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BETTER TOGETHER

A kaleidoscope of well-being to represent the participation in recreational activities of children and young people with complex cerebral palsy

Introduction/ purpose of study

Non-verbal disabled children with limited mobility have less choices for recreational activities than their peers. Very little is known about their perceptions of their own well-being. This research question explored how children and young people with cerebral palsy and their parents viewed, experienced, and chose their level of participation in recreational activities, to benefit their well-being. Positioning theory was applied, which includes a triad of their position, social forces, and their storylines (Harré and Langenhove, 1999).

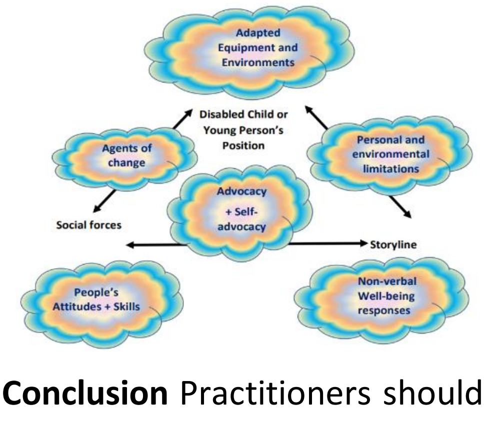
Method

A comparative case study design was developed with seven cases. The participants were aged nine to sixteen years, supported by their parents in the data collection. Each case included two interviews at the beginning and end of twelve weeks, during which time the parents also kept a diary. Observations were also carried out at one of their usual recreational activities, during this time. Photographs were taken by the parent or the researcher, which were used to elicit discussion in the second interview.

Summary of Results

Three overall themes were identified: 1. Participation enhancers 2. Champions for disabled children and young people's well-being 3.Hindrances to participation. Positioning theory was adapted to include the non-verbal children's storylines, represented by a 'Kaleidoscope of Well-being'(Figure 1). This suggests that well-being can fluctuate in different environments, influenced by the social forces of advocates who promoted their needs, with specialist equipment. Participants also showed they could choose not to participate, to determine their own storylines, by self-advocating their wishes.

Figure 1: Kaleidoscope of well-being



Conclusion Practitioners should consider how they include participation as an outcome from their interventions. Further research could explore how professionals listen to disabled children and young people to promote their self-advocacy.

Reference: Harré, R., Langenhove, L. 1999. Positioning theory: moral contexts of intentional action. Malden, Mass.: Oxford.

Authors: Pickering DM(pickeringdm@cf.ac.uk), Gill P, and Reagon C. Cardiff University, UK