

that the outcomes and challenges for children with motor impairment are the same for children born extremely preterm and at term. The unique health outcomes associated with extremely preterm birth justify the need for future research into motor outcomes for this cohort throughout childhood, adolescence, and adulthood, to understand how motor impairment impacts physical and mental health outcomes. Research is also justified into targeted interventions for children born extremely preterm with motor impairment.

Finally, like many longitudinal cohort studies, children and families lost to follow-up were more likely to be from lower socioeconomic groups, and hypothesized to be less likely to have received motor-related health care.² It is worth noting that lower socioeconomic status is associated with greater risk of preterm birth in the first place.⁴ Researchers and clinicians should continue to work to improve equitable access to clinical follow-up, timely intervention, and research participation for all children born extremely preterm and their families.

ACKNOWLEDGEMENT

Open access publishing facilitated by The University of Melbourne, as part of the Wiley -The University of

Melbourne agreement via the Council of Australian University Librarians. [Correction added on 14 May 2022, after first online publication: CAUL funding statement has been added.]

DATA AVAILABILITY STATEMENT

Not required

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Received: 25 February 2022 | Accepted: 28 February 2022

DOI: 10.1111/dmcn.15209

Quality of life in people with intellectual and developmental disabilities

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Funding information

Ministerio de Ciencia e Innovación, Grant/Award Number: PID2019-105737RB-I00 / AEI / 10.13039/501100011033

The attitude of society towards people with intellectual and developmental disabilities (IDD) has changed dramatically in the last 50 years. The 2008 UN Convention on the Rights of Persons with Disabilities (CRPD) caused a revolution in international law concerning people with IDD and their recognition as full citizens. The CRPD protects and promotes the rights of people with IDD to have legal capacity, make their own decisions, live independently, access information

and new technologies, and work and study in community and inclusive environments, among others.

Before the CRPD, the construct of quality of life (QoL) was the framework used for person-centered planning, guiding service delivery practices, and exploring the impact of individual and environmental factors for people with IDD. The main strength of the QoL model is its focus on context, measurement of person-valued outcomes, and the power to reflect the perspective of people with IDD and what is truly important to them. In parallel, the supports model was developed as a coincident and complementary approach to the

This commentary is on the original article by Jacoby et al. on pages 1145–1155 of this issue.

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QoL model to help understand people with IDD and meet their needs. The concept of supports provides a construct to enhance an individual's functioning and personal well-being through the planning and delivery of a coordinated set of person-referenced support strategies.

The synergy and complementarity of both approaches are such that they have merged into the Quality of Life Supports Model (QOLSM), in which QoL serves as a guide to obtain valuable information about what is important to the individual (*what*), while supports are the tools to achieve the required outcomes (*how*).¹ Thus, the QOLSM reflects a holistic and integrated approach to IDD, a focus on human and legal rights, an emphasis on individualized support provided within inclusive community-based environments, the evaluation of valued personal outcomes, and the empowerment of individuals and families.²

As a result of these advances, programme logic models are increasingly being used as tools for testing empirical theories and conducting theory-driven evaluations. Given their capacity to suggest relationships between relevant variables and constructs, these logic models go beyond conceptual frameworks and test the influencing factors. The inclusion of moderating and mediating variables in the QoL model—and even more so in the QOLSM—continues to be a challenge for IDD policies and practices.³ In this respect, Jacoby et al. have identified relevant predictors of QoL-related personal outcomes in children with IDD, such as sleep and community participation.⁴ When variables such as these are included in logic models, the effect of interventions and policies can be better understood and, thereby, improved.

The future of QoL models in general—and of the QOLSM in particular—is closely related to core values such as human and legal rights of persons with IDD as enshrined in the CRPD. QoL models and the QOLSM have a crucial role to play in enhancing human rights since they provide an ideal

conceptual framework for translating such abstract political concepts as self-determination or inclusion into evidence-based practices.⁵ Given the close alignment between QoL domains and the articles of the CRPD, specific QoL-based instruments to monitor the effective implementation of the CRPD are needed. Future studies should, therefore, focus on taking full advantage of the QoL model (and the QOLSM) and identify related relevant variables such as predictors, mediators, and moderators of QoL-related personal outcomes. This dual focus will be a vehicle towards better understanding and operationalization of the general values reflected in societal rights, ultimately enhancing the lives and well-being of people with IDD.

DATA AVAILABILITY STATEMENT

Data sharing not applicable

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Received: 8 March 2022 | Accepted: 10 March 2022

DOI: 10.1111/dmcn.15229

Capturing the active ingredients of paediatric neurorehabilitation

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Effectiveness research in rehabilitation faces enormous challenges. Unlike many pharmacological and surgical procedures, neither the active ingredients nor the clinical targets

of rehabilitation treatments are self-evident. Moreover, the range of clinical targets is broad because the field is unified by its intent – to enhance functional independence – rather than by a circumscribed set of physiological properties. In this complexity, rehabilitation treatments are often labeled by the discipline of the provider (‘an hour of physiotherapy’)

This commentary is on the original article by Forsyth et al. on pages 1168–1175 of this issue.