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Meeting the unmet needs of disabled adults with cerebral palsy

Shirli Werner 

Paul Baerwald School of Social Work and Social Welfare, Hebrew University of Jerusalem, Jerusalem, Israel

The study by Manikandan et al.¹ examines the use of health services and unmet needs of adults with cerebral palsy (CP) in Ireland. Findings show that although adults with CP used various health services, they still reported having unmet needs.¹ These findings point at the possibility that individuals with CP and other disabilities are not provided with accessible, high-quality services, although this right is clearly stated in the UN Convention on the Rights of Persons with Disabilities. Unmet needs may negatively affect individuals' care and quality of life, and impact the family and society.

One of the findings of this study is the relatively high level of unmet needs for personal assistance, especially for adults living with parents or other relatives.¹ Personal assistance compensates for disability by delegating tasks of choice to another individual or purchasing assistance. It enables disabled individuals to meet their needs, gain choice and control, and live in the community fully and independently.² Personal assistance supports individuals in communicating with the authorities, helps with benefit take-up, service use, and establishing and retaining social relationships. Personal assistance is also key in reducing overdependence on families, especially when they impose decisions rather than support self-determination. The current findings suggest that many individuals with CP were not adequately supported for independent living and community inclusion.¹

The study also aimed to identify factors associated with service use by adults with CP. The results show that age, living arrangements, and wheelchair use were

associated with service use.¹ These results suggest that developing effective services for underserved populations requires identifying not only general needs for all populations but also specific needs in different types of care and for different subpopulations of disabled individuals. This type of planning increases the number and quality of services provided to specific groups, adapting to their particular needs, and ensuring useful and intelligent use of resources.

Manikandan et al.¹ focused on sociodemographic factors associated with service use; future studies will benefit from examining a wider array of factors. First, extensive literature has demonstrated that stigmatic beliefs (negative perceptions of disabled individuals) and stigmatic perceptions of service use (fear that use of services may further stigmatize the individual) discourage seeking highly needed services.³ Future studies should examine how stigma associated with CP and CP services affects help-seeking and service use.

Second, future studies would benefit from examining the topic in more culturally varied samples. This will help develop and implement culturally sensitive health care services, responsive to the unique cultural values and beliefs of individuals and families.⁴

Third, future studies should focus on factors hindering fulfillment of needs by individuals who live with their families. On one hand, families and parents form a natural source of support, and the family home may be considered the most preferable community-based alternative to accommodate individuals' needs. On the other hand, living with the family may also be restrictive. Possibly, this is a last-resort choice because of lack of other community-based alternatives.

This commentary is on the original article by Manikandan et al. on pages 1270–1280 of this issue.

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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

ORCID

Shirli Werner  <https://orcid.org/0000-0002-5432-7223>

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The importance of understanding the broader experience of stuttering

Caryn Herring  | J. Scott Yaruss 

Department of Communicative Sciences and Disorders, Michigan State University, East Lansing, MI, USA

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.¹ 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.¹ 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.² sought to assess the impact of stuttering based on a variety of self-report measures. Consistent with prior studies,³ 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,³ 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 decades⁴ and which goes well beyond just ‘anxiety’), their study revealed *greater* negative impact than other studies. For example, Tichenor and Yaruss³ 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

This commentary is on the original article by Boyce et al. on pages 1297–1306 of this issue.

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