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Integrated biopsychosocial pain research in intellectual and developmental disability

Historically, it was widely believed that individuals with intellectual and developmental disability (IDD) were insensitive or indifferent to pain. Current consensus is that, although cognitive impairment may affect the ability to understand and communicate pain, there is no conclusive evidence of altered pain experience. In most cases, individuals with IDD show reliable, observable behaviors when they are experiencing pain, and these behaviors can be used as pain indicators by parents and clinical care staff.¹ This shift in perspective has led to the development of standardized tools to measure pain in this population. Currently, best practice is to use standardized observational pain scales, along with other sources of information, whenever there is a suspicion of pain in an individual with IDD. In this context, the work of Sierra-Núñez et al. has important clinical implications for pain assessment among children and adolescents with cerebral palsy (CP) in the post-surgical context and beyond.² Their review suggests that the adapted FLACC (Face, Legs, Activity, Cry, Consolability) scale³ is the tool that has been the most widely used for postoperative pain assessment in CP, and has the best reliability, validity, and feasibility evidence in clinical settings. Although further validation and refinements efforts are always desirable, consistent use of the FLACC or similarly well-validated scales is the best way to reduce disparities in pain assessment and treatment among individuals with IDD in the immediate future.

The review by Sierra-Núñez et al.,² however, also shows that there remains much work to be done. Their results indicate that, in most cases, individuals with CP and associated intellectual disability were less likely to have their pain assessed, and received lower overall pain scores when they were assessed, compared to their typically developing peers. The specific reasons for these discrepancies are currently unclear,

and further research is needed to investigate sources of variation in postoperative pain assessment in this population.

Effective pain assessment and treatment for individuals with CP and other forms of IDD across the lifespan will require integrative, multidisciplinary care that takes into account the biological, social, and psychological determinants of pain.⁴ As pointed out by Sierra-Núñez et al., input from parents regarding how their children behave when they are in pain can be an important source of information when individuals show idiosyncratic or unusual pain responses that may be missed by unfamiliar observers. How parents' own pain histories and social and psychological factors influence their perceptions of their children's pain has received little attention in the field of IDD. Our group recently documented that parents' self-reported pain catastrophizing, a psychological construct reflecting parents' thoughts and beliefs around their child's pain, was related to change in both directly-observed and parent-reported pain scores following a putatively pain relieving procedure (i.e. intrathecal baclofen pump injection) among children and adolescents with CP.⁵ The results were complicated in that the relationship between pain catastrophizing and pain outcomes was moderated by the children's language abilities, suggesting that the social nature of pain expression and interpretation may be altered among children with CP who cannot self-report. Further work in this area is needed to understand how pain expression is shaped among individuals with IDD to ensure that all individuals have equitable access to accurate pain assessment and treatment.

DATA AVAILABILITY STATEMENT

Not required.

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This commentary is on the scoping review by Sierra-Núñez et al. on pages 1085–1095 of this issue.

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Speech and augmentative and alternative communication needs in young children with cerebral palsy

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Age changes in communication, speech, language, hearing, and augmentative and alternative communication (AAC) have needed more study in cerebral palsy (CP). Thus, the longitudinal changes in the Viking Speech Scale¹ (VSS) in 101 US children from ages 4 to 10 years is noteworthy.²

The VSS classifies an individual's speech into one of four levels: (I) not having a motor speech disorder; (II) some speech errors but understandable to unfamiliar listeners; (III) speech not understandable to unfamiliar listeners without contexts; and (IV) speech is not understandable to unfamiliar listeners regardless of context.

Results from this study suggested that children starting with a VSS level IV at age 4 years were unlikely to change classification levels (i.e. not improve how an unfamiliar listener understood their speech) over 6 years. Therefore, Long et al.² suggested immediate AAC intervention when level IV was classified.

These results also imply that AAC is likely needed earlier than age 4 years for children in any VSS levels. The children starting at level II at age 4 years did not reach level I until tested at age 8 or 10 years. The children starting at level III waited even more years before reaching level I. Many children spent at least 2 to 6 years with unfamiliar listeners not understanding their speech. Since children typically start speaking around 1 year of age, lack of intelligible speech with unfamiliar individuals had likely occurred since the child with CP was an infant.

Previous research had suggested a potential systematic bias against AAC use with young children who had any intelligible speech.³ This may be due to concerns about the

effect of AAC use on speech development.⁴ Although more research is needed, speech had either remained unchanged or improved when the child used AAC. If the children's speech improved so that the children could communicate with all their familiar and unfamiliar communication partners, AAC can be discontinued. Thus, AAC can be either an interim or permanent communication tool for children to augment or replace their speech. Many speech-language pathologists recommend that AAC should be implemented whenever an individual cannot communicate with all their familiar and unfamiliar communication partners in all settings.⁴

DATA AVAILABILITY STATEMENT

Not required.

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