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Belonging, school support and communication: Essential aspects of school success for students with cerebral palsy in mainstream schools

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HIGHLIGHTS

- Students with cerebral palsy need school accommodations to enable participation.
- Teacher, parents, students and allied health collaborate to achieve inclusion.
- Qualitative methods enable experiences to be heard as evidence of success.
- Inclusive practice and pedagogy should be informed by real experiences.

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ABSTRACT

Purpose: Investigate successful school experiences for students with cerebral palsy (CP); identify and describe learning and participation at school.
Methods: A phenomenologically-informed qualitative study using in-depth interviews with students (n = 7), parents (n = 11), teachers (n = 10), principals (n = 9), and allied health (n = 10) was conducted to investigate multiple perceptions. Thematic analysis occurred within and between groups.
Results: Three themes were identified: Students belong and benefit; Classroom enablers that help; Communication is crucial.
Conclusions: Students' school experiences are enhanced by innovative classroom solutions that support classroom learning and involvement. Students rely on a diverse team that communicate well and implement individualised solutions that enable success.

Cerebral palsy (CP) is the leading cause of physical disability in childhood (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007). CP is complex and non-progressive with associated conditions including epilepsy, sleep disorders, visual and hearing impairments, sensory impairments, feeding issues, respiratory problems, musculoskeletal dysfunction and chronic pain (Colver, Fairhurst, & Pharoah, 2014; Rosenbaum et al., 2007). Children are usually diagnosed early and consequently receive services from multiple medical, allied health and early intervention services (EIS) before they enter school. EIS targets the child's development, education and health, as well as family needs around disability within the context of family-centred practice (Rodger & Keen, 2010). The aim of EIS is that by school entry, families may understand their child's physical and developmental needs and have had services from allied health disciplines who have supported their child's health and development in the early years (Davis & Gavida-Payne, 2009).

Although substantial services may be accessed in early years to prepare for school, educational attainment of students with physical disabilities is widely known to be below that of able-bodied peers and has long-ranging consequences (Rutkowski & Riehle, 2009). In particular, adults with CP who have mobility restrictions often have reduced educational achievement and associated lack of involvement in paid work and community opportunities (Huang et al., 2013; Törnbom, Jonsson, & Sunnerhagen, 2014). Past research has highlighted many challenges for students with physical disabilities and school communities including parental hesitation to enrol their child in local mainstream schooling (Leyser & Kirk, 2004); schools lack of acknowledgement of parents

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expertise and collaborative inclusive practice (Denman, 2014); insufficient curriculum adaptation, teacher training, funding support, access to professionals skilled to support students at school, attitudinal and physical barriers in schools, and bullying and harassment (Victorian Equal Opportunity and Human Rights Commission [VEOHRC], 2012).

Students with physical disabilities are known to value participation at school and inclusion in social opportunities although challenges and barriers are often described more so than successes (Curtin & Clarke, 2005; Denman, 2014; Díez, 2010; Egilson & Hemmingsson, 2009). In reality, substantial research that has investigated the experiences of students and school personnel has identified unmet need, insufficient actions and available resources to support students to be involved in school related activity to their full potential. The participation of children with disabilities has been the subject of much discussion (Imms et al., 2015). The construct of participation comes from social models of disability, the International Classification of Functioning and Disability (ICF; World Health Organization, 2001). Students with CP are in the unique position of receiving active service from the health and medical sectors whilst attending educational institutions. However in many geographical contexts, there may be no common governing or service structure to ensure the two sectors work together for student benefit. Whilst the health sector has measured participation taking a silo approach to children, grouping according to disability type (Adair, Ullenhag, Keen, Granlund, & Imms, 2015), the education sector has taken an inclusive school approach involving differentiated learning and improved education for all students regardless of diagnosis (Bines & Lei, 2011). Inclusion is a “process of addressing and responding to the diversity of needs of all children, youth and adults through increasing participation in learning, cultures and communities, and reducing and eliminating exclusion” (UNESCO, 2009).

Research about the participation of students with CP within classrooms suggests that students with CP face barriers to involvement in school, require substantial technology and assistance to participate and have variable levels of support (Colver et al., 2011; Coster et al., 2012; Schenker, Coster, & Parush, 2005; VEOHRC, 2012). A recent systematic review suggested that the ICF may be a useful practical and theoretical guiding framework within education settings (Maxwell, Alves, & Grunland, 2012; Moretti, Alves, & Maxwell, 2012). Within the education sector, successful inclusive school experiences equate to participation and involvement in curricular and extracurricular activities in the school environment (Singal, 2008). Research to understand the enabling and challenging factors is crucial to promoting more inclusive environments for children with disabilities in schools.

Children and young people with CP experience barriers to participation in activities both inside (Coster et al., 2012; Egilson & Traustadottir, 2009a,b) and outside of school (Adair et al., 2015). United Nations Educational, Scientific and Cultural Organization (UNESCO) states that assessable educational attainment that is demonstrable of performance and achievement is dependent on active participation observed by classmates and teachers (UNESCO, 2009). Further, inclusion policy that aligns with the United Nations Rights of Children with Disability necessitates reasonable adjustments and modifications for each student to individualise their access to curriculum and assessment. However, the extent to which individual students experience success is unknown in the absence of accountability or benchmark frameworks measuring these issues (McLaughlin & Rhim, 2007; Minou, 2011).

Advances in medical and health related interventions for children with CP mean more interventions are available to children and their families. Universal classification systems are now routinely used to provide a summary of the child or young person's functional status. The measures are: the Gross Motor Functional Classification System (GMFCS; Palisano et al., 1997), for mobility and gross movement, Manual Assessment Classification System (MACS; Eliasson et al., 2006), for hand use; and the Functional Communication Classification System (FCCS; Hidecker et al., 2011), for communication. All systems have five levels (I to V) indicating the person's capability and need for aides/support. Higher levels (IV or V) indicate higher need for equipment, technology and support to participate. Although widely used in health and medicine, such advances in functional terminology has not been extended into educational settings. One important step forward to promote the health and education sectors to work together for student benefit is the application of shared language. In this paper, we introduce readers from the education sector to such terminology to better explain the capabilities and equipment/technology needs of students with CP.

The aim of this research was to explore successful school experiences and the participation of students’ with CP in mainstream classrooms. The experience of students who attended classes and school activities like other non-disabled students was of interest. Some findings from this project have been reported elsewhere (Bourke-Taylor, Cotter, Lalor & Johnson, 2017). Overall aims relevant to this paper were:

1. To explore how students with CP are participating within their regular classrooms and school environment.
2. To explore and identify strategies as determined by students, parents, teachers, principals, and allied health professionals that result in a student's successful involvement within the classroom, school curriculum and school community.

1. Methods

For this exploratory study, qualitative methodology based in phenomenology enabled investigation of participants’ experiences of school success for students with CP attending mainstream schools. Phenomenology focuses on understanding the lived experience (subjective and real experience) of individuals around a phenomena—in this case, successful school experiences and participation (Creswell, 2013). Collectively, the experiences of persons who share the phenomena are compared and the essence of that shared experience is derived as common themes or an essence statement. In this study, themes were selected as the best method to present the multipronged perspective of five participant groups. In-depth interview guided by specifically designed interview guides were used to collect data. The study occurred in Melbourne, Australia. The Australian context is similar to other developed countries ratified to the Rights of People with Disabilities. Students with disabilities and their families can choose to be fully included in local schools or attend specialised settings. This research was concerned with students who attended their local school full time.

1.1. Participants and recruitment

This study sought a multipronged perspective of student and school success, seeking participants who self-identified as having experience with school success as a student, parent, teacher, principal or allied health professional with direct experience s with a person/student with CP attending local school. Purposive sampling was used to recruit participants from one state wide facility, Cerebral Palsy Education Centre provides state-wide support to 60 primary and secondary students with CP in any year and is a specialty centre that prepares and supports children with CP. This