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EDITORIAL

What is the impact of childhood-onset disability research – and what should it be?

The impact of academic research is often approached through citations, journal impact factors, and h-indices. These metrics matter, especially when adjusted for disciplinary scale; for example, cross-disciplinary citations may indicate that neurodisability research is informing education, public health, economics, or architecture. However, none of these indicators reveal whether children thrive, families receive better support, or low-value interventions are discontinued when research shows their lack of efficacy. In childhood-onset neurodisability, bibliometrics are inherently limited because outcomes are complex, long-term, and shaped by systems and environments. A highly cited paper may not change practice, whereas a single pragmatic study, guideline, definition, or classification system can reshape services across continents. Because disabled individuals live with the consequences of policies, attitudes, and service structures, impact must be understood across scientific, clinical, societal, and socio-political dimensions.

Digital engagement reflects another layer of visibility. Families, advocacy groups, policymakers, and clinicians increasingly encounter information through social media, podcasts, and infographics rather than primary journal articles and books. Altmetric attention scores can signal public engagement; for example with research on internet gaming disorder or new autism measurement tools. But attention is not equivalent to meaningful change: high online visibility may reflect controversy or novelty more than impact on practice or policy uptake.

Policy citations are more compelling. Research embedded in clinical guidelines, disability funding frameworks, or government reports can shape decisions and promote equity. The 2007 definition of cerebral palsy (CP), widely incorporated into policy statements, white papers, or service allocation frameworks, also strengthened recognition that CP includes important non-motor features. Other consensus definitions may similarly influence clinical and research practice.[1] The recent updated description of CP may further emphasize, worldwide, the life-long individual experience and help genotype–phenotype correlation research, although concerns have been raised about excluding developmental central hypotonia.

Some research changes how clinical situations are described. In CP, the gross motor function, manual ability, communication, feeding, and visual function classification systems created a shared language for registries, surveillance, trial stratification, and clinical communication. They now appear self-evident. Yet similar efforts in other conditions, such as classification systems for social communication functioning in preschool children with autism have, to date, had more limited uptake. Judging which studies 'have impact' often relies on retrospective reasoning shaped by hindsight bias,[2] whereby influential findings appear more inevitable in retrospect than they were at the time of publication. This occurs because knowledge of outcomes alters perception of prior likelihood, leading to overestimation of predictability.

Impact in low- and middle-income countries (LMICs) also requires a broader lens. Research that enables scalable, context-appropriate models of care, task-shifting, and service delivery in settings with limited specialist capacity may have profound effects.[3] This is also why knowledge syntheses should avoid excluding studies based on publication language, which systematically underrepresents LMIC research and distorts estimates of effectiveness and feasibility.

Perhaps the most profound and least measurable impact is on lived experience. Childhood disability research is increasingly co-produced with families and individuals with disability,[4] which may itself signal a mature understanding of impact. Rosenbaum and Gorter's 'F-words' (initially for disability, now for development) probably succeeded because they translated the ICF into language families could use, clinicians could remember, and services could operationalize. Beyond citations, they influence goal-setting, professional training, and the very tone of clinical conversations.

Several frameworks support multidimensional assessment of research impact.[5] The payback method maps benefits in knowledge, workforce, policy, service, health outcomes, and economic value. Social Impact Assessment methods for research and funding instruments through the study of productive interactions emphasize impact emerging from reciprocal engagement with researchers, clinicians, families, and policymakers. In childhood-onset neurodisability, where an 'impact gap' often delays translation into practice, implementation frameworks can further capture adoption, sustainability, and equity in real-world settings. For each major paper, we should ask whether it changes guidelines, decision support, clinician behaviour, or access to effective interventions. Ideally, publishers and readers will

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value prospective pathways to impact and lived experience outcomes alongside bibliometrics.

DATA AVAILABILITY STATEMENT

Not required.

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In this issue

- My Editor's Choice is a scoping review of interventions for children with developmental coordination disorder that found most studies reported improvements in motor performance, but evidence for effects on participation and psychosocial outcomes was limited.
- A scoping review of community-based physical activity programmes for young people with childhood-onset physical disabilities finds that collaborative approaches involving health professionals, families, and communities may support participation, highlighting the importance of partnership-based models to facilitate accessible and sustainable physical activity opportunities.
- A systematic review of motor skills and functional outcomes in children and adults born preterm without cerebral palsy (CP) finds that poorer motor skills were associated with difficulties across multiple domains, reinforcing the value of assessing motor function beyond early childhood.
- A prospective longitudinal cohort study of children born very preterm documents the relationship between early ophthalmological function and long-term visual functioning.
- A study of long-term outcomes after paediatric arterial ischaemic stroke and cerebral sinovenous thrombosis finds increased risks of neurological and psychiatric diagnoses.
- An observational study using administrative insurance data estimating the prevalence of spina bifida across the lifespan in the USA finds that close to 100000 people live with the condition.
- A retrospective cohort study of life expectancy in individuals with open spina bifida finds that survival has improved substantially over recent decades, with many individuals now reaching adulthood and older age, emphasising the importance of lifelong healthcare planning and support for this population.
- A prospective observational study of newborns with mild hypoxic-ischaemic encephalopathy finds that most infants had favourable early neurodevelopmental outcomes, although some developed neurological abnormalities requiring ongoing follow-up.
- A retrospective study of children with unilateral CP shows that children born extremely and very preterm had distinct patterns of brain injury and associated impairments compared with those born at term.
- A test-validation study of the Hand Assessment for Infants in infants at risk of unilateral or bilateral CP demonstrates strong internal validity and reliability in both groups, supporting its use for early evaluation of hand function and identifying emerging motor impairments.
- A population-based register study of children with CP on Tanna Island, Vanuatu, describes prevalence, clinical characteristics, and access to services in a low-resource setting, revealing substantial unmet needs for identification, support, and rehabilitation.
- A retrospective cohort study of 467 children with status epilepticus used clinical data and machine-learning approaches to identify three distinct patient clusters, showing that treatment delays were associated with poorer outcomes and that data-driven classification may improve risk stratification and clinical decision-making.
- A Delphi study of experts and families develops recommendations for follow-up and treatment registries in GNAO1-associated disorders, identifying key domains of functioning and assessment tools to support harmonized data collection, natural history studies, and future clinical trials.

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