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## Early intervention in autism spectrum disorder: The need for an international approach

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## COMMENTARY

# Early intervention in autism spectrum disorder: The need for an international approach

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Globally, autism spectrum disorder (ASD) affects approximately 1 in 100 children.<sup>1</sup> Ideally, a diagnosis is made with the onset of symptoms before 3 years of age; however, a diagnosis may sometimes be delayed until 6 years or later. There has been an increase in ASD research over the last few decades, with many systematic reviews and meta-analyses synthesizing research evidence for ASD interventions in children. Evidence tends to support the notion that intervention for ASD must occur as early as possible, close to the critical periods when early social and communication skills are developing. Therefore, early screening and intervention could improve the treatment outcomes of individuals with autism, not only helping them survive but to thrive.<sup>2</sup>

Franz et al.<sup>3</sup> have conducted an overview of reviews to synthesize early intervention literature for very young children at risk for ASD with the aim of identifying which interventions have the strongest evidence base for impact. Researchers, including Franz et al., acknowledge that while many interventions impact child development, heterogeneity in child outcome measures (behavioural coding and structured observation assessments), treatment and intervention approaches, comparison groups, and participant profiles limit the extent to which we can concretely evaluate the effectiveness of interventions. Robust high-quality evidence is urgently needed to design international programmes that can address the sometimes complex and varied needs of individuals with autism.

Moreover, there are also inadequacies regarding the regional coverage of studies on ASD. The primary studies in these reviews were all from high-income settings (e.g. the USA and UK). Not a single primary study in the review by Franz et al.<sup>3</sup> was identified from low- and middle-income countries (LMICs). There is an urgent need to generate evidence on the most appropriate intervention approaches for ASD in LMICs. Even as we advocate for more research on early intervention for children with ASD in LMICs, there is a need for further testing of interventions that provide high impact at a relatively low cost, given the limited resources in these settings

and many competing priorities in overstretched health and educational settings. It has been argued that interventions that are community-based, empower caregivers and can be used to address the needs of children with different developmental delays may be the best options in these LMICs. In recent years the World Health Organization and Autism Speaks have led in the development and piloting of the Caregiver Skills Training programme (an intervention that addresses communication and behavioural problems across developmental conditions), which has the potential to address this gap and be used at scale in resource-constrained settings.<sup>4</sup>

In addition to the inclusion of applicable interventions in LMIC settings, there is ongoing discussion on the balance of benefits and harms of interventions in ASD research, with the consensus being that there is a dearth in the reporting of adverse events or observed harms.<sup>5</sup> There is a need to address this issue and the high risk of bias through the application of fundamental standards in ASD intervention research.

In conclusion, Franz et al.<sup>3</sup> have carried out a significant piece of work in early ASD intervention research by providing an overview of systematic reviews and primary studies therein. The authors call for a balance of research strategies to bridge the community implementation gap in early ASD intervention as there is a global disparity in who participates and benefits from intervention research.

## DATA AVAILABILITY STATEMENT

Not required.

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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.<sup>1</sup> 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.<sup>2</sup> Their review suggests that the adapted FLACC (Face, Legs, Activity, Cry, Consolability) scale<sup>3</sup> 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.,<sup>2</sup> 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.<sup>4</sup> 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.<sup>5</sup> 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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