

CHAPTER 3

The true costs of difficulties with accessing education

'It has been 15 years since I left school and I am now 26. I have not once had a job. I fear the only way I can work is to work as self-employed because then at least I won't reflect badly or embarrass anyone'.¹

Introduction

3.1 The barriers to education faced by students with disability and their families are significant and inevitably incur costs. The committee heard evidence about costs affecting students, families and the broader Australian community throughout this inquiry, and this chapter will highlight some of the more significant of these.

3.2 It is important to remember that these costs are not limited to financial costs, but are many and varied. They include social, developmental, intellectual and emotional costs.

3.3 By failing to properly educate students with disability in their school years, Australia is setting up these students for a lifetime of disadvantage, unemployment, low levels of mental and physical health and social isolation, along with ongoing welfare dependence. Poor education access at an early age will have long-term effects on the students, their families and the broader Australian community. For these reasons, the committee is convinced that access to education for all students must be improved.

Costs to students

3.4 The variety of effects on students who have been unable to sufficiently attain educational outcomes from the school system is wide and includes issues such as intellectual and social development and future employment or earning potential. This is of concern because it suggests that students with disability may be condemned to a lifetime of disadvantage because of early failures to gain an education.

3.5 Mr Sebastian Cordoba from the Australian Association of Social Workers told the committee about why this issue is so important:

There are marked and profound benefits across the life span when students with a disability have a positive experience with their schooling. When students are fully engaged with their education they can develop a greater sense of self-worth, improved mental health outcomes and better career pathways and create strong social support networks that lead to greater independence and less reliance on welfare and disability services.²

1 Ms Emma Wilson, *Submission 215*, p. 1.

2 *Committee Hansard*, 29 September 2015, p. 37.

3.6 The Redfern Legal Centre outlined some of the benefits, and the converse costs, of students' capacity or otherwise to access suitable levels of education:

Outside of the clear imperative to ensure all students have access to education, including students with disabilities, having inclusive access to education providers also plays a crucial role in students' social development, as they interact with staff and peers. While this is of paramount importance for all students, this is of particularly significance for students with disabilities who may face social exclusion as a result of their disabilities. Currently, students with disabilities in mainstream schools experience incidents of bullying at a higher rate than other students. Education providers should be alert to the additional support needs of students with disabilities, particularly in responding to bullying. Appropriate response and training in this area can lead to a more inclusive education environment for students with disabilities.

It is also worth noting that, while inclusive educational experiences can produce positive social, economic and personal benefits for students with a disability, the converse is also true. That is, a failure to provide adequate access to education will be actively detrimental to the wellbeing of students with a disability, causing significant psychological and social harm with long-term effects.³

3.7 The Australian Association of Social Workers similarly noted the benefits of improved educational outcomes for students with disabilities:

There are marked, profound benefits across the life span in all domains when students with disabilities have a positive personal and learning experience in school, and further education, training and employment.

Social workers involved in this field observe that when students with disabilities are seen as valued/valuable members of society, there are far-reaching, predictable consequences. These include:

- students with disabilities grow up with a sense of self-worth and optimism at school and in the community, linked to better social experiences and mental health outcomes;
- the school community benefits from a cohesive student body;
- the message to society is that all people are valuable, impacting positively on social capital, inclusion and acceptance of diversity;
- education/learning becomes a positive experience and students are more likely to seek lifelong learning opportunities, impacting on their access to employment and reducing welfare dependency;
- positive relationships in the school and broader community result in social capital and informal support structures being established and maintained, leading to less reliance on funded disability supports;

3 Redfern Legal Centre, *Submission 101*, pp 10-11.

- appropriate levels of support in school lead to the development of better system-wide pathways to streamline referrals and structures. As a result, fewer students fall through the gaps in post-school transition.⁴

3.8 Down Syndrome Australia noted that Australia, currently and historically, has not done well in this regard, with the consequence that:

Whilst this is very hard to talk about—it can be depressing, and it is, no doubt, complex—I also want to bring to your attention the fact that this is doable. There are other countries in the world who have done a better job at this. In fact, Australia has one of the lowest educational attainment rates in the OECD countries and, therefore, not surprisingly, has one of the lowest employment rates of people with a disability in the OECD. Clearly these are related.⁵

3.9 Witnesses from People with Disability Australia, a major advocacy group, after noting shortcomings in the education opportunities for students with disability, pointed out the problems caused by failing to set these students up for life:

... as a result of these multiple failures within the educational system, children with disability turn into young people with disability and adults with disability who have greatly reduced life chances, life choices and opportunities. Those are not just opportunities within the education system—for example, the ability to transition to vocational education and training, TAFE, university but also employment. People with disability face a continuous struggle to gain and maintain employment throughout their lives. So poor educational opportunities and outcomes can lead to poor and lower economic security in adult life and it reinforces the low expectations that there are of people with disability and it reinforces a life experience of inequality and poverty. It is mentioned in our submission briefly, but the recent employment figures for people with disability show that only 54 per cent of people with disability between the ages of 15 and 64 are employed, as opposed to about 83 per cent of people without disability. Forty-five per cent of people with disability live at or near the poverty line. A recent OECD statistic states that Australia is 21 out of 29 countries for employment of people with disability.⁶

3.10 National Disability Services further illustrated this point with the following statistics on education attainment for students with disabilities:

- 26% of people with a disability do not go beyond Year 10, compared to 18% of people without a disability;
- 36% of people aged 15 -64 years with reported disability had completed year 12 compared to 60% of people without a disability; and

4 Australian Association of Social Workers, *Submission 137*, p. 2.

5 Ms Ruth Webber, Down Syndrome Australia, *Committee Hansard*, 20 November 2015, p. 2.

6 Ms Ngila Bevan, People with Disability Australia, *Committee Hansard*, 18 September 2015, pp 9-10.

- 38% of young people aged 15–24 years with disability either work, study, or do a combination of both on a full time basis compared to 56% of young people without disability.⁷

3.11 On that point, Mrs Andrea Evans-McCall, of the National Disability Coordination Officer programme, noted that the career options for students with disability are often subtly dismissed within the school system and individual schools:

And in a school, the person in charge of the young people with a disability is quite often a support worker, not someone with a qualified education background. Quite often, we even find that in the careers area: because they have a disability, the careers teacher does not deal with them; the person who is the support worker does, and they do not have a career development qualification. So they are just sort of left to be looked after by someone who is probably loving and caring but does not necessarily have the qualifications that they need to.⁸

3.12 Clearly this does not acknowledge the rights and needs of individuals to be provided with the skills to manage life after school.

3.13 The St Vincent de Paul Society National Council noted that people in Australia with a disability face significant levels of exclusion and structural disadvantage:

For example, people with a disability are less likely to participate in the labour force, and more likely to be unemployed. If employed, on average, those living with disability earn less than those without a disability. People with disability are also far more likely to experience abuse, including sexual abuse, and also face worse housing outcomes.⁹

3.14 The St Vincent de Paul Society National Council also pointed out that disability tends to intersect with other 'indicators of vulnerability', including gender and indigeneity:

For example, women with disabilities are less likely than their male counterparts to receive a senior secondary or tertiary education, and over 51% of women with a disability earn less than \$200 per week compared to 36% of men with a disability. Similarly, one in three Indigenous Australians is likely to experience discrimination in any year, compared with one in five members of the general population.¹⁰

3.15 After pointing to research on the issue, Dr Lisa-Marie Scott, a Clinical Psychologist who was worked in the disability and mental health sectors for nearly two decades, noted that:

7 National Disability Services, *Submission 172*, p. 2.

8 *Committee Hansard*, 20 November 2015, p. 21.

9 St Vincent de Paul Society National Council, *Submission 112*, p. 1.

10 St Vincent de Paul Society National Council, *Submission 112*, p. 1.

those with disabilities want to be involved in both education and employment activities. It does not take referencing from numerous research papers for us to understand that most people want to feel included and needed in society. Children and adults with disabilities are no exception.¹¹

3.16 In her submission to this inquiry, a former student with disability wrote of the ways in which the attitudes she encountered affected her:

[I] was banned from going on work experience, so instead I was forced to remain at school doing odd jobs around the school grounds with the school staff, such as laundry, gardening, library, etc. These actions have scarred me for life. Because of these events I have been given the impression and message that I cannot hold down a job, I will reflect poorly on myself and my employer and I am of no use in the community, so despite my desire to have a job the treatment I received at school has left me terrified and unable to work.

It has been 15 years since I left school and I am now 26. I have not once had a job. I fear the only way I can work is to work as self-employed because then at least I won't reflect badly or embarrass anyone. School has left me feeling ashamed and worthless and I wonder if I will ever be able to work.¹²

Committee view

3.17 The committee notes with concern the wide range of costs borne by students with disability whose education fails them. School should be an experience which sets students up for the rest of their lives, but for many students with disability, this is not the case.

Costs to families

3.18 The committee also received evidence of the associated costs to families. These take two primary forms: financial impacts and emotional impacts.

Financial impacts

3.19 A major theme in submissions to this inquiry from parents and advocacy groups was that families of students with disability can incur substantial and often ongoing costs connected to education access. For most families, this can result in financial hardship, but it also highlights concerning questions around equity, since the capacity of families to bear these costs varies widely.

3.20 The committee heard that parents with the means to be able to do so could spend considerable sums to improve their children's access to education:

11 Dr Lisa-Marie Scott, *Submission 132*, p. 2.

12 Ms Emma Wilson, *Submission 215*, p. 1.

Some of the women that I interviewed over three years were providing one-on-one support. These were wealthy families, basically. One mother I spoke to was providing more than \$25,000 a year in wages to a paraprofessional within the system. Part of that is to do with therapy choices in autism—people who go for applied behavioural analysis. This costs an enormous amount of money. It is a gold-standard treatment. The model of that is that you have 40 hours a week in the home of one-on-one. Then you continue some of that through school, and then hopefully you gradually fade that out. Parents who are committed to that and able to afford it were often continuing that in the government system.¹³

3.21 However, not all families are financially able to support their children's additional needs in the same ways or to the same extent. As Dr Lilley pointed out:

Current inequalities in access to support and services for students diagnosed with autism are of great concern. Some families whose children attended government schools were either providing funds to pay for extra paraprofessional support or employing their own staff to work one-on-one with their child through much of the school day. There is a clear inequity to situations in which the socioeconomic positioning of families may be an important determinant of the resources and supports a student receives, even in the government sector.¹⁴

3.22 For instance, the committee heard from the Association for Behaviour Analysis Australia, who noted that ongoing therapy from a behavioural analyst, while it can provide considerable benefit for the child, would cost 'an absolute fortune':

The early-intervention ages where therapy is recommended generally are 30 to 40 hours a week, and that cost could be around \$50,000 a year for the parent, which is a massive amount. Some parents can sustain that for a year, two years or three years. Others can only do a few months of that.¹⁵

3.23 Another parent told the committee of the costs she had incurred and the impact that has had on their family:

I am a sole parent with three children. My son NEEDS to see a psychologist on a weekly basis and he NEEDS speech therapy sessions on an ongoing basis. So this is what we must 'choose' to pay for. The money for these interventions comes after rent and food. We don't have anything left for swimming lessons, play centre visits, blueberries, new shoes, holidays, haircuts..... My son's funding covers the cost of an aide for three days so he cannot go to school for the other two days a week.¹⁶

13 Dr Rozanna Lilley, *Committee Hansard*, 18 September 2015, p. 41.

14 Dr Rozanna Lilley, *Submission 94*, p. 2.

15 Mrs Alex Brown and Dr Alayna Haberlin, Association for Behaviour Analysis Australia, *Committee Hansard*, 18 September 2015, p. 51.

16 *Submission 164*, p. 2.

3.24 Speaking on behalf of the Gold Coast Dyslexia Support Group, parents broke down some of the costs commonly borne by families:

Many children are so distressed by their school or at school that they require clinical psychologists for anxiety disorders and chronic depression. Parents outlay large amounts of money to provide support that does not occur in our schools. An assessment with an educational psychologist can cost anywhere from \$800 up to \$2,000. Private tuition with a specialist teacher costs between \$70 and \$120 per hour. None of this is subsidised under Medicare or can be claimed as a tax deduction. This financial cost is worn solely by the families.¹⁷

When our children were diagnosed, we went to the school to try to get support, intervention and assistive technology. We were told, 'There's no resources and no funding,' so we have funded that ourselves. I have two children who are dyslexic. The report was \$800 apiece, none of which could be claimed. Prior to having them diagnosed as dyslexic, because we knew nothing about dyslexia, we put them through an extensive occupational therapy program, which totalled \$3,200. Private tuition for my daughter this year is costing us \$13,000. We funded the technology and the assistive tech for both of our children, and that has been in the vicinity of \$3,000 or \$4,000 so far.¹⁸

3.25 Aside from the additional costs incurred, many families also experience a substantial drop in total household income as a consequence of their efforts to improve their child's access to education.

3.26 Most particularly, this occurs because one parent – often the mother – leaves the paid workforce in order to homeschool their child (or children) who has been otherwise unable to access education through the school system. One mother explained the consequences of this for her and the whole family to the committee:

Homeschooling means that I cannot work, I cannot save, I have no future and I cannot study, because it is one on one—there is no down time.¹⁹

3.27 Another parent noted that consequence of the inadequate support their son was receiving at school was that:

I gave up my fulltime job as a Senior Environmental Health Officer, which I had held with the Local Council for 13years, to be home to support and battle for my son's education.²⁰

17 Mrs Karen Ross, Gold Coast Dyslexia Support Group, *Committee Hansard*, 25 September 2015, p. 39.

18 Ms Jane Woodley, Gold Coast Dyslexia Support Group, *Committee Hansard*, 25 September 2015, p. 40.

19 Mrs Leonie Ponder, *Committee Hansard*, 25 September 2015, p. 2.

20 Mrs Tracey Scott, *Submission 114*, p. 2.

3.28 A further parent noted that, because her child received inadequate support at school, she had to leave her executive-level job to home-school her child, while also incurring additional support costs.²¹

Emotional impacts

3.29 As substantial as these financial costs are for many families, witnesses gave evidence about the emotional impacts on their families as a consequence of the struggles they faced in attempting to improve the educational prospects of their children with disability.

3.30 For many parents and other carers who shared their experiences with this committee, the battle to improve their children's education access – and therefore prospects – dominated their time, energy and emotional reserves. Many parents and carers recounted how their own experiences led them to found or join advocacy or support movements for families in similar positions. In many cases, involvement in these groups also served as an information-sharing service, often the only way parents could learn more about their child's education options and prospects.

3.31 As noted by a parent and advocate, Mrs Leonie Ponder:

I ran an ASD [Autism Spectrum Disorder] support group on the Sunshine Coast. When I started there were 250 families; there are now over 700. For about three years in a row we had, on average, a family a week drop out of education and go into home schooling because it was just failing kid after kid after kid. And there are marriages failing because of it, as well. The stress is huge.²²

3.32 Another parent pointed out to the committee that the difficulties they faced in accessing education for her daughter were on top of all the other struggles faced by parents of children with disability:

You are talking about families. It is really hard to go watch your child on life support. Lily has epilepsy. She stopped breathing. She has had brain damage. We have had such traumatic experiences. Then I have to turn up to school on the Monday and smile and fight more, when you are constantly—and it is not just education; you are doing it in health; you are doing it in all facets. That is not to mention the 90 per cent divorce rate for families.²³

3.33 This was echoed by other parents, who wrote of the widespread sense of exclusion and the consequent emotional toll felt by the whole family:

From the outset, this transition has been a very stressful and isolating process for our family. We have already experienced discrimination in other parts of our life such as sporting clubs, and that's one of the issues that is

21 Ms Tara Hannon, *Submission 285*, p. 1.

22 Mrs Leonie Ponder, *Committee Hansard*, 25 September 2015, p. 5.

23 Ms Melissa Smith, *Committee Hansard*, 18 September 2015, p. 4.

hard for others who don't experience it to see... feeling like we are a burden, and thus less welcome is not the exclusive domain of schools. This occurs in many aspects of our daily lives and the individual experiences each take a toll, but the collective experience leaves us feeling exhausted, overwhelmed and at times feeling like we can barely get through the day. These feelings do not come from Scarlett, or from Down syndrome. We have a beautiful daughter who is the light of our lives. These feelings come almost entirely from the social experience of having a family member with disability in our society.²⁴

3.34 The emotional impact on the students themselves will rarely be limited to the school setting, as the Australian Association of Social Workers noted of students with disability who have not received adequate support at school:

Typically the child's negative experience at school will spill over into the home environment, adding to family stress. At the same time, the family is stretched to commit additional time and effort to advocate for their child's support needs in the school environment.²⁵

3.35 The committee also heard that some families, after many years of struggling to access education for their children, eventually find themselves unable to continue to fight:

They are told that they can have that dual enrolment with the special school and the mainstream, but they are excluded from things like excursions and camps. So they are not really part of the whole school community. The pressure is really on them to move across to the special school. We have a really low success rate in secondary school. The transition into secondary school is made much harder... We have had a boy who has been at a really good secondary school in Melbourne, and he has gotten through year 7 and year 8, but the family has given up now. It has been a constant battle for us trying to work with that school to keep him there. They have had SSGs and the local specialist school representative there to meet with the family without even advising the family that he was going to be there. So the pressure has been on from day 1. The family has fought that battle, but they have given in. They are just battle-weary now. They also have other children they have to think about. It is just so unfair that any family should have to go through that stress.²⁶

3.36 A further consequence of these long battles on behalf of their children is that many families suffer negative effects across other areas as well, most particularly health:

Notwithstanding the stress, that puts other pressures on the system. That leads to ill health and that costs money. That is what I am saying to you. It

24 Ms Monica Kelly and Mr Murray Turner, *Submission 216*, p. 3.

25 Australian Association of Social Workers, *Submission 137*, p. 1.

26 Ms Sue O'Reilly, Down Syndrome Victoria, *Committee Hansard*, 20 November 2015, p. 7.

is bad enough at this point, when we are still in the process of wanting to advocate strongly. But when you get to the point where you feel like you are giving in, how does that feel? What are the compounding impacts of how you have felt over many years on the entire family? It is not just the person with the disability; it is the whole family. Again, I will remind you—and you are probably well aware—that the health of carers in this country is amongst the worst as well, and these are the reasons why. It may not be a cost to the education system, but it costs money elsewhere in the system.²⁷

Committee view

3.37 The committee notes with concern the severe financial stress placed on families as they seek the best educational outcomes for their children. The committee was dismayed to read and hear the evidence from so many families whose financial position has been negatively affected in this way. For many families, the costs of educating one or more of their children has impacted on the whole family, potentially disadvantaging all of them in both the short and long term.

3.38 While the committee commends those parents and carers who have founded or joined support movements, advocacy groups or other organisations, helping both themselves and others, this widespread need indicates that the support offered to families of children with disability is inadequate. The emotional impacts on parents, carers and other siblings, as well as on the children with disability themselves, cannot be overstated.

Costs to society

3.39 There are broader social costs in addition to the personal costs faced by students who have been unable to fully access education because of their disability and their families.

3.40 Most particularly, as discussed earlier, students without an adequate education will find attaining employment difficult. While this primarily affects the individual and their family, a further result is that they require welfare support for the rest of their life, thereby becoming a net burden on government revenue. As the National Independent Special Schools Association argued:

School leavers with a disability such as Autism find it very difficult to secure and then maintain employment without the provision of support networks. This means that they are more susceptible to being welfare recipients rather than wage-earners and tax payers. One parent will often have to give up work to become a full-time carer, again increasing the welfare burden.²⁸

27 Ms Monica Kelly, Down Syndrome Australia, *Committee Hansard*, 20 November 2015, p. 7.

28 National Independent Special Schools Association, *Submission 84*, p. 2.

3.41 Submitters also pointed out the lost resources Australia faces as a consequence of failing to educate its children:

The irony is that many children who are on the higher end of the Autism spectrum are extremely intelligent, but are unable to utilise this intelligence due to their autistic traits being so strong. With the correct supports in place, these children could achieve so very much – without the support, their intelligence is wasted.²⁹

3.42 CDA noted that improved access to education for all students will benefit society at large 'both socially and economically':

The OECD has cited 'social cohesion and wellbeing' as two social impacts of education. Further, the same report found that high numbers of people who do not experience the benefits of education in a society is associated with higher costs regarding health, unemployment and income support.³⁰

3.43 Following on from this, society as a whole also loses from the paid workforce those parents who are forced to resign their job in order to home-school their child after finding inadequate support in the school system. Parents who wish to work, and who have valuable skills for the workplace, are also lost to the system because of inadequate support for students with disability in many schools.

Committee view

3.44 The committee notes with deep concern the many costs and impacts on students with disability and their families as a consequence of difficulties accessing education. This wide range of costs can affect individuals and families in both the short and long term, and can entrench systemic disadvantage.

3.45 The committee further notes that these problems should be of concern to all Australians, not just on the grounds of our obligation to provide the best chance in life for all children, but also because of the ongoing costs to taxpayers of failing to set students up for life during their school years.

3.46 The committee recognises that the barriers faced by students with disability in the school system results in further losses to the wider Australian community, as the lifetime of disadvantage which these students face is coupled with the number of parents who leave the workforce to homeschool or care for their children. Thus both parent and child are prevented from attaining their full potential.

29 Change the Criteria, *Submission 97*, p. 2.

30 Children with Disability Australia, *Submission 257*, p. 50.

