Activity capacity and activity performance: time to be specific?

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This commentary is on the original article by Mitchell et al. on pages 767–773 of this issue.

The importance of exercise to improve the long-term health of people with cerebral palsy (CP) cannot be underestimated given the high prevalence of many preventable chronic diseases among this population.1 Aerobic exercise and strength training have proven to be effective at improving cardiorespiratory and muscular fitness respectively.2,3 Not surprisingly, however, once exercise programmes end, fitness levels are quick to regress to baseline values.3 This suggests that while the very act of participating in exercise interventions increases physical activity in the short-term, exercise interventions fail to change long-term physical activity behaviour in people with CP. Their difficulty in changing physical activity behaviour may largely be due to environmental and personal barriers that prevent participation in exercise and physical activity, such as lack of access, unsuitable facilities, time and financial restrictions.4

Mitchell et al.5 attempted to overcome environmental barriers to participation in exercise by delivering a web-based therapy programme to children and adolescents with unilateral CP.3 Not only did this programme eliminate difficulties with accessibility, financial barriers were removed by providing participants with a computer and internet if necessary. The benefit of implementing a web-based programme that included children from a large geographical area and a range of socio-demographic backgrounds is visible in the relatively high recruitment rate and large sample size. Further, difficulties with arranging personnel and facilities to deliver face-to-face training were eliminated, so both the frequency and length of the programme exceeded many previous exercise interventions in the literature.

The lack of face-to-face contact, however, may also have contributed to poor adherence, with participants completing on average 32.4 hours of a potential 60 hours of training. Despite the relatively low adherence rate, improvements in functional strength and walking endurance were observed. It must be noted that although participants completed only half of the prescribed dose, the vast majority of participants completed more than 20 hours of training. This exceeds the dose prescribed in many previous studies of exercise interventions and this high volume of exercise likely contributed to the positive effect. Further, researchers were able to individually progress each child’s training programme, ensuring that the intensity was adequate to induce adaptations in fitness across the 20 weeks. Although adherence was only 54% on average, it varied significantly across participants, which suggests that while the web-based programme wasn’t acceptable for some children, it was for many others.

Even though the programme resulted in improvements in activity capacity, activity performance was not altered. This is not surprising given that no intervention to date in the literature has had any meaningful impact on the low levels of habitual physical activity that are present among people with CP of all ages. The result of this study emphasises the complexity of changing physical activity behaviour in this population. Because the intervention did not include any component that specifically targeted activity performance, it was perhaps unrealistic to expect changes in physical activity. It is time to accept that while exercise interventions will by their very nature fail to change long-term physical activity habits. Further, there was a steady decline in log-ins across the 20 week programme, indicating that participation in physical activ-

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ity was decreasing even during the exercise intervention itself.

Although these results are disappointing in terms of activity performance, it should be acknowledged that research into increasing physical activity in people with CP is still in its infancy. The study by Mitchell et al. is a significant addition to the literature that will assist researchers and clinicians to identify the components that form an effective physical activity intervention for people with CP. It also provides clinicians with a potentially feasible and acceptable intervention to improve activity capacity in children with CP, particularly those who have difficulty accessing therapy services.

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Moving from health disparities to health inequities – and why it matters

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The digital archiving of large, nationally representative survey data has opened worlds of possibility for those interested in the health of children and families living with particular impairments. The number of children/families with any specific impairment may be relatively small, and the survey questions are often not ideal for identification purposes (methodological issues that the paper by Harris and Lord shares with many other studies). However, the combination of a representative sample of children, the range of data available, and the prospect of longitudinal data makes studies such as the Millennium Cohort Study invaluable to researchers seeking to document and understand health inequalities throughout childhood.

Harris and Lord examine whether there are differences in indicators of psychopathology (as reported by parents and teachers using a standardized measure, the Strengths and Difficulties Questionnaire [SDQ]) between 11-year-old children with vision impairment compared to sighted children (and also between children with vision impairment who have or have not been identified as having a special educational need). For the total SDQ scale and for all the subscales (emotional symptoms, peer problems, conduct difficulties, hyperactivity, and prosocial behaviour), children with visual impairment were reported by both parents and teachers to have more problems than sighted children. (I am less convinced by the analyses within the group of children with visual impairment by special educational need identification, because some categories of special educational need, such as social, emotional, and mental health needs, will by definition include children experiencing emotional and behavioural problems).

The differences between 11-year-old children with visual impairment and sighted children are pervasive and stark, and the authors have clearly demonstrated a health disparity or inequality – a systematic difference in health between two groups of children. However, the authors have not gone on to investigate whether this difference may constitute an example of health inequities or ‘differences in health that are unnecessary, avoidable, unfair and unjust’ which are usually associated with social determinants of health.

The risk of stopping at the point of demonstrating a difference is that this can give rise to (or reinforce already existing) assumptions that such mental health differences are an inevitable consequence of the child’s impairment; that any policy or practice responses should lie within mental health services, be reactive, and act to ameliorate the harsh-est impact of ‘inevitable’ mental health difficulties.

I am part of a research group that has been investigating similar issues with children with intellectual impairments (or learning disabilities in UK terminology), some of which has involved secondary analysis of the Millennium Cohort Study. We have also found pervasive differences between