

JULIE WHITE

7. LEARNING IN ‘NO MAN’S LAND’

Policy Enactment for Students with Health Conditions

INTRODUCTION

School-aged children and young people who live with serious health conditions face challenging educational as well as health issues in Australia. Through consideration of ways in which social inclusion, disability and education policy are enacted at the intersection of health and education, this chapter examines educational possibility for these young people. The intention of this chapter is to focus on the theme of ‘vulnerability’ through examination of key issues related to young people who are of school age and who live with long-term health conditions. Four main groups have been identified as vulnerable for the purposes of this discussion: (1) the young people who live with chronic health challenges who are enrolled in schools, (2) the parents of these young people, (3) state education systems and (4) government-funded special schools and education facilities associated with paediatric hospitals. Before these vulnerabilities are explored, medical and educational contexts and legal frameworks pertaining to this particular group of students are considered. Discussion about the vulnerabilities of the identified groups forms the final section of the chapter.

The ‘no man’s land’ in the title refers to World War I trench warfare where land between the opposing sides lay unclaimed (Ayrton, 2014). In this chapter, I develop the argument that the intersection between health and education is a similarly desolate and barren space, for which nobody is claiming responsibility.

WHO ARE THESE STUDENTS AND WHY IS THIS NOW IMPORTANT?

In recent years significant advancement in biomedical science has resulted in substantial extension of life for children and young people who live with serious long-term health conditions. Those who would have previously died are now living into adulthood and even into old age. The prognosis for surviving childhood cancer, for example, is much improved from 25% in the 1970s (Griffiths, 2009) to 82% in the years 2006-2010 (Thursfield et al., 2012) with 75% of those surviving childhood cancer living for at least another 20 years (Baade et al., 2010). For those born with cystic fibrosis, the survival rate has increased by 700% over the past few decades (Morad et al., 2004), with the adult survival rate doubling since 1998 (Cystic Fibrosis Australia, 2013).

JULIE WHITE

There are many different causes of long-term and serious health challenges for Australian children and young people. Apart from more obvious conditions like cancer, cystic fibrosis and diabetes, other conditions such as immune system disorders, organ transplants, stroke and Crohn's disease need to also be on the list. The Royal Children's Hospital's (2014) website provides an indication of how very long a comprehensive list of conditions would need to be (see reference list for a link).

In addition to the wide range of medical causes, there is also variation in how individuals are affected. And for some children and young people, their health condition is intermittently challenging, while for others, their challenges remain constant. How each individual is affected by their health condition also differs considerably. Nevertheless, the numbers of these children and young people are growing (Sawyer et al., 2007) due to dramatic improvements in biomedical science. And these children and young people are also students who are enrolled in schools.

Smith et al. (2013) estimate that 20% of American children and young people have chronic illness. Guided here by the more conservative estimate that at least 12% of young people live with a chronic health condition (Sawyer et al., 2007, p. 1481) and combining this with official student enrolment numbers, it appears highly likely that of the approximately three and a half million students (3,545,519) enrolled in Australian schools, nearly half a million (437,462) live with serious health challenges (Australian Bureau of Statistics, 2014).

Interestingly, this is a significantly higher figure than the annual number of international tertiary education students (Australian Government Department of Education, 2014), a group that has been the focus of considerable research and media attention over the past ten years.

By contrast, students with serious health challenges are rarely considered as a collective group in education, despite their high numbers and significant levels of absenteeism from school (White & Rosauer, 2015). Likely explanations for this begin with the number of different medical conditions, which doesn't readily lend itself to consideration of these students as an *educational* group. Secondly, these students are scattered across the country in individual schools in all three education systems: government, Catholic and independent. And thirdly, many of the health conditions these students live with are not visible, thereby limiting school-level awareness of their health conditions and perceptions of entitlement to special consideration or assistance.

Societal knowledge and structures have not kept pace with substantial improvements in medical care and there is little evidence that equivalent support for the success of these young people in education is provided. In contrast to health systems, education systems do not sufficiently acknowledge these young people in policy nor do they monitor, accommodate or support them towards participation or success in any systematic way. Most schools remain inexperienced and ill equipped and operate without guidance from government departments of education for such students. System level policy and expectations of accommodation for these students are minimal (White, 2014). Schools do not automatically know

POLICY ENACTMENT FOR STUDENTS WITH HEALTH CONDITIONS

about the health challenges these students face and communication with and within schools has been characterised as ‘haphazard’ (Yates et al., 2010, p. 11).

So education for these students is compromised, which has far-reaching consequences. It is known that low levels of educational achievement is linked to social exclusion (McLaughlin et al., 2013), and educational success is connected with employment and earnings (Thursfield et al., 2012), which are associated with quality and enjoyment of life. Because this group of students is now expected to live well into adulthood, they will be expected to be economically self-reliant, which means that educational success is as important for this group as it is for other students. As the recent World Health Organisation and World Bank (2011) report noted, ‘Education contributes to human capital formation and is thus a key determinant of personal well-being and welfare’ and not supporting students in education ultimately ‘has high social and economic costs’ (p. 205).

LEGAL FRAMEWORK AND POLICY ENVIRONMENT

In this section, legal frameworks informing policy that relates to this group of young people are considered. Firstly, social inclusion policy is examined followed by consideration of Australian Disability Discrimination Act (1992) and the 2005 amendment to the 1992 Act known as the Disability Standards for Education (Commonwealth of Australia, 2005). The key concept of ‘reasonable adjustment’ is raised to support discussion about vulnerabilities in the final section.

The multilayered challenges faced by the families of children and young people with serious illness, including those related to education, would be well served by social inclusion policy and services designed to assist with the management of complex needs. The families of children and young people with serious illness face considerable hardship. For example, in a major Australian educational study about these students:

Parents ... reported other challenges which emerged in tandem with the young person’s ill health. For example, financial pressures as a result of parents (usually mothers) having to limit their hours of paid work in order to cater for the specific and unpredictable needs of their unwell son or daughter. (Yates et al., 2010, p. 54)

This should not be surprising as the connections between disability and poverty are well documented (McLachlan, Gilifilan, & Gordon, 2013; Australian Institute of Family Studies, 2012; Gonski, 2011; World Health Organisation, 2011).

Australia’s social inclusion policy was borrowed from the UK where the Blair government developed a model to simplify services through ‘joined up government responses to multilayered social problems’ (Cappo, 2002). However, the enthusiasm with which social inclusion policy was adopted at all levels of government in Australia has now diminished to the extent that the incumbent conservative Australian government, upon taking office in 2013, disbanded the Social Inclusion Unit, indicating that this was no longer Australian government policy.

JULIE WHITE

The Disability Discrimination Act (DDA) (1992) applies to all educational institutions including schools. The DDA's definition of disability is consistent with those of the World Health Organisation and the United Nations' Convention on the Rights of Persons with Disabilities (2006), and clearly includes those school aged young people with serious health conditions, even if this isn't apparent to teachers or school systems. Three concerns about the nature of the Australian disability legislative framework relate to this discussion.

Firstly, while it is unlawful to discriminate against anyone in education because of disability, the system is nevertheless complaint-based and requires no action until a complaint is lodged with the Human Rights Commission. As Innes (2000), the former Australian Commissioner for Human Rights, commented:

It is my view that...the elimination of disability discrimination in the area of education in particular, using an individually based and essentially private complaint investigation and conciliation process, followed by hearings in a small minority of cases, has not, and will not, be successful. It takes too long, is very difficult for participants on both sides; only provides solutions (when they are provided) for individuals; and fails to address the systemic change that is necessary.

Secondly, the legislation requires local interpretation of the requirement for 'reasonable adjustment', which has proved difficult for young people with health conditions. Reasonable adjustment is defined as:

a measure or action (or a group of measures or actions) taken by an education provider that has the effect of assisting a student with a disability ... in relation to a course or program – to participate in the course or program ... on the same basis as a student without a disability ... or a service that the student requires because of his or her disability. (Commonwealth of Australia, 2005, p. 10)

Knowledge about the legal rights and entitlements of these students, and those of their 'associates' (often parents) is limited. Schools and school systems do not have personnel acting in intermediary roles like the disability officers found in universities, who manage processes of reasonable adjustment. This concept of reasonable adjustment has also proved to be problematic for schools because judgement calls are required, together with consultation and negotiation with the individual students and their parents. However, little guidance is provided for schools that are expected to undertake these complex tasks without support.

The provision of brief fact sheets and 'guidance' notes on the Department of Education website does not adequately meet the recent review recommendations that guidance materials be developed that, "include practical examples to support consistent interpretation and application of the terms 'reasonable adjustment', 'unjustifiable hardship', 'consultation' and 'on the same basis' are developed" (Department of Education, Employment and Workplace Relations, 2012, p. 58). Education systems, by and large, continue to refer to the Disability Standards for

Education (2005) and provide information about resourcing and programs for those at the more extreme end of the disability continuum.

While the requirement for reasonable adjustment varies considerably for individual students with health conditions, it is worth noting here that this is not always dependent on allocation of additional resources, often requiring instead consideration and accommodation of individual circumstance and a sensible approach to the modification of tasks and timelines. The Disability Standards in Education (2005) are unequivocal about the obligations of education authorities and institutions in this regard, but the problem appears to lie in communication, interpretation and enactment at the school level, that is unsupported by government departments of education guidance or policy. Policy, or lack of it, is seen here in terms of text, discourse (Ball, 1993) and intention, and will be taken up in a later section of this chapter.

And thirdly, the disability legislation is problematic because most complaints are heard behind closed doors in formal dispute resolution processes. This means that case law examples are few and far between and those related to education tend to focus on issues of access (both physical and enrolment), ignoring issues of participation and success in education. Provision of access alone does not constitute educational inclusion (Mittler, 2012; Slee, 2011; Ainscow et al., 2011).

Australian legislation directs that individual 'disclosure' of disability is not mandatory in education or employment (DDA, 1992). Interestingly the Disability Standards for Education (2005) remains silent on this issue of disclosure. Nevertheless it remains an important issue for school level education. University disability services, as seen for example on The University of Sydney's (2014) website, provides guidance and clarity for students about the importance and implications of disclosure. For schools or other organisations to be able to assist with education through making reasonable adjustments, there needs to be disclosure by the individual students and awareness of legal obligation on the part of teachers, schools and education systems. This point also relates to a lack of knowledge about entitlements under disability legislation on the part of students, their parents and school personnel.

WHO IS VULNERABLE AND WHY?

While the term 'vulnerability' demands to be problematised, as it has been troubled by Radhika Gorur in this volume (See Chapter 1), I will not address it further here, beyond pointing to an ethical and methodological concern. In arguing about the vulnerability of these young people, I draw upon a comment made by eminent education policy researchers from the UK, who noted similar concerns in their own studies of young people:

We wanted to avoid either portraying the young people as simply victims of their circumstance or pathologising – othering – them. (Ball, Maguire, & Macrae, 2000, p. 18; Maguire, 2010, p. 139)

JULIE WHITE

Most scholarly attention paid to this group of young people provides perspectives from medical and psychosocial fields with little attention paid to educational concerns. While medical research has tended to group and categorise according to disease or condition, little research has reported on how these young people fare as a *collective* group of *school students* in education. This group tends instead to be viewed, if indeed their condition has been communicated within the school, as isolated individuals characterised by their medical conditions and absences.

Mothers of children with disabilities are more likely to be divorced, separated or never married and unemployed (Morad et al., 2004) and the stress levels of parents of unwell children have been well documented (Griffiths, 2009). Under Australian law, a parent is considered the ‘associate’ of the individual student with the disability and therefore is accorded rights and entitlements. However parents on the whole do not seem to be aware of these legal rights or those of their children and many parents have reported their lack of success in advocating for their children within schools (Yates et al., 2010; Donnan, 2011). Unlike the systematic approach in the UK (see Department of Education UK, 2013), Australian parents have no clear lines of communication available to them, particularly in regard to advocacy within schools. In Australia, parents are left to negotiate complicated education systems without supporting intermediaries. Teachers with expertise in supporting students with health conditions are not employed to assist students while they recuperate at home or are reintegrated into mainstream schooling. Instead they employed by government education departments remain in special schools in hospitals or associated services that do not prioritise this sort of assistance.

With the lack of formalised professional responsibility for these young people, parents are reliant on the goodwill of individual teachers and on being able to find someone in their child’s school willing to listen, to take responsibility, to communicate with others in the school, to advocate and to follow through, even when the child is absent for long periods of time. In short, the system is mostly impenetrable and relies on the resilience and communication capacity of these parents. This burden makes parents vulnerable on many fronts, including socially, and in terms of their own health as well as longer-term economic wellbeing.

HOW ARE EDUCATION SYSTEMS AND EDUCATION SERVICES IN HOSPITALS VULNERABLE?

The Australian Education Department’s (formerly called the Department for Education, Employment and Workplace Relations) commissioned report on inclusive education concluded that in Australia, ‘All jurisdictions have well-developed policies that support inclusive practices’ (ARACY, 2013, p. 20). However, as outlined in this chapter, government emphasis has been on referencing the Disability Standards for Education (2005), rather than interpreting and providing guidance about what these standards mean in terms of inclusive practice. In essence, inclusive education operates within a complaints-based legal system with national, state and territory education departments ensuring that perceptions related to disability comply with the letter of the law, rather than educational

inclusion *per se* (see Slee, 2011; Ainscow et al., 2011). Policy texts and discourses (Ball, 1993) are largely silent about young people with serious health conditions who consequently tend to remain unnoticed by education systems and schools.

By way of example, the Victorian Department of Education and Early Childhood Development (DEECD) has published notification of its coordinated service and resourcing for students with disabilities, where the individual students have been classified as having moderate to severe impairments. For example their *Home-Based Educational Support Program*, ‘supports schools to provide students with severe disabilities and comorbid fragile health with an educational program when they are unable to attend their enrolled school, due to the nature and impact of their disability and health needs’ (DEECD, 2014, p. 3). And some government special schools accommodate ‘students from 5-18 years who have physical or multiple disabilities or highly complex health needs’ (Glenroy Specialist Schools, 2014). However the group under discussion here does not reside at this extreme end of the disability continuum and consequently does not rate a mention.

A sizable number of children and young people exist in Australia who manage serious health conditions and who are enrolled in government schools but are unlikely to be offered accommodation or reasonable adjustment for their programs of study. A potentially significant problem for government education systems therefore exists, but is apparently being ignored. Therefore it is reasonable to argue that this policy oversight by Australian departments of education, together with the lack of guidance or systematic processes for schools, represents a policy of convenience. This large number of students is not acknowledged as an *educational group* warranting systemic attention, but is consistently treated as isolated individuals about whom education policy has nothing to say.

That governments accept little responsibility for these students is of concern and demonstrates how out of step with health advances education has become. Systematic educational support and monitoring processes during extensive and repeated periods of home-based recuperation have not been established. Nor are processes of systematic support provided for these young people when they return to school. Not only is this large group of Australian school students overlooked by their own schools, they are also not noticed by education systems. While biomedical science is saving and prolonging the lives of these young people, government education systems are neglecting their entitlement to educational accommodation, in all likelihood resulting in reduced success in education and low socio-economic status in adulthood.

Parents, usually mothers, have reported their attempts to advocate for their child and retain contact with schools, but they often do not succeed (Yates et al., 2010; Donnan, 2011). Individual teachers are not usually informed about the health conditions, hospitalisations or recuperation periods of individual students, particularly within secondary schools. Processes to follow up on these students do not tend to occur. To be fair to those in schools, however, it is usual for there to be few students from this group in each school, making it problematic to discern the need to develop specific programs or to allocate staff – or to learn from experience.

JULIE WHITE

Nevertheless, it is a fact that government education systems fail to monitor or notice these students slipping through the cracks.

Together with the complaints-based legal framework focused on the individual, the policy intention of government departments of education policy for disability in Australia appears vague and unspecific. Therefore, guidance, direction and expectations about enactment of reasonable adjustment in education programs of study are lacking. Consequently, schools are left to their own devices, without adequate processes or accountability. And students with limiting physical impairments are more likely to be resourced and provided with attention in schools than students with challenging and serious health conditions because such impairments are more visible and knowledge about assistance requirements is less complex. This goes some way to explaining why individual students tend to be overlooked in Australian education. Unlike recent work on how schools enact policy in the United Kingdom (Ball, Maguire, & Braun, 2012), in Australia teachers and schools can't locate or grasp any policy intention regarding this group of students. Therefore schools and teachers have little guidance and students remain unnoticed.

Government departments of education, nationally as well as in the states and territories, would be hard pressed to defend a charge of policy convenience because of their silence about these students, who are erroneously considered to be rare and individual *medical* aberrations, rather than collectively as a sizable group of school-aged *students* requiring specific accommodation. By making repeated reference to disability legislation and how this must be observed, the boxes are ticked and technically, legal compliance is achieved. However, families continue to report (Donnan, 2011; Yates et al., 2010) that little occurs on the ground that supports these young people, their families and their schools.

Section 4.3 of the Disability Standards for Education (Commonwealth of Australia, 2005, p. 16) clearly outline the measures for compliance with standards, that indicate what is required by teachers and schools:

Measures that the education provider may implement to enable the student to participate in the course or program for which the student is enrolled and use the facilities and services provided by it on the same basis as a student without a disability, include measures ensuring that:

- a) the course or program activities are sufficiently flexible for the student to be able to participate in them; and
- b) course or program requirements are reviewed, in the light of information provided by the student, or an associate of the student, to include activities in which the student is able to participate; and
- c) appropriate programs necessary to enable participation by the student are negotiated, agreed and implemented; and
- d) additional support is provided to the student where necessary, to assist him or her to achieve intended learning outcomes; and

- e) where a course or program necessarily includes an activity in which the student cannot participate, the student is offered an activity that constitutes a reasonable substitute within the context of the overall aims of the course or program.

By contrast, in the UK clear guidelines and processes for this group exist (Department of Education, 2013) where roles, processes and entitlements are detailed and responsibilities and key contacts outlined. This policy text replaced the earlier *Access to Education for Children and Young People with Medical Needs* (2001). Interestingly the summary begins, ‘The Government’s policy intention is that all children, regardless of circumstance or setting should receive a good education to enable them to shape their own futures ... enable them to thrive and prosper in the education system’ (p. 3).

As educational policy travels (Ball, 2008; Ozga, 2005) and Australia tends to borrow heavily from the UK (Lingard, 2010; White, 2010), questions need to be raised about the policy silence regarding students with health conditions. Australia routinely imports education policy from the UK, but by choosing *not* to borrow this one – a policy clearly intended to support these students and their families – Australian government departments of education have left themselves vulnerable. They are vulnerable to litigation for not accepting responsibility for these students and for not complying with the disability standards (see 4.3 excerpt above), and by failing to provide guidance or policy for enactment processes in schools, and for leaving these particular students to fend for themselves.

Australian government departments of education have also not met the more obvious educational needs of this group and have allowed philanthropic organisations instead to fund what are basic government obligations. Expert educational personnel are increasingly funded by philanthropy to work in hospitals to support young people with serious health conditions. Educational experts are also employed by philanthropy to support transition back to school, to provide teacher professional learning programs, to give lectures for university pre-service teachers and to provide psychological and education assessments as well as extensive national tuition support programs for students who have missed out on school because of illness (see Ronald McDonald Learning Program, 2014).

Government-funded education services in hospitals have developed their own priorities, including bedside teaching. They tend to offer educational activities only to those who stay at the hospital for periods that are longer than a week. However the average length of stay at paediatric hospitals is three nights (based on 2014 data from Royal Children’s Hospital Health Information Services). Most children and young people instead spend lengthy periods of time at home recuperating – in no man’s land – acknowledged by neither education nor health systems. Generally, hospital special schools and associated services do not accept responsibility for these students once they have left hospital. Nor do schools or education departments assume responsibility for these students in any systematic way. As Donnan (2011) observes: ‘no direct teaching/lessons occur whilst the student is unwell at home but not yet able to return to school’ (p. 16). An independent

JULIE WHITE

evaluation of government funded educational services associated with paediatric hospitals would be likely to conclude that these services are outdated, lack relevance and do not provide value for money to government departments of education who ultimately have responsibility according to the legislative framework:

The standards also give students with disabilities rights in relation to specialised services needed for them to participate in the educational activities for which they are enrolled. These services include specialist expertise, personal educational support or support for personal and medical care, without which some students with disabilities would not be able to access education and training. (Commonwealth of Australia, 2005, p. 27)

While in hospital, students are likely not to be well enough to engage in educational tasks, especially those that bear little relation to work requirements from their actual schools. Those who are funded by government to take responsibility for the education of these students appear to have other priorities, while it is philanthropic organisations instead who have recognised the urgent need to step into this breach and provide appropriate services.

Philanthropic organisations have traditionally stepped into significant but unrecognised areas of need until governments accept responsibility for them. The time has come for Australian government departments of education to accept these students *as an educational group* and develop more appropriate policy discourses that go beyond legal checklists. These government departments of education should also review and redirect existing funding towards more relevant educational support services, rather than continue to fund traditional hospital-related special schools and services, so that the contemporary needs of this burgeoning group is met. Government departments of education should also monitor these students over time and move to ensure that legally mandated reasonable adjustments are routinely negotiated and enacted in schools. Policy reform is urgently required, as schools and teachers require information about the rights of these students as well as direction and expectations. If it is not the responsibility of these government departments of education to provide this guidance, then who should be asked to assume it? Government departments of education do appear to be in a precarious position, open to public criticism as well as increasing vulnerability to litigation.

A class action lawsuit where parents of young people with serious illness sued a department of education (national, state or territory) would serve to clearly establish how the DDA (1992) and the Disability Standards for Education (2005) should be interpreted by school systems and within schools. The reasonable adjustment required for individual students to participate, be included and to succeed in education, ought to become the focus for those in education, rather than medical conditions or absences. The establishment of case law in this area is required in Australia, to focus the attention of government departments of education and schools to accept responsibility for the education of these young people.

Hospital schools and government-funded education services associated with paediatric hospitals are particularly vulnerable because their practices would not bear close scrutiny, particularly in terms of the numbers of young people they serve or the nature of that service. Nor do these facilities provide adequate assistance that reflects the reality of medical success and the profound need for appropriate support for these young people, their parents and their teachers.

These students are legally entitled to an education that accommodates and adjusts learning programs for them. However, many students and parents are not aware of these entitlements, or are not making full use of them. There are complex reasons for this related to adolescence itself (Sawyer et al., 2007), because young people with significant health challenges desperately desire to fit in and to be seen to be an ordinary student (see Yates et al., 2010) and not be noticed as needing special attention because they are resilient and self-reliant (see White, 2014). Nor do parents seem aware of the importance of disclosure requiring the association of their children with disability, in order to obtain legal entitlements within education.

CONCLUSION

This chapter has focused on legal frameworks and the policy shortcomings for the education of young people who live with serious health challenges, who therefore reside at the intersection of health and education. The article has identified four groups who remain vulnerable through a lack of action and attention, despite considerable legal muscle in terms of the DDA (1992) and the (2005) Amendment to that Act, the Disability Standards for Education. The OECD (2007) identified *fairness* and *inclusion* as two dimensions that define equity in education. Ainscow (2012) takes up key points from that definition and comments that the OECD report argues that:

a fair and inclusive education is desirable because of the human rights imperative for people to be able to develop their capacities and participate fully in society. It also reminds us of the long-term social cost of educational failure, since those without the skills to participate socially and economically generate higher costs for health, income support, child welfare and security.
(p. 290)

In Australia the group of children and young people who are enrolled in school and who live with serious illness is conservatively estimated to number almost half a million. By and large, these students and their parents are not treated with fairness, nor are they included in Australian education, despite legislation purported to protect their rights, leaving both groups vulnerable to social exclusion. Policy silence has been identified as a major problem, particularly for government departments of education, who are left vulnerable to public criticism and litigation. Somewhat surprisingly, these government departments of education continue to fund special schools and other education services associated with paediatric hospitals that belong to a bygone era when prolonged stays in hospital were the norm. Medicine has made extraordinary advances over the past decade but these

JULIE WHITE

educational institutions have not kept pace. They do not serve the interests of the majority of these young people, the schools to which these students belong nor the government education departments that fund them.

ACKNOWLEDGEMENTS

Preparation of this chapter was supported through the Australian Government's Collaborative Research Network (CRN) program. I am grateful to a number of people who assisted with the development of my thinking for this chapter. My research colleagues Sarah Drew, Anita Neville, Tracey Webster, Karen Rosauer, Barb Donnan and Fiona Giles added to my knowledge about the issues facing these young people and their families. Murray Greenway, Law Librarian at VU assisted with case law searches and Karen Rosauer provided valuable feedback during the drafting process. I also thank Kitty te Riele and Radhika Gorur for including me in the ASSA workshop shortly after I arrived at The Victoria Institute and for inviting me to contribute this chapter.

REFERENCES

- Ainscow, M. (2012). Moving knowledge around: Strategies for fostering equity within educational systems. *Journal of Educational Change*, 13(3), 289-310.
- Ainscow, M., Dyson, A., Goldrick, S., & West, M. (2011). *Developing equitable education systems*. Abbingdon UK: Routledge.
- Australian Research Alliance for Children & Youth. (2013). *Inclusive education for students with disability: A review of the best evidence in relation to theory and practice*. Commissioned Research Report. Retrieved from ARACY website: http://www.aracy.org.au/publications-resources/command/download_file/id/246/filename/Inclusive_education_for_students_with_disability_-_A_review_of_the_best_evidence_in_relation_to_theory_and_practice.pdf
- Australian Bureau of Statistics. (2011). *Statistics on Australian schools 2010*. Retrieved from ABS Website: <http://www.abs.gov.au/ausstats/abs@.nsf/lookup/4221.0Main+Features32010?OpenDocument>
- Australian Bureau of Statistics. (2014). *Statistics on Australian schools*. Retrieved from: <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4221.0main+features42013>
- Australian Government Department of Education. (2014). *International students: Research snapshot*. Retrieved from Australian Education International website: <https://aei.gov.au/research/research-snapshots/pages/default.aspx>
- Australian Institute of Family Studies. (2012). *The longitudinal study of Australian children (LSAC) Annual statistical report 2011*. Melbourne: The Australian Institute of Family Studies. Retrieved from: <http://www.growingupinaustralia.gov.au/pubs/asr/2011/index.html>
- Ayrton, P. (2014). *No man's land: Writings from a world at war*. London: Profile Books.
- Baade, P. D., Youlten, D. R., Valery, P. C., Hassall, T., Ward, L., Green, A. C., & Aitken, J. F. (2010). Population-based survival estimates for childhood cancer in Australia during the period 1997-2006. *British Journal of Cancer*, 103(11), 1663-1670.
- Ball, S. J. (1993). What is policy? Texts, trajectories and toolboxes. *Discourse*, 13(2), 10-17.
- Ball, S. J. (2008). *The education debate*. Bristol: The Policy Press.
- Ball, S. J., Maguire, M. and Macrae, S. (2000). *Choice, pathways and transitions post 16. New youth, new economies in the global city*. London and New York: RoutledgeFalmer.
- Ball, S. J., Maguire, M., & Braun, A. (2012). *How schools do policy: Policy enactments in secondary schools*. Oxon, UK and New York: Routledge.

POLICY ENACTMENT FOR STUDENTS WITH HEALTH CONDITIONS

- Cappo, D. (2002). *Social inclusion, participation and empowerment*. Paper presented at the Australian Council of Social Service (ACOSS) Congress, Hobart. Retrieved from: <http://search.informit.com.au/documentSummary;dn=821327833027836;res=IELHSS>
- Commonwealth of Australia. (2006). *Australian disability standards for education (2005) plus guidance notes*. ACT: Attorney General's Department. Retrieved from the Australian Department of Education's website: <https://education.gov.au/disability-standards-education>
- Cystic Fibrosis Australia. (2013). *Cystic fibrosis in Australia 2012: 15th annual report from the Australian cystic fibrosis registry*. NSW: Cystic Fibrosis Australia.
- Department for Education, United Kingdom. (2013). *Ensuring a good education for children who cannot attend school because of health needs: Statutory guidance for local authorities*. Department of Education, London. Retrieved from: <https://www.gov.uk/government/publications/education-for-children-with-health-needs-who-cannot-attend-school>
- Department of Education, Employment and Workplace Relations. (2012) *Report on the review of disability standards for education 2005*. Canberra: DEEWR.
- Disability Discrimination Act 1992 (Cth) (Austl.).
- Donnan, B. (2011). *White paper: Educational pathways for children, adolescents and young adults with cancer*. Sydney: Ronald McDonald House Charities. Retrieved from the Ronald McDonald Learning Program website: <http://learningprogram.rmhc.org.au/about/educational-pathways-project.php>
- Glenroy Specialist School. (2014). School website. Melbourne. Retrieved from: <http://www.glenroyss.vic.edu.au/>
- Gonski, D. M. (2011). *Review of funding for schooling: Final report*. Canberra: Department of Education, Employment and Workplace Relations.
- Griffiths, M. (2009). *Parent and child experiences of childhood cancer: An interpretative phenomenological analysis approach*. Unpublished PhD Thesis. School of Psychology and Counselling, Faculty of Health, Queensland University of Technology.
- Innes, G. (2000). 'The disability discrimination Act seven years on. Transcript of presentation at the *Pathways Conference*. Canberra, 6th December. Retrieved from: <https://www.humanrights.gov.au/news/speeches/disability-discrimination-act-seven-years>
- Lingard, B. (2010) Policy borrowing, policy learning: Testing times in Australian schooling. *Critical Studies in Education*, 51(2), 129-147.
- Maguire, M. (2010). Leaving school and moving on: Poverty, urban youth, and learning identities. In C. Raffo, A. Dyson, H. Gunter, D. Hall, L. Jones, & A. Kalambouka (Eds.), *Education and poverty in affluent countries*. New York and London: Routledge.
- McLachlan, R., Gilfillan, G., & Gordon, J. (2013). *Deep and persistent disadvantage in Australia*. Staff Working Paper, Productivity Commission, Canberra: Commonwealth of Australia.
- Mittler, P. (2012). *Overcoming exclusion: Social justice through education*. Abbingdon, UK: Routledge.
- Morad, M., Kandel, I., Hyam, E., & Merrick, J. (2004). Adolescence, chronic illness and disability. *International Journal of Adolescent Medicine and Health*, 16(1), 21-27.
- OECD. (2007). *No more failures: Ten steps to equity in education*. Paris: The Organisation for Economic Cooperation and Development.
- Ozga, J. (2005). Modernising the education workforce: A perspective from Scotland. *Education Review*, 57(2), 207.
- Ronald McDonald Learning Program. (2014). *RMLP Website*: Retrieved from: <http://learningprogram.rmhc.org.au/>
- Royal Children's Hospital. (2014). *Kid's health info: Fact sheets*. Available at: <http://www.rch.org.au/kidsinfo/#tab-All>
- Sawyer, S. M., Drew, S., Yeo, M. S., & Britto, M. T. (2007). Adolescents with a chronic condition: Challenges living, challenges treating. *Lancet*, 369, 1481-1489.
- Slee, R. (2011). *The irregular school: Exclusion, schooling and inclusive education*. Abbingdon UK: Routledge.

JULIE WHITE

- Smith, A. W., Denzer, A. Q., Wildman, B. G. and Anhalt, K. (2013). Teacher perception of burden and willingness to accommodate children with chronic health conditions. *Advances in School Mental Health Promotion*, 6(1), 35-50.
- The University of Sydney. (2014). *Disclosure*. Disability Services Webpage. Retrieved from: http://sydney.edu.au/current_students/disability/about/disclosure.shtml
- Thursfield, V., Farrugia, H. Karahalios, E., & Giles, G. (2012). *Cancer survival Victoria 2012: Estimates for survival for 2006-2010*. Melbourne: Cancer Council Victoria.
- United Nations Convention on the Rights of Persons with Disabilities (2006). New York: United Nations. Retrieved from the UN Website: <http://www.un.org/disabilities/default.asp?id=259>
- White, J. (2010). Speaking 'over' performativity. *Journal of Educational Administration and History*, 42(3), 275-294.
- White, J. (2014). Overlooking entitlement. *International Journal of Inclusive Education*, 18(4), 241-252.
- White, J., & Rosauer, K. (2015). *Young Australians, illness and education: Report on the national database project*. Melbourne: The Victoria Institute, VU.
- World Health Organisation and the World Bank. (2011). *World report on disabilities*. Geneva: World Health Organisation. Retrieved from WHO website: http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf?ua=1
- World Health Organisation. (2014). *Disabilities*. Geneva: World Health Organisation. Retrieved from the WHO website: <http://www.who.int/topics/disabilities/en/>
- Yates, L., Bond, L. Dixon, M., Drew, S., Ferguson, P., Hay, T., Moss, J., St Leger, P., Walker, H., & White, J. (2010). *Keeping connected: Identity, social connection and education for young people living with chronic illness*. Victoria: Melbourne Graduate School of Education, The University of Melbourne.

Julie White
Victoria Institute for Education, Diversity and Lifelong Learning
Victoria University, Melbourne