

FACT 2:

Collaborative Partnerships Support Students in Local Schools

Findings from the research project:

“Successful School Experiences for Victorian Students with Cerebral Palsy in Local School Communities”¹

KEY MESSAGE: The team of support around a child needs to be proactive and parents play a key role.

The research indicated that parents of children with cerebral palsy offered a wealth of knowledge to share with schools. Families worked behind the scenes throughout the student’s school life, and at times were very involved in classroom and other curricular activities. Families valued support, offered support to schools, and helped coordinate the students required services between school and outside supports. Allied health and outside organisations recognised parents as keys to their child’s success.



*“The parents are just crucial. They need to be the advocate for the child... the parent really has known that student or that child since the beginning, so they know them the best.” **Principal***

*“The first part of [a good experience for the student] is the family and school co-operation and communication, working together. The parent of this family came in with this young bloke and had lots of information, obviously because they’ve lived with the child since birth. So lots of information and was really freely sharing it and helping to make those early connections with places like CPEC and other places. So I think it is vital to do that.” **Principal***

Conclusions & Recommendations

- 1. Students with cerebral palsy, physical disabilities and complex communication needs can and do attend local schools.** Students make friends, enjoy school, learn alongside their peers and develop a sense of independence and belonging that is highly valued by students and their families. Therefore, the preparation of students and families before school begins, the efforts by schools and external agencies, and the dedication and hard work contributed by families, are all worthwhile actions and aims.

“We really have an open door policy here with families and it’s a partnership and we could not have integrated him into our program as successfully without parent support and involvement. His mum was very involved in the early days... mum has always provided information about him so that the students can go home and talk about it with their families in a more private way and has been open to the kids”

Teacher



Families and school “It seems to me that the parents feel happy to send [their child with CP] to school, they see benefit in sending the child to school, they see it as a good use of time for their child; they feel that the child is safe within the school environment and will be looked after. It’s a real positive shift within the family”

Physiotherapist

“It is a team that has to work things out and everybody has to be willing to spend a bit of extra time. And I’ve found the school to be really good, although it has been stressful for us because we have to try and initiate everything. I guess that’s part of what we have to do to make it successful for [my son] at school.”

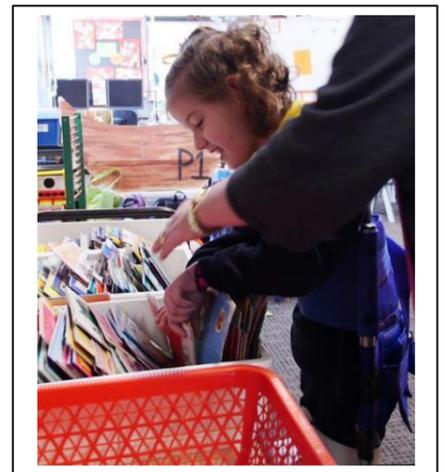
Mother of teenager with CP, spastic quadriplegia—GMFCS level 5

“Just push your kids to be able to do what you think they can do because they can. You know, I don’t think I would be in the best condition if it wasn’t for mum and for dad pushing me through the physio, through the OT, through sport as well or some sort of physical activity... I think that’s something I need to thank them for as well” **Teenager with CP, hemiplegia--GMFCS level 2**

- 2. Families play a crucial, substantial, ongoing and sometimes difficult role in advocating, organising and navigating the school system on behalf of their child.** With the help of skilled allied health practitioners who know their child, and with structured support from an agency like the Cerebral Palsy Education Centre (CPEC), families can develop skills and contribute substantially to the school’s capability to achieve successful participation. Schools should recognise and embrace the role of families in the inclusion of students with disabilities in every practical sense.

“I was contacted by the mother mid last year and she had been told at the time she needed to really work towards a transition...plenty of notice so we could put things into place. The child is in a wheelchair so we needed to have ramps and all of that infrastructure installed, etc, so we needed plenty of time. The mother was really positive and I think by working with her, we’ve forged quite a good connection. She feels comfortable talking with me, I’m very comfortable talking with her. She is so supportive of the school and she sees it as a very supportive environment for her child...the experiences have been very positive because of the attitude of the family and the attitude of the staff in the school as well.” **Principal**

“[Providing support at school]...it’s heavy. Over the years it’s been...like we’re in a really good spot now...it’s running like clockwork now. But look, there’s a different issue every week. And so you need to be available to problem solve, on a regular basis. Like I mean you have to be dedicated to the idea. That it’s the right thing. And [as a parent] you have to have time to make it work.” **Mother of student with CP, spastic quadriplegia--GMFCS level 5, visual impairment with CCN**



3. With training and support, teachers and aides can adapt, modify, tailor and offer innovative solutions to the daily curriculum issues that arise for students with disabilities. When educators have access to experts, collaborate with a student’s family, receive adequate and appropriate support from school leadership, and receive training, teachers can and do create great and appreciated school experiences for students with disabilities. Therefore, teachers must have access to education and experts who work with them inside schools and provide professional development, so that they can feel confident educating students with disabilities.

“[The] mother made some little mini communication books and so we did an activity today where the kids all had their own communication books and [child with CP] was there and in their group they were all discussing the book that we’d just read in our literacy session, so using the book and practicing communicating to each other using the book, not just to [child with CP]... [The mother] is very active in making those things happen... she does a lot of work at home...So she’s very hands-on with what we’re doing in the classroom....” Teacher

“The Mum had to be here all the time until the aide was trained up in [student’s] care because it’s so intensive...we had two different aides learning. [The student] can’t always communicate exactly what’s going on and of course we don’t want her to get upset or we don’t want to do the wrong thing. The parents were very supportive. Mum was very willing to be here and do everything she could but now I think they’ve sort of backed off and are letting [student with CP] have her time at school... So other than the pick-up and drop off they don’t actually spend any time at school.” Teacher

“It was pretty emotional, particularly for the mother...she looked around at all these kids and they were all looking up at her and she had to explain what had happened and why [her child] was the way he was and what that meant...a lot of the kids didn’t know anything about him or were too scared to talk to him or didn’t know, “Can he hear me?” even, why he was in that chair, why he had all that equipment. It was really, really great because they learned that he was just like them except that he can’t speak the way they speak, he speaks differently, he speaks through his DynaVox or through his communication book. It started that day where the kids would come up to him to interact and talk with him. I don’t think that was really happening previously...like fear of the unknown...the wheelchair is so big and there’s this big computer, almost like a machine...[so] that was really great.” Teacher

4. Allied health experts are recognised as useful providers and essential experts. Experts can and do assist teachers, aides and schools to make appropriate and reasonable accommodations and adaptations that will enable individualised success for students, particularly in the areas of communication, physical access and modifications of tools and curriculum, technology and timetabling. Schools should also be inclusive of allied health practitioners as key team members who can and do provide services to students and their families before, during and after the school years.

“Two integration aides and he has his three therapists, he’s got a speech therapist, his occupational therapist and his physiotherapist. But of course his family as well, his mum puts in a lot of time to make sure that he’s given the best opportunities he can be and is really helping him out with anything home-wise as well as at school. So there’s a very large support team.” Teacher

“I will not withdraw a student ever unless it’s critical for assessment or if they’re unwell or if we’ve got to make a lot of noise doing some programming or something like that...I have learnt that I need to do what the class are doing... working in the classroom, me problem-solving, how that student will do everything that everyone else does... I have to make sure that my goals that I write with the teacher...the mum and dad, are doable by the aide in the classroom environment.” Speech pathologist

“...sometimes parents will write to other parents. So when kids go home and ask questions, [parents] know what to say. So for example: Why is there a tube in that person’s tummy? The mum just doesn’t have a guess, and talk in the negative, they can actually ...answer that question correctly without saying what the child can’t do, just how they do it differently...So that’s actually [a] really good tool...” Speech pathologist



5. Schools cannot build up expertise to assist students alone. Students and school communities often embrace students with disabilities, although physical accessibility, knowledge and use of student's particular communication methods or needs, and social participation must be carefully addressed through a strategic plan that includes appropriate experts. Those experts could include speech pathologists trained in alternative and augmentative communication, occupational therapists trained in technology and switch access, and physiotherapists with expertise in childhood physical disability. Collaborations with the same aim – a successful school experience for the student – should underpin all interactions between schools and external experts and agencies.

“Maybe initially...it’s overwhelming for people but the majority of students that I support out in schools have very severe physical disabilities and complex communication needs and a lot of them have friends and have play dates and have genuine friendships and the whole school gets behind them when there’s fundraising like a marathon and they have trivia nights to support equipment for that child. So I don’t think severity [influences success], I think it’s the attitude and then if that parent goes in and whether the child has a disability or not they’re a child, they’re part of the group, they’re part of the school and that community and capacity building for schools is I think really important.” **Speech pathologist**

“The first part of it [what makes a good inclusive experience] is the family and school co-operation and communication working together. The parent of this family came in with this young bloke and had lots of information, obviously because they’ve lived with the child since birth, so lots of information and was really freely sharing it and helping to make those early connections with places like CPEC and other places. So that I think is vital to do that.” **Principal**

“Success happens when school becomes a real celebration of this is what the child can do, rather than this is what they can’t do.” **Physiotherapist**

6. Organisations such as CPEC are centres for excellence with considerable expertise in low incidence disabilities such as cerebral palsy, associated conditions, and complex communication needs. Such organisations offer long term services to students with disabilities and their families before school entry, across the school years and after school completion. Families identify such services as essential to their child's health development and participation in daily activities. Schools identify services as useful in preparing schools to accommodate the needs of students with disabilities. Funding is an issue that needs attention to ensure that the right skilled practitioner or service can be engaged to assist schools, teachers and students to experience optimum success at school.

“I think it was through the guidance of CPEC... that we just realised that mainstream is real life, and [student] needs to operate in the mainstream...in the real world. And...the benefits are that he’s, more normal, he’s less special.” **Mother of student, 12 years old with CP, spastic quadriplegia--GMFCS level 5, visual impairment with CCN**

“It [staff training] was done in a variety of ways. Basically we used anyone that we could think of. CPEC have been enormously helpful. CPEC are just wonderful. We have used the various people from CPEC like [speech pathologist] and such. We have tapped into people from [local special school] and [other disability service]...it was a multitude of people and a multitude of organisations. So it was not one thing.” **Principal**

“Our parents play a massive role in supporting school staff. They play a massive role in training and teaching and those sort of things. Because they’re in there every day. I’m in once a fortnight, once a month. They play a really, really important role. I think they’re also part of the advocacy for their child and helping that process along as well. So a key role for a successful outcome, is their involvement and support of staff and the school.” **Occupational therapist**

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¹This information sheet has been compiled following a research project called: Successful school experiences for students with cerebral palsy. The William Buckland Foundation proudly sponsored the study. Dr Helen Bourke-Taylor, researcher and occupational therapist and Ms Claire Cotter, Manager of Cerebral Palsy Education Centre (CPEC) collaborated to produce the findings contained in this fact sheet. The research project was a qualitative study that involved interviewing 47 people about their perspective of the experience of students with cerebral palsy in local schools. The rigorous research involved analysis of interviews: 7 students; 11 parents; 10 teachers; 9 principals; 10 allied health therapists. This fact sheet is number 2 of a set of 6 fact sheets. Each fact sheet summarises one theme that was derived from the data that represented the collective experience of participants. The fact sheets may be downloaded from the CPEC website (<http://www.cpec.org.au/>).