

Barriers to and facilitators of physical activity for children with cerebral palsy in special education

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2	Barriers and facilitators to physical activity for young people with cerebral palsy in specialist
3	schools: A qualitative study
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1 TITLE:

ABSTRACT

AIM: To explore the barriers and facilitators to physical activity for young people with cerebral palsy in specialist schools.

METHOD: Eleven focus groups involving 73 participants (10 students with cerebral palsy, 13 parents of children with cerebral palsy, 27 teachers, 23 therapists) were held at two specialist schools. Focus groups were audio-recorded, and transcribed verbatim. Transcripts were analysed using inductive thematic analysis by two researchers, independently.

RESULTS: Four main themes emerged from the focus groups: school priorities, student factors, staffing and environment, and roles and relationships. Physical activity was promoted when academic work and physical activity were seen as equally important school priorities. Student factors that reduced physical activity included fluctuating health, school absences, and protracted rehabilitation after surgery. The staffing and environment unique to specialist schools played a pivotal role in assisting students to be active, as was the importance of collaborative, relationship-based care.

INTERPRETATION: Physical activity programmes developed in specialist schools need to take into consideration complexities associated with the age, developmental stage, and academic requirements of young people with cerebral palsy. Particularly for adolescents, motivation was discussed as having a substantial influence on physical activity participation. These findings may assist school leadership teams, clinicians, and teachers in planning physical activity interventions.

WHAT THIS PAPER ADDS:

 Young people with cerebral palsy in specialist schools described the importance of physical activity in their lives, alongside managing the complexities of their condition

 • Specialist schools offer custom-built environments that are perceived to promote physical activity and inclusion for students with physical impairments

 Therapists and teaching staff in specialist schools described working creatively and collaboratively to incorporate an 'all-day' approach to providing physical activity opportunities

 Despite physical activity being a school priority, tensions existed in balancing time spent on physical activity versus academic work

SHORTENED TITLE:

Understanding physical activity in specialist schools

Participation in physical activity has important health and social benefits for young people with cerebral palsy. Young people with cerebral palsy do not take part in physical activity to the same extent as their typically developing peers, or to the levels recommended by national guidelines. This in part may be because they have difficulty with movement and posture. However, many other factors, both internal and external, also contribute to the low levels of physical activity and high amounts of sedentary time that are typical of young people with cerebral palsy. A number of studies have detailed the barriers and facilitators of physical activity participation for young people with disabilities (including cerebral palsy) in the community; however, little is known about the barriers and facilitators to participation in physical activity at school. While one study did explore the experiences of physical activity of students who attended a special school, and gave great insight into the views of the students, the views of parents, teachers, and therapists were not included.

Specialist schools provide an alternative educational option to mainstream school, for students with complex physical and cognitive impairments, medical needs, or accessibility requirements. They are predominantly government run and have physically accessible environments. Specialist schools employ teachers skilled in the provision of special education, and students have access to custom-modified curriculum with high staff to student ratios. Students also have access to on-site therapy teams not present in mainstream or other schools, including physiotherapists who collaborate with teachers and develop personal rehabilitation and fitness programs. Considering the importance of children with cerebral palsy reaching their physical potential in childhood, ¹⁰ and maintaining their function in adolescence, ¹¹ specialist schools can be an attractive option for some parents when selecting a school. ¹²

While the study by Conchar et al ⁹ described physical, psychological, social, and environmental factors that could act as barriers or facilitators to physical activity for young people with cerebral palsy attending a special school, there is limited understanding of the perceptions, knowledge or priority-levels their parents, teachers, and therapists place on their participation in physical activity. Given young people with cerebral palsy spend a large amount of their time at school, it is appropriate to involve teachers and school-based therapists in a discussion about participation in physical activity. ^{1,13,14} Therefore, the aim of this study was to qualitatively explore the barriers and facilitators to all physical activity across the school day, as well as the perceptions, knowledge and priority levels of physical activity in specialist schools for young people with cerebral palsy.

Method

Design

A descriptive study using qualitative methods was completed.¹⁵ This design allowed for an in-depth exploration of the experiences of physical activity of young people with cerebral palsy during school hours, from multiple viewpoints (person, family, professional, policy).¹⁶ We used thematic analysis and an inductive approach to analyse the data i.e. the themes emerged from the available data. These methods are consistent with interpretive description (REFs), which focuses on generating new knowledge by understanding complex experiential phenomena related to health, and are similar to the pragmatic approaches used by other qualitative studies (e.g. Kolehmainen and McNuff (REF)).

The concept of physical activity in the specialist school setting among young people with cerebral palsy was explored through a series of focus groups with students with cerebral palsy and their parents, teachers, and therapists. Physical activity was defined as movement that took place across the school day, and included timetabled sessions, as well as incidental movement. The aims of the focus groups were to draw out the participants' thoughts, perceptions and specific experiences of what helped and hindered participation in physical activity for young people with cerebral palsy in the specialist school setting, to help inform practice and future research. Focus group methods for data collection were used to take advantage of group interaction to encourage discussion between the participants to compare and contrast their experiences and views.¹⁷

The University Human Ethics Committee and the State Department of Education and Early Childhood Development granted ethics approval for the study. Written informed consent was obtained from all participants prior to their participation. Students with cerebral palsy were invited to provide their own written assent in addition to their parent's written consent.

Participants

Four groups of participants – young people with cerebral palsy, parents of a child with cerebral palsy, teachers, and therapists from all disciplines - were recruited from two Australian, metropolitan specialist schools. This varied sample enabled us to examine if similarities and differences between the views and experiences of the key groups involved (students, staff, parents) existed, and was consistent with a matrix approach (REF AVERILL). Both schools were located within regions of social disadvantage ¹⁸ and had large catchment areas, with enrolled students travelling by bus up to 2 hours each way to attend school. The schools had enrolments of 90 to 150 students, aged 5 to 18 years, and three to four equivalent full-time on-site staff for each of physiotherapy, occupational therapy, and speech pathology services. Class groups in these two schools had approximately seven students, and were based on cognitive level, rather than physical function, of which there was wide variation. In both schools, twice-weekly 'gross motor sessions' led by physiotherapists took the place of traditional physical education classes. For some students, these classes may have involved fitness based activities, though for others the sessions may have been focused on gross motor skills development or rehabilitation. Classroom teachers and physiotherapists worked together to timetable other physical activities across the week, such as bike riding, walking between classes, or outdoor play, in addition to these gross motor sessions.

Potential student participants and their parents were identified by the school staff by going through school enrolment lists. Teachers and therapists were recruited through advertisements in the school newsletter and promotion of the study by school staff. Young people with cerebral palsy who attended specialist school full-time or part-time, were aged 8 to 18 years, had sufficient language to take part in a group conversation (either verbally or through augmentative alternative communication), and behaviourally were able to participate in a group setting were eligible to participate. Parents of any child at the school with cerebral palsy were eligible to participate if they had sufficient English competency to converse in a group.

Procedure for the focus groups

Separate focus groups were held for each of the four groups of participants. The focus groups for students and parents were held during the school day, while focus groups for therapists and teachers were scheduled outside of school hours. Focus groups were scheduled to run for one hour and were audio-recorded. An experienced, independent facilitator with no

- 1 involvement in the school was employed to run each group, based on a pre-determined
- 2 framework of questions and prompts (Table 1), with a member of the research team (SC)
- 3 present as note-taker recording emergent themes for each group. The conversation was led by
- 4 the facilitator, guiding the discussion back to physical activity within the specialist school
- 5 setting, where needed, while allowing a broad and flexible discussion, directed by the
- 6 interests and experiences of the participants.

Trustworthiness and rigour

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- 8 There are four components of qualitative research design that contribute to its overall
- 9 trustworthiness: credibility, transferability, dependability, and confirmability. ¹⁹ The
- practicalities of these components of trustworthiness are described by Letts et al., ²⁰ and form
- the bases of the design of this study. Credibility was ensured by conducting multiple focus
- groups for each stakeholder group, by triangulation of data between groups, and by involving
- multiple researchers in the analysis and peer review. The researchers were all
- physiotherapists and had a strong interest in physical activity for young people with
- disabilities. SC had five years of experience in community-based paediatrics, NT and NS
- were active clinical researchers, which included experience in paediatrics and qualitative
- 17 research, and KD was involved in academic management and had experience in community
- based paediatrics and qualitative research. To help verify interpretation of the data, a list of
- themes generated during initial analysis was sent to the participants for validation (member
- 20 checking) and their feedback on the accuracy of the summary was encouraged.
- 21 Transferability was enhanced through description of the specialist school settings and the
- 22 participants involved. Dependability was achieved through detailing the processes of data
- collection, analysis, and interpretation, and by peer-review of the data analysis at multiple
- stages of the analysis by three members of the research team (SC, NS, NT). Confirmability
- was achieved through discussion of the data at each stage of analysis by the research team.

27 Data analysis

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- Focus groups were transcribed verbatim. NVivo software²¹ was used to manage and organise
- 29 coding. Data were analysed using a process of inductive thematic analysis. Data were coded
- independently, line-by-line, by two researchers (SC, NT). The codes emerged from the data
- and were not predefined. From the data collected from each focus group initial codes were
- 32 identified and grouped. Following this, three researchers (SC, NT, NS) discussed the first
- dentified and grouped. Following this, three researchers (Se, 141, 145) discussed the life
- stage of coding and from these discussions the overall themes emerged. The researchers
- 34 discussed interpretation of the data until consensus was reached. Transcriptions were re-read,
- and key word searches performed to ensure no data had been overlooked. There was ongoing
- 36 dialogue throughout the process, to ensure themes and sub-themes were not missed. 37

Results

- 39 Eleven focus groups were conducted, with 73 participants (10 students with cerebral palsy,
- 40 13 parents of children with cerebral palsy, 27 teachers and 23 therapists) (Table 2), with
- 41 groups ranging in size from 2 to 12 participants. Most student participants were teenagers
- 42 who used either specialist walking frames (Gross Motor Function Classification System
- 43 (GMFCS III) or wheelchairs (GMFCS IV to V) as their primary source of mobility. All
- students had cognitive impairments ranging from mild to moderate. Parents predominantly
- had children who were about to enter the teenage years and who were dependent on
- 46 wheelchairs for their mobility (GMFCS IV to V). Their children also had cognitive
- 47 impairments ranging from mild to severe. Of the 13 parent participants, 11 were mothers. The
- 48 teachers and therapists who participated were experienced in working in specialist schools,

with teachers having 8.3 (SD 5.9) years of experience, and therapists 4.5 (SD 4.6) years.

Participants predominantly spoke English as their first language.

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Participants gave four key reasons why physical activity was important for young people with cerebral palsy: (1) health benefits, (2) cognitive development and learning, (3) their right to participate and (4) developing independence. Specialist schools were seen as settings where students' abilities and independence were maximised.

"You need to be physically active in order to be healthy, more independent as you can possibly be." Student, 18 years old, GMFCS II

"...kids need to be active ... that's the way that they learn, especially at early ages...." Teacher 1

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Four main themes were identified across the four groups of participants: school priorities, student factors, staffing and environmental resources, and roles and relationships (Figure 1). These four main themes were described by participants in all groups as both barriers and facilitators for physical activity in the specialist school setting.

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School priorities

Teachers and parents thought physical activity was promoted when academic work and physical activity were seen as equally important. Clear priorities promoted unity among teaching and therapy staff. Staff at both schools spoke about the effort involved in transforming their culture into one that valued physical activity. All groups commented on formal structures that facilitated physical activity, including timetabling and formal twiceyearly goal setting meetings.

"We've had to mandate physical movement at times." Teacher 2, Principal

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School priorities were described as a barrier to physical activity when these priorities were unclear, or conflicting. Participants gave examples where academic work took preference over physical activity, due to pressure from school management and where no practical framework for physical activity existed. Participants recognised the difficult balance that existed between physical activity and academic work.

"I also feel the pressure that my kids should be doing academic work all the time. So this year I cut bike riding. Even though they're little kids and bike riding is something they enjoy and three quarters of the class would benefit from, we had to do maths." Teacher 3

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Student factors

Students with cerebral palsy described how their physical impairments made physical activity more challenging, and the effort needed to improve or maintain physical condition.

"Well, it is physically hard for me to play football in the sense that I can only use one hand, [and] this hand not that well." Student, 18 years old, GMFCS II

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Fluctuating health, absence due to illness and medical appointments, and protracted rehabilitation after surgery were reported as factors that reduced physical activity.

"Surgery and intervention is ongoing, so [name] is just up on her feet and she's got to go and have surgery again...she has worked really hard to get to this point and now I have to work hard to get her back to it...." Parent of a 14 year old child, GMFCS III

47 48 Motivation was identified as a complex factor, including changing body perceptions, and peer group influences. All participant groups discussed the need to know what motivated each student, so physical activity could be targeted, appealing, and empowering for students, and so students could make informed physical activity choices.

"...motivation is the key...the school can try as much as they want but it's got to be about you, whether you want to do it." Student, 14 years old, GMFCS IV

Staffing and environmental resources

All participant groups recognised therapists as 'experts in physical activity' and as the promoters of physical activity in the specialist school setting. Therapists were admired for their ability to integrate physical activities with curriculum. This was achieved by therapists working collaboratively with teachers to plan sessions, and by therapists working alongside teachers in classes.

"The most important thing is that the school has specialists,because if it didn't then the opportunity to do physical activity would be limited." Parent of a 14 year old child, GMFCS IV

Teachers were identified as implementers of physical activity within the curriculum through their creativity, flexibility and problem solving. Participants felt skilled and passionate teachers saw the possibilities for physical activity for their students across the day, and worked resourcefully to ensure these opportunities occurred.

"...if you get a really proactive class room teacher then that teacher will draw on more of the resources that the school will have, ... and really make physical activity a priority and make it happen." Parent of an 8 year old child, GMFCS IV

Staff availability was identified as a facilitator of physical activity, particularly for students with high physical support needs. However, fewer staff, or staff unable to physically assist, limited opportunities for students to be physically active. Working with young people with cerebral palsy was described as 'physically tiring', and staff wellbeing needed to be actively protected.

"It's hard on your body. The staff have to be healthy all the time so they need to look after themselves." Teacher 3

Participants believed the schools were well resourced with specialist equipment to facilitate physical activity (e.g. including walking frames, modified bicycles, hoists, tracking systems). Equipment meant students were able to move in their environment. The schools' custom-built design for students with physical impairments, with wide corridors and open spaces, were reported to enable students more easily and safely walk between classrooms, and accommodate multiple children using equipment.

"If we didn't have the equipment I wouldn't be able to do it." Student, 14 years old, GMFCS III

However, therapists described how time for physical activity was reduced when students shared equipment, due to the need to adjust equipment between users.

 "Because we share a lot of walking frames, they are always set up differently – if each student had their own designated walking frame, they could use them. Then it could be so much easier for them to use them at lunchtime and recess." Therapist 1

Roles and relationships

Positive staff-student relationships were thought to facilitate physical activity. Parents commented their children eagerly participated in activities when they got along well with their therapists and teachers.

"I don't think we can underestimate the influence that the teacher and therapists have on the kids...if she [physiotherapist] says 'come on I want you to get up and go and walk around the school seven times', [name] will go 'okay, I'll do it eight times for you.'" Parent of a 9 year old child, GMFCS III

All participant groups <u>spoke of</u> the challenge of doing enough physical activity. Parents acknowledged the importance of physical activity for their children, and encouraged it, though expressed a desire to have fun at home, rather than focusing on therapy during family hours. Travel time, and medical appointments, meant parents placed importance on the provision of physical activity at school. Teachers and therapists recognised this, though spoke of the need for balance in their roles e.g. catering to students' academic and physical needs, balancing expectations of families and school management. Students <u>described</u> how cerebral palsy and the impact of surgery limited the extent or the ease with which they could participate.

"As a parent I just want them, them the school, to get her doing as much as she can do to her potential..." Parent of a 9 year old child, GMFCS III

"It's a changing environment every day, and I think that's part of it [the challenge]. Just trying to work out what you can do in that particular day that's the best balance for everything." Teacher 4

"Sometimes it feels like you're an old car, you go to the factory to get fixed and it takes such a long time to get back into the motion of doing things the way you used to and all of that, so it takes a little while." Student, 14 years old, GMFCS IV

Discussion

All participants emphasised the importance of physical activity for physical and psychosocial health and placed a high priority on young people with cerebral palsy being physically active, converging with evidence that fitness training, as a structured form of physical activity, is a safe and effective intervention for young people with cerebral palsy (Novak et al 2013 REF). This contrasts with other studies of young people with disability that described a lack of

This contrasts with other studies of young people with disability that described a lack of understanding of the need for physical activity as a barrier to participation. ^{5,6,22} The data suggest school leaders' understanding of the importance of physical activity and their modelling of their school's policy over many years created the cultural expectation of students being physically active at school. Nevertheless, a tension existed between academic goals and physical activity participation that continued at times to pit one against the other. The beneficial impact of physical activity on learning was not always recognised, despite evidence it is positively associated with cognition over a range of functional measurement areas²³ and that increased time spent in physical activities is not linked with reduced academic performance. ²⁴ Similar to benchmarks for academic curriculum, a regulated evidence-based requirement for physical activity and sedentary time limits in specialist schools, promoted and steered by school leaders, may work toward ensuring physical activity remains a classroom necessity.

Complex factors that influence physical activity participation in the specialist school setting were described, similar to previous studies in paediatric populations.^{5,6,9} Motivation emerged

as a major influencing factor across all participant groups. It was described as being impacted by student's self-belief and perception of their physical ability, their interests, their relationships with parents or staff, and their knowledge of physical activity. Despite literature in typically developing populations suggesting peer relationships are a powerful motivator for adolescents and their physical activity behaviours, ^{25–27} this did not emerge as a theme in our study. Physical activity research into motivation in typically developing adolescents suggests positive physical activity behaviours in schools are associated with being task oriented and effectively supported by staff. ^{28–30} In addition, motivation should be self-determined, arising from internal factors, ³¹ such as a child wanting to improve their own fitness, rather than from externally imposed directives. It is unclear exactly what promoting self-determined motivation should look like for young people with high levels of cognitive impairment, and this may warrant exploration with experienced clinicians. In this study, experienced teachers and clinicians described having skill in providing meaningful opportunities for physical activity. These experienced practitioners' development of rapport, and use of environmental development likely promoted student self-determined motivation for physical activity.

The unique staffing and environment of specialist schools was perceived to play a pivotal role in assisting students to be physically active. The perceptions of all stakeholders was that specialist schools provided an environment that optimised the physical and cognitive development of young people with cerebral palsy with moderate to severe disability. They believed that it gave students who may have otherwise have experienced barriers, the opportunity to participate in regular, meaningful physical activity. Our results are consistent with other literature, that for those with more severe impairments, the expertise of the teaching staff is crucial³² to their participation. While there has been important movement toward the inclusion of children with disabilities in mainstream schools,³³⁻³⁴ there remain ongoing challenges for their participation in mainstream settings.³⁵ Evidence suggests there are greater participation benefits in mainstream schools for students with higher physical function compared to those with lower physical function.³⁶ Our study is important as it provides parents with an important perspective on participation facilitation to consider, when deciding the best school setting for their child.

Consistent with the idea that flexibility and innovation within the curriculum may increase participation for young people with disabilities,³⁷ physical education classes in the traditional sense did not exist in the specialist schools where this study was conducted. Instead, the schools timetabled 'gross motor' sessions that focused on physical activity or skill development, in addition to an 'all-day' physical activity approach, where therapists and teachers worked toward optimising activity, and minimising sedentary time for students of all functional levels, across the day, in line with physical activity guidelines.³⁸ Unlike a study involving physical education teachers in mainstream schools,³⁹ the teachers in our study did not report barriers to participation linked to a student's level of function. Rather, they described the collaboration between therapists and teachers as enhancing physical activity opportunities for young people with cerebral palsy and moderate to severe disability. A related study, also in a specialist school setting, reported a similar finding, that high levels of communication between therapists and teaching staff resulted in better postural management for students. 40 Our study highlights how the alignment of the attitudes and the goals of students, parents, teachers, and therapists, around participation in physical activity, can lead to an atmosphere of inclusion within the school community.⁴¹

A limitation of this study is that a theoretical framework was not specified a priori; rather, a descriptive qualitative approach, consistent with interpretive description, was used to answer

the research questions posed. A further limitation of this study is that it describes two specialist schools (73 participants) in metropolitan locations. The outcomes may not be representative of other specialist schools, for example in rural locations or in other countries. Additionally, the experience of physical activity in specialist schools may not reflect the experiences of young people with high level needs, and their parents, who have chosen mainstream education. Future studies into the physical activity experiences of these groups would add a rich and important voice to our understanding. A strength of this study is the possible practical implication; the barriers and facilitators identified may be utilised by school leadership teams, clinicians, and teachers to inform the planning of programs in similar settings for young people with cerebral palsy.

In summary, this study adds to the limited literature specific to specialist schools. It incorporates the views of parents, teachers and clinicians, as well as students with cerebral palsy, highlighting the strong desire for young people with cerebral palsy to take part in physical activity. The tailored specialist school environment was described as being developed to facilitate physical activity for students with complex needs, and this study describes how teachers and therapists work creatively and collaboratively to best utilise the resources on offer. There remains a tension between the academic work that must occur, and physical activity participation, which can be seen by some to be a secondary aim of schooling. Knowledge of these barriers and facilitators to physical activity for young people in specialist schools provides education and health professionals with important insights on potential avenues to increase physical activity in this setting.

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- 27 Hill, who facilitated the focus groups.

Segment focus	Details of segment				
Facilitator introduction	The facilitator and the note-taker (researcher) introduced				
Introduce purpose of the group	To explore participant knowledge and experience Written timeline for the hour produced				
Participant introduction	Name, role provided				
Context question	What sorts of physical activity do you (or your children/students) do at school?				
Facilitators	Which things in the specialist school make physical activity easier?				
Barriers	Which things in the specialist school make physical activity more difficult?				
Benefits	Should young people with cerebral palsy participate in physical activity? Discuss. What are the benefits to participation?				
Priorities	Where does physical activity for young people with cerebral palsy rank in the level of priorities for you, and in this school?				

Table 2 Description of teaching and therapy staff focus group participants

Students (n= 10)		Parents (n= 13)*		Therapists (n= 23)			Teachers (n= 27)	
Mean age (SD) (years):	GMFCS (n):	Mean (SD) age of child (years):	GMFCS of child (n):	Mean (SD) practicing (years):	Mean (SD) at specialist school (years):	Discipline (n):	Mean (SD) practicing (years):	Mean (SD) at specialist school (years):
14.1 (2.2)	I: 1 II: 1 III: 5 IV: 2 V: 1	12.9 (2.7)	I: 1 II: 0 III: 1 IV: 7 V: 4	8.3 (6.5)	4.5 (4.6)	SP: 5 OT: 8 PT: 8 MT: 1 N: 1	12.9 (11.8)	8.3 (5.9)

Note. *= n=11 mothers, n=2 fathers; GMFCS= Gross Motor Function Classification System; SP= speech and language pathologist; OT= occupational therapist; PT: physiotherapist; MT= music therapist; N= nurse.

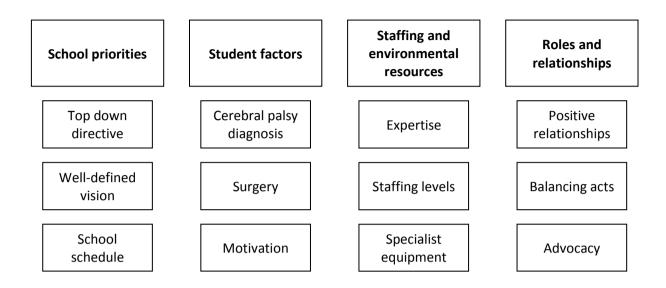


Figure 1 Barriers and facilitators to physical activity in specialist schools, as described by young people with cerebral palsy, parents, therapists, and teachers.

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