

Living longer and stronger: Are children and young adults with Down syndrome experiencing healthier and better lives?

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Down syndrome (DS) is the most common genetic cause of intellectual disability and is associated with multiple medical conditions affecting various organ systems, impacting the individual's health, development and function.¹ In Singapore, the life-birth prevalence of DS was 0.89 per 1000 births in the 1990s, a figure expected to decline further due to improved antenatal testing methods, despite the increasing trend in maternal age.² Advances in medical technology, including surgery for complex congenital heart disease, have extended the life expectancy of individuals with DS to around 60 years.³ Although global life expectancy and disability-adjusted life years for individuals with DS have remained largely stable, the overall disease burden has increased due to longer years lived with disability. From 2010 to 2019, the estimated annual percentage increase in years lived with disability was 1.07 years.⁴ Therefore, it is essential for service providers to shift their focus from merely prolonging life expectancy to improving the quality of life (QOL) for individuals with DS, which is the focus of the study by Chan et al. published in this issue of the *Annals*.⁵

The study highlights a significant gap in the literature regarding QOL in children and young adults with DS. This systematic review addresses this gap by providing a comprehensive analysis of QOL issues. The findings reveal that children with DS have significantly lower Pediatric Quality of Life Inventory (PedsQL) scores in social functioning compared to typically developing children. Social functioning is likely affected by intellectual disability and impaired social communication skills, which can impact the ability to form friendships with peers. Interestingly, older persons with DS report minimal difficulties in forming friendships, despite external perceptions of poorer peer relationships.⁶ Additionally, this review found that children with DS tend to report higher QOL scores compared to their parents, indicating a discrepancy between self-reported and caregiver-reported QOL. This discrepancy highlights the challenge of QOL

screening for individuals with intellectual disability and cognitive impairments, as assessments often rely on caregivers' perspectives. The studies in this review used several validated tools, including caregiver versions of PedsQL and KIDSCREEN. However, these tools are not specifically designed for children with intellectual disability and complex medical needs. One study utilised the newly developed KidsLife Down scale, tailored for caregivers of children with DS.⁷ Another tool not used in the review but relevant is the Quality of Life Inventory-Disability measure, which is reliable across the spectrum of intellectual disability, including DS.⁸

PedsQL and KIDSCREEN are not interchangeable, as PedsQL focuses more on function, while KIDSCREEN emphasises well-being.⁹ Customised QOL measures are essential to accurately assess specific patient populations, and clinicians need to be aware of the domains each instrument measures. Regular quantitative assessments for children and young adults with complex medical conditions are valuable, but in-depth conversations with caregivers are necessary to understand the specific unmet needs and challenges of the child and family. The review identified specific risk factors contributing to QOL outcomes in children and young adults with DS. Physical or functional comorbidities, such as low muscle tone, obesity, autism and epilepsy, as well as lower socio-economic status, were associated with poorer QOL scores. This highlights the importance of screening, early treatment and preventive measures to mitigate the impact of comorbidities and social discrepancies on physical health and QOL, especially in school functioning. DS, once considered a life-limiting condition, is now managed as a chronic disease. Numerous international guidelines provide evidence-based recommendations for the holistic and multidisciplinary care of individuals with DS.^{1,3} The study recommends focusing on support in social and school functioning, suggesting evidence-based interventions such as standardised guidelines for health supervision, anticipatory guidance

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for caregivers and educators on behavioural monitoring, and increased opportunities for inclusive schooling.^{3,10} Adapted physical activity and sports programmes, as well as activities supported by adaptive technology have also shown benefits for autonomy and all aspects of QOL in individuals with DS.¹¹

Despite longer lives, children and young adults with DS still do not experience a QOL on par with typically developing individuals. Healthcare professionals and educators should advocate for sustainable education systems that support skills development beyond typical schooling years. As society better understands the potential for development and socialisation of individuals with DS, there must be adaptations in social awareness, adaptive technologies and employment opportunities. This will enable them to contribute meaningfully to their community, reduce caregiving burden, and enhance the QOL of individuals with DS and their families.

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