexual relations). Only a holistic and structural examination of the needs of disabled individuals and their family members can meet their needs and provide the care and quality of life they deserve.

#### DATA AVAILABILITY STATEMENT

Not required

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## The importance of understanding the broader experience of stuttering

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Stuttering is often viewed by listeners as consisting primarily of overt disfluencies, such as repetitions, prolongations, and blocks; however, the experience of stuttering involves much more than just observable speech disruptions.<sup>1</sup> Individuals who stutter consistently report that the defining characteristic of a moment of stuttering is a sensation of being 'stuck' or of 'losing control' of their speech, and this feeling ultimately leads to adverse impact in their lives.<sup>1</sup> Because this fundamental aspect of stuttering may not be fully apparent to listeners, it is imperative that assessment (and, ultimately, treatment) accounts for individual experiences of stuttering. This is most commonly done via self-report measures.

Boyce et al.<sup>2</sup> sought to assess the impact of stuttering based on a variety of self-report measures. Consistent with prior studies,<sup>3</sup> they found that individuals who stutter exhibit their own unique phenotype reflecting their unique personal characteristics and experiences with stuttering. Also consistent with numerous prior studies,<sup>3</sup> they found

that speakers experience a range of affective, cognitive, and behavioral reactions, as well as adverse impact, related to their stuttering. Compared to other published reports, however, the experiences of Boyce et al.'s participants were strikingly negative: over 90% reported experiencing anxiety related to stuttering, 81.5% reported avoiding specific words, and 60.5% shared that they give up after they have started speaking. Although the authors did not fully acknowledge the large body of existing research on the broader experience of stuttering (which goes back several decades<sup>4</sup> and which goes well beyond just 'anxiety'), their study revealed *greater* negative impact than other studies. For example, Tichenor and Yaruss<sup>3</sup> surveyed over 500 individuals who stutter about their experiences using a variety of self-report measures and found that, while 45% felt ashamed, only 15% avoided speaking, 10.3% avoided situations, and 9.4% had someone speak for them.

This led us to wonder about the reasons that the Boyce et al. participants reported greater negative experiences

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associated with stuttering. One possible explanation may be related to the therapy experiences of their participants. The majority of their participants reported receiving therapy focused on fluent speech (either smooth speech or the Lidcombe Program). Interestingly, other research<sup>3</sup> has shown that individuals who take 'being fluent' as their goal when speaking are more likely to experience adverse impact due to stuttering than individuals who focus on saying what they want to say. We wonder whether the fluency-focused therapy that Boyce et al.'s participants received might be associated with the greater adverse consequences that they reported. This potentially controversial finding would appear to be a worthy topic for further investigation.

Regardless, it is critical that we fully understand the impact that stuttering (and stuttering therapy) may have on an individual's life if we are to provide intervention that yields real benefits for people who stutter. The data presented by Boyce et al. support this effort by confirming what many prior studies have shown: stuttering involves more than just disrupted speech, and we must consider the importance of all aspects of the stuttering experience,<sup>1</sup> not just observable speech disfluencies in all of our clinical work. More specifically, 'Treatment should focus on the ways a person responds to the sensation of being stuck or

of losing control when speaking, the specific forms of adverse impact that the person experiences, the reactions of those in that person's environment, and the unique activity limitations or participation restrictions they experience in their lives.'<sup>5</sup>

## DATA AVAILABILITY STATEMENT

Not required

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