



HEADS TOGETHER FOR ABI

Connecting & supporting young people & families impacted by acquired brain injury

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Submission to the Department of Education, Skills & Employment Disability Standards for Education Review 2020

Heads Together for ABI is a Victorian non profit organisation established in 2002. We connect and support young people with brain injuries and their families through a range of peer based social, educational and leadership programs.

The Heads Together community is united by a shared passion to improve the quality of life for people with an acquired brain injury and their families.

We are not about 'helping' people; instead, we create environments where people feel safe to share and build positive lives. As a community, we learn from each other and break down the barriers.

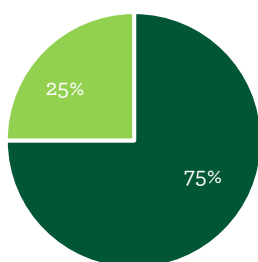
Inclusive education is one of the biggest challenges facing our Heads Together community. We support a review of the Disability Standards for Education to improve the education experience for people with disability. We asked our community a number of questions relating to the ideas identified in the discussion paper, and collated their perceptions, thoughts and suggestions as quotes and audio (🔊) to form this submission.

Awareness of the Disability Standards for Education



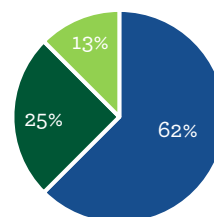
Although the majority of the families in our community have some awareness of their child's rights when it comes to accessing and participating in education, the majority were unaware of the Disability Standards for Education. For those that were aware of Standards, there is a perception that schools are free to interpret the standards as they like, without being held accountable to their implementation.

Are you familiar with the Standards and what they are designed to do?



■ No ■ Yes

Do you feel like you understand your child's rights when it comes to being able to access and participate in education?



■ Somewhat ■ Yes ■ No



Well, I haven't heard of the Standards & my son has had a brain injury now for 8 years!

I knew that it was there, but it was not described or provided to me with help. They were not going to explain these rules just that they are there. It wasn't fully explained, I was misinformed.

Our community overwhelmingly believe that schools should be required to explain the standards to parents and staff to ensure a comprehensive understanding.

ALL schools across the Country, whether Government, Catholic or Independent, should have mandatory training on the disability standards for education.

There should be financial implications to the Independent system for not following Government Guidelines.

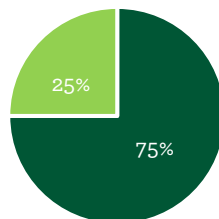
Explain these to the parents so they are aware of what they are. If they are on a flyer or handout they are likely not to read it

Experiences accessing and participating in education and training



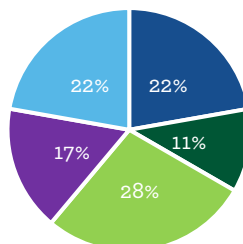
The vast majority of families in our community believe significant barriers exist in achieving access and participation in education. We asked our community about support and adjustments received, consultation experienced, enrolment, compliance and victimisation and harassment to gain an understanding of how their experience with the education system aligns with the standards in place.

Do barriers still exist for students with disability wanting to access and participate in education and training?



■ Yes ■ Somewhat

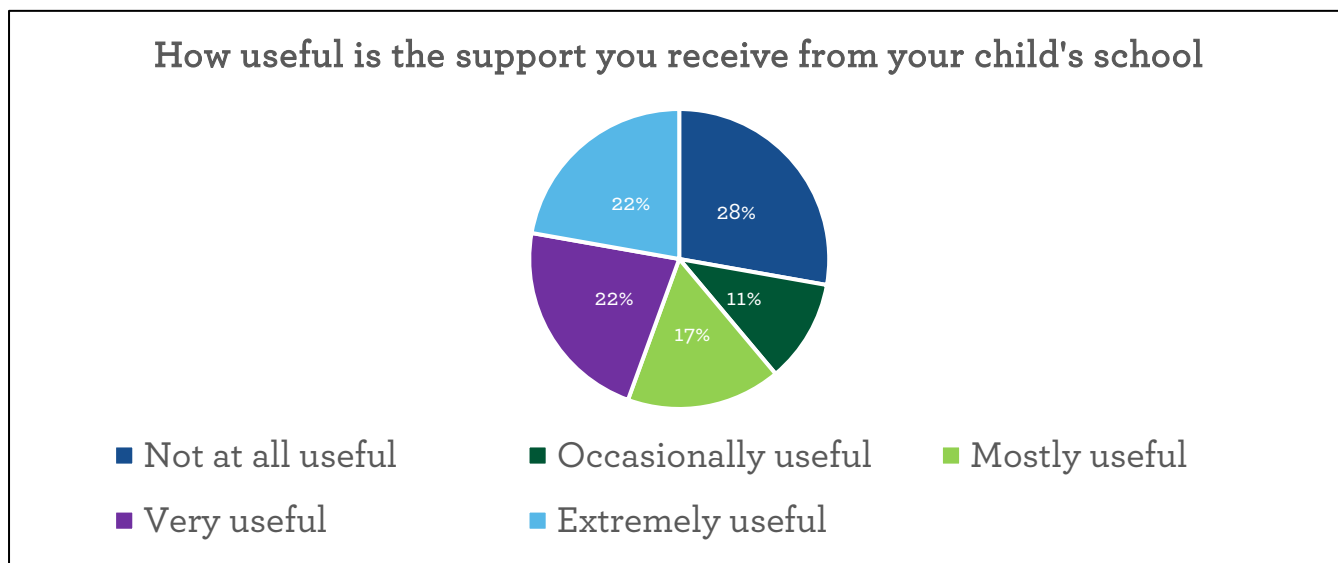
How would you rate the quality of your child's school experience



■ Excellent ■ Good ■ Ok ■ Not good ■ Awful

SUPPORT

It shouldn't be that you have to go looking for the supports, they shouldn't be hidden, they should be there and known.



Most families feel adjustments have been made to some extent to ensure their child can participate in education. It is clear however, the support provided and adjustments made are entirely dependent on the capacity and willingness of a school's leadership and in turn relevant staff to understand the needs of students and learn how best to support them.

Some teachers are not open to learning about the disability & how best to work with the child.

You have to fight for adjustments and the level of modification made to the curriculum is very much dependent on each teacher.

The first 2 schools that my son attended were already chosen because his older sister went there. All schools so far have been mainstream. Our experience so far has been that there are lots of things put in place initially. After 2 years, the assistance stops. My son's disability is hidden. His brain challenges vary from day to day & because he is sometimes capable of keeping up with his classmates it is assumed that he can maintain this same level every day!

My son's current VET/VCAL TEC school (school number 3) has been excellent at adjusting education to cater for my son! It was a mid-year enrolment & he has been going there now for a little over a year. This school has embraced learning more about ABI & because it is small, my son does not get forgotten if he falls behind in his schoolwork.

Our local school assured us they would listen to our feedback, comments and direction, however they have been very hard to convince to listen to external experts ie VPRS and put their recommendations into practice.

For the most part positive. The school really tries to meet their needs.

The school, whilst seeming to take on board the complex learning requirements they (the school) have done little to support him. The class teacher however has gone above and beyond to support us. At our last SSG how we proceed was referred to the teacher (by the principal and Vice P) to arrange.



The experience as it relates to Education has been utterly appalling. My child in his last year of Primary has been consistently excluded from the class room since Prep and unable to access anything that resembles a modified curriculum or access an Individual Learning Plan that has any meaningful goals. We have attempted since Year 1 to implement assistive technology which is reasonable and necessary, yet the school has refused. This has led to continued school refusal. For example Year 3 my child attended 33% of the year and NO ONE supported our child in returning. As a consequence there have been severe impacts to mental health and access to Education.



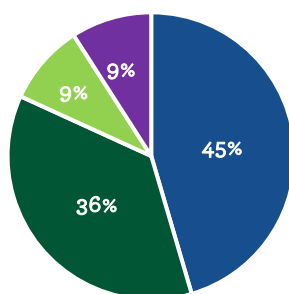
Our community believe that the Integration Aide allocated to work with the child plays an enormous part in the success of the students' participation in education. Our community have experienced aide support which supports students to participate and access education as well as aide support which creates increased barriers to inclusion and when the aide does not work well with the student it can also result in exacerbated behavioural issues. Many parents expressed concern with the minimal level of education and training that is required for aides. They were also concerned about schools choosing to use designated 1:1 aide supports across a number of children.

Aides need to be matched to the child, not just allocated. Parents need to be involved in the recruitment of aides.

Aides need to be 'facilitators' not teachers/babysitters/minders

Aides need to be given opportunities for specific training related to the children then are supporting.

If there was one thing you could change about your child's education and experience of school what would it be?



- Teacher's and/or aide's capacity and/or willingness to understand and meet your child's needs
- School's understanding of acquired brain injury
- Curriculum and/or schedule
- Friendships and social connections

Some of the young people in our community experienced a lack of autonomy when it came to choosing their pathways and having a voice in their education

When I returned to school after my accident the school informed me that I couldn't continue with drama and all of the things I wanted to do and that I had to do cooking as that was something I could handle and manage. I wasn't interested in Cooking I wanted to take part in drama again but they



said I couldn't handle it. The school was not asking me what I wanted and needed they were telling me what I could handle and what was available to me. They wouldn't listen to me, they would ask my therapists who would then ask me and communicate back to the school rather than just speaking with me and asking me what I wanted.

What was fascinating was the difficulty I had trying to get into university, I did become a student again but there were some struggles. Occupational Therapist (OT) said to do Tafe, that mode of education was more accessible to me. The support I was offered was much better. Person centred I learnt through an aged care course, the support I got in Tafe was that, person centred. So much more helpful. There were many times that if I said something it wasn't taken as real until a professional was saying with him and assisting. It creates a potentially massive lapse that it has to be said by your OT instead of you. If it's not in text it didn't happen.


At Uni, you're in a lecture theatre with 250 students and 1 lecturer, then there's a tutorial which is a little more 1 on 1. I couldn't handle the student numbers in the lectures and could only take in information when I had a chance to speak in tutorials. At Uni, in my tutorials I would add something to the discussion or raise and question/ answer a question and the tutor would never respond to me, my aide would then say exactly what I had just said and the tutor would respond immediately. I couldn't understand why they couldn't hear my voice, so I stopped speaking, I thought I was an idiot, like I didn't belong there and I couldn't contribute.

At Tafe it was more like constant tutorials, 1 on 1, in every session I tried to make myself as outspoken as possible to make myself known and get heard. This came as a result of my education journey, I feel like I'm being treated as what's wrong with me and not what I actually wanted, that is why I wanted to speak up as I did. Very happy about how I was treated in TAFE. I explained to the teacher how much trouble I was having, the teacher said that he would drop some subjects without any negativity at all. I was shocked to receive such encouragement. That was the biggest take away lesson for me, the brave person raises his hand and says he is having trouble.

It has been discussed that the funding for some students with an ABI is being used to support other children in the school rather than specifically for the child it was allocated to. It appears that these decisions are being made by the school, as to how the funds are allocated, rather than in response to the child's needs.

I had requested an iPad to be purchased through my funding to support me with my studies and note taking. The principal told me there wasn't any money available for the purchase of an iPad, the school was given \$50,000 to support me at school and I questioned them about those funds, I was told that it was being used to help all students with learning difficulties and disabilities not just me.

When I had a meeting with key team teachers and principal, they asked why were services attending? Even though I had medical certificates and documents I was met with resistance, through fighting I could get through it. All I need is an iPad so I can go back to school; and I was not given that assistance. My Psychologist said, I shouldn't need to know or have to worry about all this stuff.

 We asked our community about the impact COVID-19 has had on participating in education, and responses have been mixed. While some students report that remote learning is more suitable, for most families remote learning has exacerbated many existing problems students and families are facing.

My child has become more anxious & sensitive to noise

Supports and distance have compromised his experience.



My child has essentially been forgotten about. He has no individual learning programme and has spoken to his class teacher twice in the space of 6 months. On site learning for my child has been refused.

No supports. No access to aides. Paid for a tutor as we could not provide the support our daughter needed with schooling. We never used an iPad for schooling or even used them at school until the first day of home learning: kids had to learn the hardware and software. They had no idea how to use it. Schools in Melbourne have been using the technology in the classrooms for years. Here we were not even knowing how to log in. I needed to take time off to support my child. There was no way I could work and set my child up for home learning- plus the siblings.

My son attends some of the Zoom classes but has struggled with planning, motivation to do work alone & failed to submit a lot of the work. At this moment in time he will fail!

Building safe relationships with staff and students has been halted just as we were making progress.

Loss of social connections, which take a long time to create.

During the pandemic we realised that our daughter was not receiving specialised or additional support in school because her disability cannot be seen and therefore is overlooked. Home school has made us realise how much dedicated support she requires during her school hours and that the teacher is only able to give general instructions not tailored to kids with additional needs and often "helicopters" over things she's done and not flagging that there is a gap in her knowledge and understanding of the curriculum.

CONSULTATION



We asked families how they were consulted in regard to adjustments made to support their child. For the majority of our families the consultation process is insufficient and at times they don't feel listened to.

Face-to-face, phone, email & parent/teacher/student conferences. We now also communicate through zoom as well. I have also sent specialists to the school to provide ABI education for teachers.

We have had regular PSG meetings to discuss our child's progress. academically, she is falling behind and this is expected, however, we have decided its important for her to stay in a mainstream school to maintain social connectedness/awareness.

The main aim for her PSGs were to be placed in a class with a couple of existing friends, as she struggles to make long term relationships. This aim was agreed by both the school and us. This new school year, she was placed in a class with no friends at all. We addressed this with the school and they would not change their decision. Consequently, this year has been very hard for our daughter.

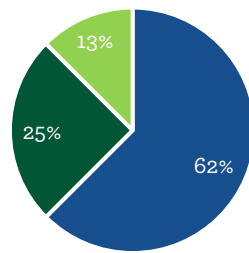
Lots of meetings leading up to and post transition.

We have team meetings with medical professionals, myself, school & DET psychological representative. The College where my child is currently is enrolled ignore all advice and recommendations given to them - either from me as a Parent or the significant number of Professionals who have been involved in my child's care.

We have PSG meetings; however we need to constantly check up on school because if you don't they will allow the aide to work with other kids when they are naughty instead of your good child who needs help but will sit there and not do anything- they are swept to the side if you are not checking.



Has your child's school/education provider made reasonable adjustments to ensure your child can participate in education?



■ Somewhat ■ Yes ■ No

ENROLMENT



We asked our community about the enrolment process they have experienced. Their responses show that it is evident that there is a lack of guidance and support for parents to find the right school.



Initially school was very helpful when realising they would get funding.

Overwhelming & it always seems such a mammoth task! Paperwork, passing on relevant ABI specific information, etc is huge (I think it relevant to mention that I am a solo parent & do not have a partner to discuss decisions & share the load) This year I enlisted the assistance of his Neuropsychologist to educate his teachers directly about ABI before the school year started.

Standard. Fill in form. We were pre ABI when we started and the schools spoke to each other when transitioning to high school.

We were left out of ALL orientation days given we requested extra we got none.

My child was enrolled at his current school prior to his acquired brain injury. After sustaining his injury we were advised by the Principal that the school would not be able to support our child and he would be better in a special school! We have attempted to make a shift into the State system but were provided with no support or assistance by the Education Department. The school my child currently attends has now updated its enrolment policies to automatically preclude children with medical conditions and disability.

We had to give multiple assessments costing us personally thousands before she started school to ensure she had an aid when she attended the school

HARRASSMENT AND VICTIMISATION

We asked our community if they had experienced harassment or victimisation in an education setting. It was evident that schools are defying the Standards with no apparent consequence.

My child has been consistently excluded and discriminated against. He has been subjected to physical violence and bullying. Example 1. Assaulted by three students. My child was made to apologise because he swore at them when he was surrounded by the other students who then went on to physically assault him. That same day his class teacher called to enquire about his brain injury to remind her what part of his brain it was again that had been affected and the size of the injury as a senior member of staff had enquired about this.



Example 2. Grade 2 Teacher tells my child there is no room for him on the bus to attend his swimming class off campus and he must be taken separately by a Support Worker. Example 3. Not allowed to attend Grade 5 School Camp unless he has a support worker attend as the school cannot support him.

Prep teacher would yell at my daughter for not listening when she was having a partial complex seizure. She would come out of the seizure and have someone yelling at her instead of comforting her. She said I would use her condition as an excuse for her learning. Teacher would criticise her work instead of encourage her. She would compare a brain injury to autism, she said she has behavioural issues when she had fatigue or was over stimulated from her brain injury. She would tell me I was a bad parent for not doing her readers or words but she could not remember due to her brain injury and needed lots of repetition to learn. Teacher refused to have VPRS(clinicians) to come in and talk to the school about brain injury. Thought they knew better. Prep was a waste of time and set my daughter up to hate school or even try at learning as she was not going to be the same as others.

The current school has been excellent. In the previous school my son was accused of something very serious & I was stopped from discussing the matter with the Principal, advised to address it in a letter, which I did & when I tried to enlist the disability support for advocacy (who was his regular school support) was denied the access. In the official response from the Principal, I was told that his disability was not relevant!

She was being bullied, however, due to her disability, she did not realise she was being picked on and didn't react. However, her twin sister stuck up for her, so the bully changed her attention to her twin sister, due to the fact they got a reaction. After 6 months, this seems to have settled down a little though.

Misjudgement from staff stating he was in control of his emotions when he wanted to be. Also constant feedback of problems IN FRONT of the 6yr old child until I had the DET instruct the principal to cease.

Once I started back at school (after my brain injury) the school didn't support me in the way I wanted to be supported, everything I asked for was met with resistance. The only thing that really got through was the funding available to support me, it came down to money. The school had labelled me as a 9 on a scale of 1 to 10 as being nearly incapacitated and getting money in funding for me but not delivering any assistance to me.

They were thinking 'don't ask you don't need to know,' closed curtains, closed doors. Every time I genuinely wanted/needed something I had to keep going back to my support at the rehab centre to get information, all my services were telling me was why do they keep contacting them and not contacting me or my mum. They aren't starting at the person but starting at the services.

We asked our community what was done to address these incidents and sadly education providers were not taking reasonable steps to prevent these situations from happening

They put my son on internal suspension for a week, put him in a glass room to do his schoolwork, given different recess & lunch times (which isolated him from his friends) & my son refused to go to school! The following week he was allowed to go back to regular class & the matter was never discussed again!

Not much except to then complain to me that my daughter was unhappy to be told how to conduct herself. The College has consistently done very little to address the many number of issues we have raised. They have only very recently acknowledged the problems and have apologised.

Reported it to the learning support welfare teacher who made excuses for the teacher as it was a small school and they were friends. So we spoke to the Principal who was going on leave before retiring so they did not care.

I was told I wouldn't win against the principal.

DET have become a member of all SSG and team meetings.



Ended up doing mediation with another teacher after the prep teacher apologised for saying I was a bad parent due to the memory issue and seizures.

COMPLIANCE



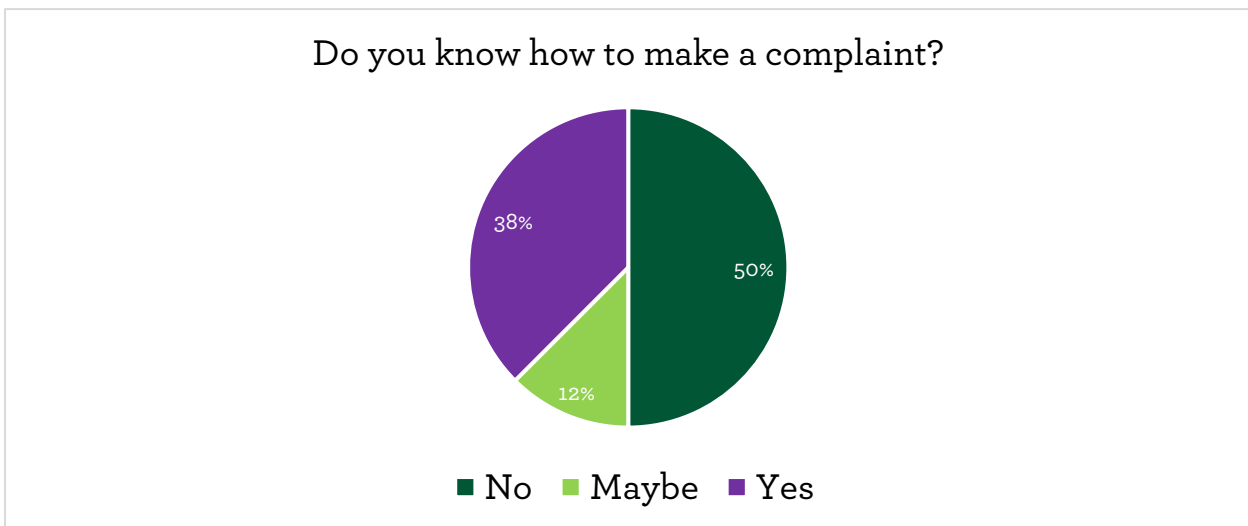
We asked our community if they knew how to make a complaint and found the majority of families did not know how to make a complaint. In the cases they were able to make a complaint they have been ignored.

We approached the CEO about the PSG goals of maintaining friendship groups and said we felt that the school was not sticking to the PSG goals. The CEO brushed us off and said it's the schools decision, basically we felt like they told us to go away.

My complaints have been consistently ignored. As such I am taking the matter to VCAT for them to review and hopefully resolve.

One member of our community was able to take their complaint further

I have written formal complaints to the Principal. I have sought advice from the ACD (Association for Children with Disability). I have this year formally complained to the College Board Chair by way of following a formal complaints process and now in discussion with school Principal. I currently have a solicitor involved who deals with Disability Discrimination and they are preparing an application to VCAT.



Recommendations

Our community have significant concerns about the standard of education for children and young people in Victoria with acquired brain injuries

We believe the standards themselves are comprehensive and reflective of the needs of students with a disability. The key area of change required is in the awareness and implementation of the Standards in education centres. The problem is schools not adhering to the standards and the department of education not holding them accountable.



Our primary recommendation is that an inclusive education model is developed and implemented through all early learning, primary, secondary and tertiary levels and types of educational settings, with a strong focus on accountability, continuous quality improvement and performance management processes. Without this framework, all subsequent changes are largely reactive and unlikely to result in real and lasting change.

In order for Disability Standards of Education to be successfully met, families and young people need to be supported to fully understand these standards, and provided with a clear path for registering complaints and receiving support from the Department of Education to rectify any issues of compliance.

We recommend that from a funding standpoint, Acquired Brain Injury (ABI) is recognised as a specific condition, rather than having to find ways to fit under other classifications ie. autism, learning disability, physical disability, behavioural issues etc. It is a complex, multi system condition which is permanent and evolves as a child develops. Schools need to understand that ABI doesn't "get better". There can be lifelong recovery while still having lifelong impairments in several key areas of function including cognitive, emotional, communication, sensory, physical, and endurance.

We recommend that all relevant educational staff receive training to better understand acquired brain injury, and that this education include the lived experience perspective. Ideally, this would begin at the teacher training level in university, as well as upskilling teachers and education staff who are currently working. Given the large numbers of children with additional needs being educated in mainstream schools, and the standards of education clearly stating that ALL children have the right to fully access and participate in their education, it is imperative that teachers are provided with the appropriate education in how to provide inclusive education for a diverse range of children. Otherwise, these children, as evidenced by our community responses, will be excluded, forgotten and inadequately supported resulting in less successful educational outcomes, negative impacts on the child's sense of self and ultimately impacting their opportunities to pursue meaningful vocational pathways.

We recommend that integration aides are required to have higher levels of education and training and be paid better wages commensurate with this training. Our community clearly communicated that the integration aide plays a pivotal role in the child's education, spending more time with the student than the teacher, and as such it is vital that they are properly trained in each student's individual needs. Untrained aides are more likely to lead to child "care" rather than education and is not supportive of an inclusive education model. As reported by our families, social connections and building friendships is a major issue for young people with brain injuries and the role of the aide is often key in either facilitating this or creating further barriers preventing young people from connecting with their peers.



We recommend that a consistent structure of supporting inclusive education is implemented with the understanding and the processes in place to ensure that individualised support is provided to the child and family in an ongoing manner. This support needs to utilise a collaborative, partnership model where families, young people, and the school work together, with the support of the families' clinical team, to achieve positive education outcomes. These must be regularly reviewed, with ongoing training provided to teachers, aides and other staff each year to ensure that their understanding of the students' needs is always up to date.

We strongly recommend that young people's voices are placed at the centre of any educational support. It is imperative that their voice is respected and valued in all aspects of their education, including representation in all student support meetings, as well as with individual teachers and aides. The educational environment must promote self advocacy if the young person is going to actively engage in their education, and if they do not actively engage it is much less likely that positive outcomes will result.

We have been supporting families and young people since 2002, and we know that positive educational outcomes are possible when an inclusive and collaborative approach is used. We also know that the impact of this is huge and long lasting on the young person and their family. Sadly, these positive stories are rare and we are genuinely desperate on behalf of our families to change this for the better.



Demographics

We do not have the staffing capacity to provide a full analysis of demographics. However, based on our knowledge of our community and the families/young people who contributed to this submission, our demographic is largely comprised of Caucasian Australians from a mid to lower socioeconomic bracket.

Our Community responses include all levels of education.

Our community responses represent families from Metro, Regional centres and Rural Victoria.

We have a small percentage of Aboriginal or Torres Strait Islander families.

We also have a small percentage of families from culturally or linguistically diverse backgrounds.

