An ethnography examining the institutional challenges and contradictions arising from approaches to supporting school engagement for young people with ongoing health conditions: an institutional ethnography

Brenda Liston Tait

Submitted in total fulfilment of the requirements of the degree of
Master of Philosophy-Education

February 2015

Melbourne Graduate School of Education
The University of Melbourne
Abstract

Significant developments in paediatric health care have extended and saved the lives of countless children. With shorter hospital stays and enhanced outpatient facilities, many young people are now able to continue their schooling even whilst undergoing treatment. This group of school aged children are not typically identified as disabled, although this depends upon the extent of the impairments related to their health condition. They can, however, require considerable support from teachers and medical professionals, as well as their family, in order for them to remain within the school system.

This research was conceived as a three year ethnographic project focusing on the work of a not-for-profit agency which supported the education needs of children with on-going health issues as they moved between hospital, school and home over extended periods of time. The project began with investigating the history and workings of the agency, gradually developing a detailed account of the approaches it had taken over time to addressing the issues associated with school access for this particular group of school aged children. Through observations, textual analysis and interviews with Education Support Workers and their managers, as well as education professionals working in regional state education support systems, the thesis identifies systemic tensions that continue to present obstacles to achieving inclusive education for all students. The research employs Dorothy Smith’s (1987) critical sociology, institutional ethnography (IE), to investigate the social organisation of education support in this setting focusing on understanding how individual experience and knowledge are shaped by institutional processes and policy imperatives. By examining localised practices in the initial stages of the research it became apparent that the
emphasis on enabling individualised learning utilising new technologies and providing ongoing support, particularly in the hospital, is strongly linked to coordinated trans-local interactions. These interactions, which take place across multiple sites of activity, reinforce standardised practices and particular types of knowledge about the assessment of individual needs.

A key problematic in this type of support work involves the need to either focus on a child’s medical deficit in order to secure funding and/or additional classroom resources, or to foreground their ability and capabilities in order for them to gain re-entry to school. Interestingly, at the same time schools and classroom teachers are increasingly called upon to supervise and perform quasi-medical procedures, while the hospital is presented as an environment for ‘quality learning’.

This thesis argues that educational professionals need to be critically aware of the implications of categorising educational needs as well as the language of self-advocacy in promoting educational engagement. Furthermore, the research raises issues about the limits to the provision of so-called flexible and supportive learning environments, which this research reveals as problematic in addressing issues of educational inequality.
Statement of Authorship

This is to certify that the thesis comprises only my original work towards the Master of Philosophy- Education.

Due acknowledgement has been made in the text to all other material used.

The thesis is less than 50 000 words in length, exclusive of tables, bibliographies.

All research procedures reported in the thesis were approved by the University of Melbourne Human Ethics Committee.

Signed………………………………………… Date………

__________________________________________________________________
Publications:


Presentations:

Brenda Tait, Troubling aspects to Difference and Inclusion within Education Policy and Practice, Graduate Research Conference, Melbourne School of Graduate Education, University of Melbourne, December 12, 2009.


Brenda Tait, 'Fieldwork: Getting my Ethical Bearings' Faculty of Education 14th Annual Postgraduate Research Conference University of Melbourne, December, 2007
Acknowledgements

Many times I doubted that I would ever complete this thesis. It was only after peering over the abyss at the eleventh hour that I drew back and took the plunge once more.

To those who directly assisted in the salvation of this dissertation I offer my sincere gratitude. I am deeply indebted to Professor Johanna Wyn for generously overseeing the final drafts of the thesis after my candidature had lapsed. Words cannot convey how grateful I am to Dr Katie Wright for her friendship and critical feedback throughout this long process. Thanks also to Dr Alicia Evans for her support and encouragement to persist with institutional ethnography.

I am also indebted to Professor Lyn Yates for her initial supervision of the thesis and providing valuable feedback during the final months before submitting my thesis for examination. I also wish to acknowledge Dr Sarah Drew in her role as secondary supervisor.

I am particularly indebted to the education support workers along with staff and managers at Integrate, along with other research participants who freely gave of their time and knowledge during my fieldwork. They introduced me to the complexities and challenges within their work, as well as the realities facing children and families where long term illness, treatment and the effects of traumatic injury are a constant in their lives. Without their generosity this study would not have been possible. I also wish to acknowledge the Board and the management of the agency who, in conjunction with the previous Executive Director, funded the first three years of my research.

The completion of this thesis would not have been possible without the enduring and loving support provided my husband Mark who never stopped believing in me. His willingness to read and discuss my work inspired me not to give up, unless of course, “you really want to!!”

This work is dedicated to my sons, Nathan and Nicholas who continue to bring joy into my life and astound me with their enthusiasm for the future. For my late parents Jean and George Wragg. Thanks also to my dear sister Linda, my wonderful in-laws the Stammers, Evans, Smith and Munro families, and my wonderful nieces and nephews.

To my dear friends you have supported me through thick and thin. You know who you are and yes, it’s going to be some party. In memory of Julianne Regan for her friendship and wisdom.

The age of entitlement is not over and for too many it never began.
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Introduction

This research focuses on the effects of the coalescing of two phenomena, one arising from developments in paediatric health care and the other within education. The first is connected to significant improvements in the treatment and survival of children experiencing illness and trauma, and the overall decline in the number of days patients are actually spending ‘in’ hospital, as outpatients clinics, day facilities and the delivery of services in the home are increasingly deployed to deliver treatment and ongoing care. The second phenomenon concerns the numbers of school aged children with long term health conditions who are returning to or continuing their education often whilst they are undergoing medical treatment. In the wake of these developments both Australian and international research had shown that the educational experiences and social outcomes for students with long term health conditions are often poor, especially when the support provided in schools is inadequate (Asprey, A. and T. Nash, 2006; Needham, Crosnoe, & Muller, 2004). In addition, multiple absences from school can leave these students feeling ‘invisible’ and disconnected from their school community (Asprey and Nash, 2006; Dockett, 2004; Shui, 2004, 2004a).

The Australian Bureau of Statistics (ABS) released a report in 2006 signalling concerns about the patterns of new morbidities and social problems for children despite considerable improvements in health care, education and living conditions. The report defines a ‘long term health condition’ as one which lasts, or is expected to last, for more than six months. The ABS report stated that:

There were 4 million children aged under 15 years in Australia, representing one-fifth (19%) of the total population (ABS 2006a). Health gains brought about by better living conditions, education, medical care and
vaccination would suggest that this generation of children should be the healthiest ever (Patton et al. 2005). However, there are emerging concerns related to rapid social change and the associated new morbidities such as increasing levels of behavioural, developmental, mental health and social problems (AIHW 2006) (Australian Bureau of Statistics 2007 Health of Children in Australia: A Snapshot, 2004-05 (cat no. 4829.0.55.001 Previous ISSUE Released at 11:30 AM (CANBERRA TIME) 15/02/2007).

In 2004-05, 41% of children aged under 15 years had a long-term health condition compared with 44% in 2001 (footnote 1) (ABS 2006 & ABS 2002) (ibid). Although the ABS definition does not include hospitalisation within its criteria for a long term health condition, researchers suggest that admission to hospital for more than one month is also a component (Dockett, 2004). In addition, research conducted in Catholic Schools indicated for instance that mental health issues, conduct disorders and family breakdown are placing considerable strain on teachers and resources within schools (Cahill, Wyn and Smith, 2004). Against this wider backdrop, this ethnographic study is focused on a not-for-profit agency and the experiences of front line professionals delivering support services to school aged children who are hospitalised or in the process of returning to school.

Accepting the proposition that policy is made at all levels (Fulcher, 1989) I became curious about how an assessment of educational need, as a means to achieving inclusion, is understood and interpreted on an everyday basis in a non-school setting. Furthermore, what does inclusion and diversity mean within education when working with children and young people who have a range of medical conditions which are not necessarily categorised as ‘disability’, but may require special arrangements in order for them to continue their education? What discursive steps contribute to the labelling of a child as educationally at risk or a ‘school refuser’? What happens when they do not fit such criteria?
Institutional ethnography (IE) seeks to unravel the interconnected web of social relations which permeate everyday activities. This type of ethnographic investigation is particularly useful in exploring the experiences of frontline workers in areas such as teaching, healthcare and the community sector because it demonstrates how they are enmeshed in and organised by ruling discourses (Smith 1987, p. 160). Research focused on intermediary roles where workers assess, refer and/or manage individual cases requires the collection of particular information, information which corresponds with managerial strategies, eligibility criteria within funding guidelines and the like. Understanding how information in the form of ‘texts’ is collected and used is critical within IE. It is:

especially important because they make the linkages between clients and ruling discourses, “working up” the messiness of everyday circumstances so that it fits the categories and protocols of a professional regime” (DeVault and McCoy, 2006, p.27.

Importantly, the scholarly literature is interrogated in a particular way by the institutional ethnographer because it is treated as part of a set of directives which offers consistency and uniformity in language and processes informing for instance, the application of selection criteria for client referrals, the writing of funding and research applications, defining the roles of front line workers as well as documenting evidence of the implementation of ‘successful’ initiatives and programs. IE makes explicit the ways in which education is connected to larger frameworks of institutional relations including managerial strategies and professional discourses foregrounding particular forms of knowledge and shaping the texts and actions applied within local settings. Within education for example, the influence of ‘child development’ and ‘child centred’ discourses have
been identified by researchers as being central to shaping the expansion in the types of roles and expectations of the ‘work’ of teachers, (Griffith, 1995; Manicom, 1995). Research by Gillian Fulcher (1989) has similarly revealed the dominance of education, medical, lay, charity and professional discourses in shaping the depictions of disabilities across medical, welfare and education sectors. This has had an enduring and powerful influence, not only on legislative frameworks, but also on the management and funding of disability support in schools.

I am not contending in this thesis that education support via providing teaching services in the hospital is not worthwhile for children and families, or that learning activities are not useful for making the experience of being in the hospital more tolerable or even enjoyable in ways which may help them remain connected to their education. Rather, my aim in this analysis is to consider how the exclusive focus providing support in the hospital meets particular organisational concerns which are distinct from the issues facing children and families seeking support in schools. Throughout the dissertation I utilise the term Education Support Worker (ESW) to refer to staff of the agency who provide educational support for individual children. There were two key reasons for choosing to do this. Firstly, in the course of the study the job titles of workers changed a number of times. Secondly, it was important to distinguish them from teachers working in schools.

The actions taken by ESWs reflect a reframing of the lived experiences of children and families, revealing how institutional imperatives, instead of the actual needs of children, reshaped their role. The children became objects of professional interest in order to demonstrate the efficacy of changes being implemented by the Board and management of the agency, and shaped by influential education policies about the role of technology and influence of ‘research’ on education practice. Consequently, ESWs were increasingly implementing strategies and processes to gather evidence to support such
changes. The new reporting systems, research initiatives and learning in the hospital being implemented by Integrate\(^1\) were not only inextricably linked to Education department policy priorities, but to broader organisational interests of the hospital. In this way one can begin to see how a model of professional practice which seeks to respond to the needs of children with health conditions in schools becomes a ‘ruling’ activity.

This thesis begins with the experiences of education support workers then goes on to explore how the issues which arise in this setting are connected to external networks and bureaucratic responses which manage the allocation of funding and resources to schools for students with a diverse range of educational needs. The origins of the study are discussed in the next section which describes the connections between the ethnographic project and a larger Australian Research Council funded project, ‘Keeping Connected’, which focused exclusively on the experiences of young people living with long term health conditions.

**Background and Context for the Ethnographic Study**

The origins of the ethnographic study are linked to the funding of a major Australian study, ‘Keeping Connected’\(^2\), which sought to better understand the situation of young people living with an ongoing health condition. My research complements that project with an ethnographic study of ‘Integrate’ who was an industry partner with the university research project and the funding body for my research. Integrate provides educational support services in a paediatric hospital to school aged children, the majority of whom attend government funded schools. Prior to beginning my fieldwork, I was given access to transcripts from two focus group interviews

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\(^1\) Integrate is a pseudonym for the agency where I conducted the research

\(^2\) The project was developed in association with the agency, and ‘Keeping Connected Project’ with a view to writing an ethnography about the agency.
conducted with ESWs by researchers from the ‘Keeping Connected’ project. The focus groups were intended to provide background information for the Keeping Connected project to give the researchers interviewing young people some insights into the type of work done by the organisation and the issues facing the staff in supporting young people with health conditions. These interview transcripts provided the first pieces of data prior to the beginning of my fieldwork and raised some key questions and clues about the issues shaping the delivery and role of education support in schools and in the hospital.

**Preliminary Research Questions**

In reading the transcripts a number of themes and issues emerged, some of which informed key questions in my research. One concerned the role of ESW’s and their involvement in providing professional training to classroom teachers in schools to support students with on-going health conditions. The second concerned the reluctance of schools to enrol or ‘accept’ students when they had on-going health issues. The third issue concerned the way in which different health conditions attracted different levels and types of funding and how that affected the types of services offered by Integrate. Below, I provide examples of each of these themes with excerpts from the Keeping Connected project focus group transcripts.

The first excerpt involves an ESW describing how she had visited a school to instruct classroom teachers on the management and care of a student with a tracheostomy tube:

> A tracheotomy is a surgical procedure where an incision or opening is made in the trachea to assist with breathing. The tracheostomy relates to the opening or stoma left after the incision where a tube is sutured into place within the trachea.
Sometimes irrespective of the illness a lot of my experiences are about a school’s fear in a sense and how to support the young person with chronic illness. So a) is it their responsibility or isn’t it? Like that’s the question they ask themselves and then what do they do about it and how do they do it and I think that sometimes if it’s all too hard. I mean yesterday, to be honest I went out to a school visit yesterday and I really felt for this teaching staff because I sort of thought, yes, it’s their role and their responsibility but actually what we’re asking them to do is really quite extreme. So they had a session yesterday, a number of them on learning to change the inner tube of a tracheostomy for a kid in year seven. Now that’s a really challenging ask. One of the teachers said actually I’m not squeamish, I just don’t want to do this, I don’t want the responsibility of having to do this. So I think that’s also, there is fear on the part of the schools, but sometimes what we’re being asked to do you know is huge (2007 Keeping Connected Focus Group 1).

It was surprising to me not only that ESWs were instructing classroom teachers on these types of medical procedures but, that classroom teachers were expected to take on these responsibilities rather than a school nurse.

The second issue that arose for me from the interview transcripts concerned schools refusing or delaying the return of a student to school. It was puzzling that despite departmental policies and anti-discrimination legislation some schools were refusing to accept students with health conditions either because the school considered the student was not well enough or they were ‘fearful’ that student may ‘scare’ other students. In this excerpt ESWs discuss the issue of students returning to school after treatment or hospitalisation.

ESW-1: I’ve told schools that they just really just have to take this child back.

ESW-2: I’ve told them that but at the same time I can’t, there’s no point me going to the Principal and having a huge argument to drag this kid back, which is in the long run
going to have a more negative effect on her. Well I’ve done that sometimes but that’s still a challenge.

ESW-3: Better a carrot than a stick.

ESW-1: Yeah. But it’s not about going in and arguing but it may be going in educating and bringing on board

ESW-2: If they will have you in their door.

ESW 4: Oh come on.

ESW-1: They can’t not have you in their door.

ESW-2: The kid with the frame, I haven’t got her back to school yet.

ESW-3: Really.

ESW-5: That’s where there’s massive grey areas because the school could easily say no, do you think this will hold up. We are waiting for this young person to be well enough to come back into our school environment, we still support her, we’re happy for her but we feel that she just needs to get better and really that, there’s nothing written.

ESW-2: Perhaps that’s medical, you draw on your multidisciplinary team.

ESW-5: Well we can, we can draw on research but where is it written, the policies within schools to actually say as a school you have a requirement …

ESW-3: The Disability Discrimination Act.

ESW-5: Well you can pull in the Discrimination Act but …

ESW-6: It’s also about how families are dealing with that school.

ESW-2: And whose role is that? Is that our role?

ESW-3: No, I’ve never said that to a school, I’d never do that in a school, I could never do that no. I’ve been out to one school four times and met with four different groups of people trying to make it happen but I wouldn’t say that (2007 Keeping Connected Focus Group 1).
The final troubling issue raised in the Keeping Connected focus group transcripts concerns the unequal funding and support available for some medical conditions such as cancer over less well known ones such as brain injuries. I discuss the funding and resourcing issue more fully in chapter three when I provide an overview of the chronology of Integrate, including the closure of the hospital special school in 1998, the reasons for the establishment of Integrate in 1999 and changes in its corporate vision between 2007 and 2010.

It was apparent that certain medical conditions, such as cancer, attract more funding and resources, largely because cancer has a much higher profile in the community than other conditions such as brain injuries or behavioural disorders. This was raised by ESWs as a particularly concerning issue because when certain medical conditions or disorders were misunderstood this could have an adverse effect on the way a child was supported within a school. The final account I provide vividly describes this problem.

ESW-1: Well I’m happy to talk. I joined the [Cancer] team about twelve months ago and so it’s a program for keeping kids connected, obviously to their school and local community and to assist the families by their undergoing treatment. I am really, really enjoying the role. It’s a whole new learning curve because prior to that I was with the Rehab part of the [generalised] Education Advisory Service, so a great change and many challenges, but I guess one of the things that struck me about it that the word ‘cancer’ is a universal language (2007 Keeping Connected Focus Group One).

ESW-5: I know cancer has got a high profile and that does give you an automatic, as you said an automatic entrée in, but [...] and I work in rehab so we’ve got students with
ABI[Acquired Brain Injury] and it’s an invisible illness in itself so often the schools are dealing with an illness they can’t see. And we get more requests about behaviour and naughty children, naughty boys in particular, we get the “naughty adolescent” that schools struggle with without them looking that that’s an illness connected with that behaviour and some of the professional development that I’ve done in schools, when I go to whole staff and do that, it’s because the student has had nuisance value, and nuisance value gets much more attention than illness value, which is a particular problem in the other diagnostic area that I work in, which is cardiac. That’s also more recognized and so it depends out in the school community how they view the different diagnostic areas of illness and therefore how they treat those students (2007 Keeping Connected Focus Group One).

The issues raised in the two focus groups from the ‘Keeping Connected’ project formed the first pieces of data which guided the initial focus of my research. However, for the research to fully progress I also had to consider what sociological and methodological approach would be most appropriate, particularly as I wanted to consider the issues arising from the accounts of ESWs within a wider discussion about school inclusion, equity and access. My introduction to ‘Institutional Ethnography’ was a critical point in the development of the research project.

**Chapter Overview**

**Chapter one** examines key literature around what is broadly known as inclusive education and the ways it features in educational policy reforms, academic writing and the broader disability activism community. The first

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4 Acquired Brain Injury (or ABI) refers to any type of brain damage that occurs after birth. ABI can result from numerous causes, and every brain injury (like every individual) is unique. ABI can affect a person’s cognitive, physical, or emotional functions. In some cases, all three functional areas are involved, with serious effects on the previous level of independence enjoyed by the person with an acquired brain injury. The impairment experienced can range from mild to profound (2004 ‘Getting Your Head around ABI- Resource Manual).
section of the chapter examines the historical and discursive shifts in education policies concerning special education, integration, social inclusion and more recently educational or school engagement. The second section explores the conditional aspects of inclusion where the risks for educational dis-engagement are judged by the extent of individual deficits rather than on the basis of rights. **Chapter two** will explain how I have undertaken the research, guided by Dorothy Smith’s conceptualisation of the social organisation of knowledge. The chapter explains the key steps taken in an institutional ethnography in order to identify how discourses operate at a local level but most importantly how they link across settings. The larger goal of the chapter is to show how the social organisation of knowledge around improving educational engagement and inclusion at a local level has its roots, in what Smith (2005, p. 69) refers to as ‘ruling relations. **Chapter Three** provides a brief history of Integrate utilising a combination of ‘internal’ documents including funding applications and planning documents and a larger number of ‘public’ documents, such as annual reports, web documents and publications. The documentation provides important clues to the institutional interests shaping the work of the agency and its links with the Education department and the hospital. The chapter then explores the actualities of the work that is the focus of the agency and the interplay between institutional processes which merge into apparatuses across multiple sites of activity. The final section of the chapter identifies the research problematic which brings to the fore the difficulties arising in the work of ESWs as they adopt new processes to tackle pre-existing issues concerning the provision of education support in schools. **Chapter Four** focuses on change within Integrate, particularly the creation of a new system to identify and refer children leaving the hospital and at risk of educational disengagement, to external support systems in the education. **Chapter Five** maps how the hospital was increasingly becoming the focus of the work
done by the agency. Most particularly, the chapter focuses on how the notion of the hospital becoming an alternative learning environment, with children being viewed as ‘learners’ instead of only being patients, is shaping the activities undertaken by the agency. **Chapter Six** concludes my analysis of how education support in this localised setting is linked to the education support apparatus of state education. The social relations organising the identification of students with additional educational needs within the broader agenda of school inclusion and the right to education has important implications for education support workers, along with the children and families they support. The intermingling of disability, medical and charity discourses with prevailing ‘normalising’ education discourses have considerable influence in how the risks for educational dis-engagement are assessed but perhaps equally importantly how educational engagement is judged.
Chapter One: Interrogating the Literature

The theoretical and pragmatic imprecision of this thing we, and it is a very broad we, call inclusive education, has permitted all manner of thinking, discourse and activity to pass itself off as inclusive (Slee, 2006, p. 111).

Introduction

This chapter examines key literature around what is broadly known as inclusive education and the ways it features in educational policy reforms, academic writing and the broader disability activism community. Institutional ethnography explores the literature not only to read what is known about a subject, but to consider how particular facts and concepts are constructed and socially organised (Campbell and Gregor, 2004, p. 51; Smith, 2004, pp. 51-2). The literature may speak about a topic in one way but it may be discussed in a completely different way by people on the ground (Campbell and Gregor, 2004, p. 52). The first section of the chapter examines the historical and discursive shifts in education policies concerning special education, integration, social inclusion and more recently educational or school engagement. The second section explores the conditional aspects of inclusion where the risks for educational disengagement are judged by the extent of individual deficits rather than on the basis of rights.

Section 1: Integration and Inclusive Education

The concept of inclusion within the realms of our everyday experience requires a belief and an act of acceptance which acknowledges individual rights rather than an attitude in which the only action taken is a response to
a particular need or deprivation (Szoke, 2009). Yet, in many ways the gap between the two positions typifies the tension within education and the broader community about how to respond to difference and address individual rights. Ainscow and Miles (2008) in examining the international research concerning the application of inclusion within education identified the concept as covering five distinct areas: the first, has inclusion concerned with ‘special needs or disability’; the second, inclusion as a response to ‘disciplinary exclusions’ often related to ‘bad behaviour’; the third, concerned with ‘groups vulnerable to exclusion’; the fourth, as the promotion of ‘schools for all’; and lastly, inclusion as ‘education for all’ (2008, p. 17). Exploring the various guises which inclusion has taken within education provides a starting point for my exploration and critical reading of the research and scholarly literature.

Inclusion has been defined by van Kraayenoord as ‘the practice of providing for students with a wide range of abilities, backgrounds and aspirations in regular school settings’ (2007, p. 391). In Australia the ‘concept of the inclusive school’ emerged in the 1990s when a new state funding model for special education re-framed inclusion within the discourse of ‘flexibility’ for schools. This changed the ways that schools could deploy funding and resources, and it purportedly gave families ‘options’ about where to enrol their child (Jenkinson, 2001, p. 28; Forlin, 2006, p. 266). These inclusive reforms, however, were ‘distant’ from the influential Collins review held in Victoria in the 1980s which had five guiding principles: the right of every child to be educated in a regular school; that every child can learn and be taught; non-categorisation should inform all legislation and service delivery; the optimal resourcing of regular schools and finally, that collaborative rather than professional interests should drive decision making (Lewis, 1989, p. 346; Jenkinson, 2001, pp. 22-23). Special schools had been initially established to ‘include’ children with disabilities in education (Jenkinson,
2001, p. 3), but they also served multiple purposes including acting as a ‘safety valve’ (Lewis, 1989, p. 345) by shifting children out of regular schools to enable their smooth running (Lewis, 1989, pp.337). However, integration also unintentionally contributed to the development of a culture which perpetuated negative attitudes towards people with disabilities and reinforced the powerful role of professional interests directly involved in the assessment of disabilities. Lewis argues this contributed to more children being labelled under the category of disability, and consequently being placed under the purview of special education, than perhaps had been originally intended. This also included ‘hospital schools’ which were re-established as special schools in one Australian state in 1924-25. To this day the most commonly adopted approach to supporting the educational needs of school aged children in hospitals continues to be funded as a ‘special school’ with provision for teachers and classroom facilities in the hospital. The arrangement for such schooling in the hospital would usually involve a nurse unit manager referring a child when they are well enough to benefit from educational activities, and/or if their period of hospitalisation was likely to impact adversely on their education. The young person may then attend on a daily basis the school room staffed by qualified teachers.

However, as Lewis argues this reliance on the category of special education services had particular consequences for who is covered and who isn’t:

The net increase in the categories of disability deemed to be part of special education’s territory has traditionally been viewed as the extension of proper care to those who have been in hitherto unfulfilled and special need. The result has usually been calls for even more resources to cater for their individual differences. However this response assumes that the expansion of special education services is equated with progress, a view which has prevailed, despite a lack of convincing evidence that it has been helpful to clients. This traditional view of special education does not adequately explain why existing categories of children are sometimes removed from special education’s field, or why existing regular schools have been added (ibid:335).
Lewis refers to Tomlinson’s conclusions that the expansion in special education reflected more than humanitarian interest, instead it represented a ‘complex of social forces and vested interests’ which competed to define vulnerable groups in society (Lewis, 1989, pp. 345-36; Lewis 1993, p. 18; Fulcher 1989, p. 213). The continuing concentration of interests is observable was not only in the 1980s and 1990s in Australia, but in the United Kingdom where Tomlinson observed that ‘professional bureaucracy and formal structures or machine bureaucracy both’ struggle with ‘heterogeneity’. In the process children are ‘separated out’ or segregated by processes which categorise them as either as ‘normal, capable or able’ whilst others with problems are ‘labelled and/or ‘treated’ (Tomlinson, 1995, pp. 4-5).

In 1988 the complex of forces and interests had led to one state in Australia developing a ‘dual’ education system whereby special schools were retained and specialist support was funded in regular schools, and ‘integration aides’ were introduced into regular schools but they remained largely under resourced (Jenkinson, 2001, p.23) leaving parents and schools to implement what passed for inclusion (ibid. 2001, p. 28). As Fulcher (1989) observes the complex arrangements between state and federal government in shaping education policy and legislation (1989, pp. 192, 195, 198.), combined with an ‘extensive array of administrative-political-bureaucratic practices’ within a state Ministry of Education, can ‘undermine’ the democratic resolve to desegregation of education (1989, pp. 201-203, 228). Fulcher argues that these difficulties need to be viewed ‘neither as purely political nor economic’ but a resulting from conditions which are ‘institutionally complex’ (1989, p. 213). Slee views the shift from special education to inclusion mainly as a ‘linguistic adjustment’ which blended dominant disabling discourses into that of inclusion (1997, p. 407).
The next phase of education reforms from 1989 onwards provide evidence of how the concept of inclusion broadened from one exclusively focusing on special education and disabilities to one of ‘social inclusion’. The historical and discursive shift to improving educational engagement for ‘all’ students is reflected in a series of recent reform measures negotiated between state and federal governments in Australia. These are also informed by international trends in education and the importance of standards and improving performance of schools and students in education (Paul, 2008). In 1989 Australian States and Territories signed with the Commonwealth government the ‘Hobart Declaration on Common and Agreed National Goals for Schooling in the Twenty-First Century’ which committed a national framework of cooperation in which ‘schools and education authorities were required to improve educational outcomes and reduce differences across Australia’ (Ministerial Council, 2007, p. 7). In 1999, ten years after the Hobart Declaration, the Adelaide Declaration identified ‘ten common and agreed’ national goals for schooling in Australia including the provision of ‘excellent education for all’; developing the ‘talents, capacities of young people relevant to the social, cultural and economic needs of the country’; emphasising the promotion of ‘equality of educational opportunities’ including those with ‘special learning requirements’ (Ministerial Council, 1999, p. ix). Inclusion also became connected with ‘diversity’ encompassing individual development, culture and personal differences, whilst emphasising the requirement of schools to meet the needs of ‘all’ students (Van Kraayenoord, 2007, p. 391). Van Kraayenoord goes on to quote from the Department of Education in Tasmania in 2006 which was considered as having one of the most ‘comprehensive’ definitions of inclusion in Australia:

Inclusive education means that all students in a school, regardless of their differences, are part of the school community and can feel that they belong. The mandate to
ensure access, participation and achievement for every student is taken as given (ibid., p. 391)

The Melbourne Declaration on Education Goals for Young Australians (2008) also reinforced the role of education in building a ‘democratic, equitable and just society’ (Ministerial Council, 2008, pp. 04-05) specifically identifying ‘disengagement’ from education as a problem for vulnerable groups such as Indigenous and Torres Strait Islander students, and emphasising the role of specialised support services in providing targeted and specialised support (2008, p. 16). However, despite legislation and the visionary statements within policy reforms the outcomes in producing more inclusive education remains problematic for schools and students. As Yates, Collins and O’Connor (2011) observe, the rhetoric is the easy part (2011, p. 309). Critics argue that reforms have not radically changed the organisation within schools rather they are even more ensconced in protecting the ‘status quo’ than in the past (Slee, 1996; Graham and Slee, 2007, p. 277). Policy guidelines such as those entitled as ‘Effective Schools are Engaging Schools’ (2009) developed by one state education department within the Student Wellbeing and Health Support Division is a case in point. The characterisation of an inclusive environment which ‘engages’ students incorporates a guide for schools about managing discipline and processes for the expulsion of students whilst encouraging ‘positive behaviours’. This takes up Ainscow and Miles (2008) point that inclusion has a number of focal points within education but, it continues to rely upon ‘specialisation’ and deficit models to assess disabilities and additional needs. Research in Australian schools reveals that whilst school principals regard the Disability Discrimination Act as ‘extremely important’, they rarely used it for ‘administrative guidance’ when making decisions about the enrolment of students with disabilities (Keeffe-Martin, 2003). In addition research also suggests that in reality inclusion is ‘uncritically adopted’ within the language
of organisations without sufficient understanding being given to the origins of ‘exclusion’ (Grahame, K. 1998, p. 381).

Despite the notion of inclusion being adopted in school and education policies it was also becoming clear that a considerable number of young people were ‘slipping through the cracks’ of the education system (Ashton and Bailey, 2004). The failure to address the structural barriers to participation without continually reverting back to individual deficits (Fischer, 2007, p. 172) and the reliance upon establishing specialised programs was highlighted in 2007 by the ‘Project to Improve the Learning Outcomes for Students with Disabilities in early, middle and post compulsory years of Schooling’ (Shaddock, T. J., Smyth King, B. and Giorcelli, L., 2007). The project emphasised that the expansion of ‘mainstream thinking, structures and practices’ was important in order for all students to be accommodated in regular schools (ibid., p. 30). Critics suggest the ‘conditionality’ of inclusion (Slee, 1997, p. 408) with the creation of new categories of disadvantage has ironically created new areas of ‘exclusion’, particularly concerning legal and funding uncertainties, leaving many of the systemic barriers in access to education unchallenged. Research has shown that the connection between diagnostic criteria and resource or funding allocation has created unintended and adverse implications for families, children and practitioners (Tomlinson, 1995; Belanger 2000; Slee, 1993; Slee and Allan, 2001, p. 180) What is commonly overlooked when a diagnosis is inconclusive are the realities for families and young people who are often left feeling unsupported and desperate. In this situation, professionals may feel under pressure to identify children with a particular condition in order to meet eligibility criteria to enable the release of much needed educational and health resources (Corman, 2008). Ballard (1999) argues that the ‘dichotomisation’ of education’ creates particular spaces for children and young people who have ‘special needs’ which positions them as a ‘technical
problem’ to be addressed by policy and ‘resource management’ (Slee, 1997, p. 412; Slee, 2001). Increasingly, inclusion has become the domain of policy makers and bureaucrats which has shifted the focus from ‘rights’ to that of managing the distribution of funding and resources (Slee, 1996, p. 22). This type of response Young (1990) warns, mistakenly ‘reduces social justice to distribution’ and ignores the ‘social structure and institutional context which contribute to determining distributive patterns’ (1990, p. 15). Not only does this continue to reinforce the role of special schools and specific programs to deal with the ‘grit’, which Lewis referred to, but the problem (1989, p. 71) keeps the wheels of mass education and the ‘disability industry’ turning (Jung, 2000, p. 23). How that affects those students who do not automatically fit within the category of ‘disabled’ yet still have particular needs is not so clear. The addition of further groups to the list of those experiencing discrimination and marginalisation results in the continual growth of funding for the establishment of specialised programs including support for children within the regular school system who have health conditions. Importantly, international studies identify children in the education system with life limiting and life threatening conditions, including cystic fibrosis, chronic renal disease or juvenile diabetes, as representative of a group within education who can often go unnoticed (Asprey and Nash, 2006, p. 12; Shui, 2004a, p. 240). Emerson, Honey, Madden and Llewellyn commented in 2009 that data suggest:

At a time of significant economic prosperity, existing Commonwealth, State and Territory government policies and services relating to disability, which typically use the language of rights and participation, failed in the first half decade of the 21st Century to redress the pervasive social and material disadvantage faced by Australian adolescents and young adults with a self-reported long term health condition, disability or impairment (Emerson et al., 2009, p. 48).
Llewellyn also reports that the poor understanding about the needs of young people with disabilities is compounded by national data often not fully accounting for how young people experience living with a disability. ‘Disability’ is often reported as an outcome and often a poor one or not reported at all in national data (Llewellyn, 2010) which compounds the invisibility and/or deficit view of disability. These types of selective reporting and exclusions are compounded by students with a range of disabilities often being exempted from national testing and assessment within reporting frameworks for the National Goals for Schooling in Australia (Dempsey and Conway, 2005).

**Section 2: Long Term Health Conditions as ‘Risk’ for Educational Disengagement**

The connection between vested professional interests and the identification of students with additional needs is identified by Lewis (1989) is particularly relevant to the agency in which this research is situated. Debilitating illnesses have been described as devastating and largely private experiences for the individual, chiefly managed within the home by individuals and family or carers, and isolating as they are often invisible to the wider community (Jung, 2000). Jung’s research demonstrates that these experiences are exacerbated by policies within institutions which instead of supporting their participation in education actually undermines their full inclusion (Jung, 2000, pp. 30-31). Bureaucratic responses in the form of specialised programs which require the meeting of specific eligibility criteria, as well as the implementation of particular policies in schools and the adoption of pedagogical approaches such as ‘differentiated teaching’ to suit the individual needs of students, all feature in the lexicon of inclusive discourse. Ainscow (2007) argues that the focus on ‘deficits assumptions’ needs to be scrutinised for the perceptions concerning particular students (2007, p. 5)
which one might say turns them instead into difficult students. These
tensions are compounded by shifts in education policies which seek to
improve overall performance and success yet, without fully addressing the
structural issues contributing to underachievement and poor performance.
This has had the effect of lowering the expectations for many students,
including those from racial minorities and people with disabilities (Artiles,
2003, pp. 167-9). The focus on the role of education in developing human
capital has thus compounded pre-existing problems within ‘special
education’ concerning whether to affirm or ignore difference (Artiles 2003,
pp. 168-9, 193) and created other difficulties within education when
‘disability’ is not established (Corman, 2008). Rizvi and Lingard (2010) make
the point that all policy is ‘value laden’ reflecting a ‘web of decisions’ (quote
from Easton 1953), with values allocated ‘authoritatively’ as evidenced by
the funding of some things but not others (2010, p. 7).
These issues form the backdrop for some of the difficult issues raised in my
inquiry and go to the heart of Fulcher’s assertion that policy is not only a
top down process, but one which affects all levels of education.

Policy is made at all levels; no one level determines another,
though it may establish conditions for other levels. One
reason government-level policies may fail, then, is that their
social theory of how that bit of the world works – the bit
which they hope to influence – is wrong….Putting policy in
a political framework and locating it in a wider model of
social life as consisting of discursive social practices: we act
on the basis of our discourse about an aspect of the social
world, such as whether we divide schoolchildren into those
with disabilities and those without, or whether we see all
schoolchildren, firstly, as pupils (Fulcher, 1989, p.16).

The problematic relationship between more recent depictions of inclusion
and whether they address questions of rights and discrimination draws
attention to the rhetorical nature of many claims within policy statements
about achieving equity through education. Establishing ‘difference’ or being
‘different enough’ remains a key issue in the way educational support for
students with additional learning needs is identified and delivered. Whilst there is considerable research and debate about how to achieve inclusive education there is little research which specifically focuses on how organisations working as intermediaries across the education and health spheres promote inclusion (Booth and Ainscow, 2004; Ainscow, 2007). This includes exploring how medical professionals and teachers communicate and share information about the needs of young people living with long term health conditions (Hobbs and Perrin, 1985; O’Keeffe and McDowell, 2004; Asprey and Nash, 2006). Educational research has repeatedly shown that teaching environment and individual attitudes to inclusion within an organisation are key for developing and adopting inclusive practices (Weisel and Dror, 2006, p. 169; Heshusius, 2004). Thus, if teacher expectations are low then students will have a corresponding low self-image. These issues extend beyond the classroom involving the whole institution (Heshusius, 2004, p. 76) as well as the personal and professional values of educationalists (Diamond, Randolph and Spillane, 2004). Forlin found in reviewing the research literature that as ‘perceptions of the severity of disability increased, that acceptance decreased’ (2006, p. 270).

Finally, the assessment of the risk for educational disengagement utilises particular criteria and assumptions in order to allocate funding and resources throughout the education system and, importantly, manage the experiences of students, families, teachers and service providers. Inclusive practices often focus on providing specialised support where information about individual needs is gathered in order to demonstrate their eligibility for additional funding and resources. A further consideration is the extent to which the success of the individual in gaining additional support involves ‘self-advocacy’ by the individual, parent or carer. This raises two questions for investigation. The first concerns the social organisation of current inclusive guidelines and policies in shaping approaches to school
engagement by specialised support services. Secondly, if special needs or disability discourses are not central to making a case for additional support, then what alternatives are available to support workers when promoting educational engagement?

**Conclusion:**

The research literature and education policy concerned specifically with issues for students with a range of disabilities and educational needs, as well as broader policies concerning school inclusion, promoting education engagement and improving performance demonstrate the various ways in which ‘inclusion’ has been taken up by policy makers, politicians, bureaucrats, academics and teachers in schools. The shift away from emphasising individual rights towards individual responsibility and the greater focus on identifying individual deficits has resulted in policy solutions that often concentrate on managing the distribution of resources and funding rather than addressing needs. At the same time school policy concerned with inclusion has often been more concerned with celebrating diversity and the social inclusion of ‘all’ students, further diminishing the original intentions of those who sought greater access and equality within education.

The focus on individual responsibilities and identifying deficits has further contributed to the development of processes to assess and categorise, whilst leaving those children and families not meeting specific eligibility criteria with few options. Consequently, the more difficult issues concerning the production of inequality in education and the reasons for educational disengagement are often secondary to the focus on deficits residing entirely within the individual. At the same time celebrating diversity and more generalised aspirations around social inclusion feature within education.
policy, often leaving aside the thorny questions of what it actually means for students in schools when their educational needs are not met.

The effort and time taken up focusing on identifying, assessing and categorising school aged children, whilst at the same time presenting the education system as inclusive, distracts attention from the real issues contributing to inequitable outcomes in schools. Even though much of this activity may be well intentioned, the extent to which education is involved in these activities demonstrates the continuing dominance of deficit discourses in policies promoting school inclusion and educational engagement, rather than recognising individual rights. The role of these discourses in the shaping of institutional responses raise important questions about the consequences for people who do not wish to be identified as ‘disabled’ or who do not meet eligibility criteria within specialised programs for additional support. The highlighting of individual deficits and identifying barriers and risks to education engagement is only part of the picture. My research and analysis explores other elements within education support work, notably, that of promoting individual capabilities and the role of flexible learning environments. The data I analyse later in the thesis provides evidence of the disjuncture between the goal of inclusion and the everyday realities of working in a hospital environment with children and families who are seeking to maintain connections with schools. The question of ‘how things happen this way’ begins by exploring the issues which face people on a daily basis. In this chapter, I have provided an overview of the literature, which has been ‘read’ through the lens of institutional ethnography. In the following chapter, I more fully explicate the research paradigm and the strategy I undertook to investigate the issues.
Figure 1

S.O.S.

Help Schools' Hospital Day

Sept 14, 1926
Chapter Two: Institutional Ethnography: Developing a Theoretical and Methodological Frame

This chapter will explain how I have undertaken the research guided by Dorothy Smith’s conceptualisation of the social organisation of knowledge. It explicates the key steps taken in an institutional ethnography in order to identify how discourses operate at a local level but most importantly how they link across settings. The larger goal of the chapter is to show how the social organisation of knowledge around improving educational engagement and inclusion at a local level has its roots in what Smith refers to as ‘ruling relations’ (2005, p. 69).

Introduction

Organisations can be difficult places for researchers, particularly when issues of access and authority arise. John Galliher (1980) has argued that the power dynamics between researchers and participants are often reversed when conducting research in ‘public agencies’, making them distinctive from research done with individuals who are often on the margins of society. Research in organisations can also be viewed as ‘risky business’ especially if professional interests and the public interest are in contention or where the issues are highly politicised or sensitive. These questions along with other concerns about the efficacy of conventional ethnographic research and its relevance to the lives of participants were all issues of concern to me at the beginning of this project. During the process of writing my university ethics application I was introduced to ‘institutional ethnography’ (IE) by a colleague and I began to explore what IE might offer this research project. A few months later I was fortunate to attend a conference in Geelong in 2007 where Dorothy Smith, the founder of this relatively new sociological approach, was presenting along with other key researchers in this field.
Central to Smith’s approach is a questioning of what passes as conventional knowledge when at its base are theoretical assumptions which often silence alternative meanings and lived experiences. The conventions and discursive practices within sociological theory not only treat accounts of experience as instances of particular institutional processes or theory (Smith, 2004, p. 153; Campbell and Manicom, 1995, pp. 7-9) but, the standpoint of those outside such conventional interpretations are ‘subdued’ by taking this approach.

Smith argues that theory acts as a regulator which shapes dialogue, consciousness and the practices of participants and most importantly, marginalises the intrusion of other voices which are troubling to those who speak from within the discourse (Smith, 2004, pp. 152-154). Smith explores discourse not purely as statements but as ‘practice’ within local settings where discourse is mediated by texts. Texts in this case are ‘skeins’ or strands of social relations which connect and coordinate the activities of people in multiple diverse localities (Smith, 2004, p. 158). The power of texts for researchers lies in recognising the way they produce an ‘internally consistent picture of the world’ orchestrating the ‘terms’ under which policy is written and decisions are made. Recognising the conceptual linkages between discourses across settings is integral for understanding how the activities within institutions are coordinated (Griffith, 1995, p. 110).

Demonstrating the connections and commonalities between people and discourse, rather than evaluating work practices or analysing instances of individual or group behaviour in order to generalise to larger populations, is an important distinction within IE. It enables a shift in the analytical focus to discovering how social problems arise and are perpetuated despite good intentions. Smith’s approach seeks to produce ‘maps’ which expose the strands of social relations which inform everyday activity (Jung 2001, p. 57).

In this research setting identifying intersecting discourses became critical to understanding how the delivery of education support is shaped by theory,
policy and practices which regulate what is recognised as successful educational engagement and inclusive outcomes.

Tracing social relations involves three main stages in the following sequence: an experience is identified, then the researcher identifies some of the institutional processes shaping that experience and finally, an investigation of those institutional processes is undertaken to provide an analytical description of how they provide the grounding for that experience (DeVault and McCoy, 2006, p. 20). The entry point begins with a generous notion of work. Historically ‘work’ had referred to paid employment in the formal economy, before the women’s movement drew attention to the unrecognised work done by women in the domestic sphere. Institutional ethnographers extend this view of work by including ‘anything or everything people do with purpose, requiring effort and time, in a particular place and under specific conditions (Smith, 2006, p. 10). Smith’s re-conceptualising of work enables the researcher to build a detailed and expansive picture of people’s engagement with institutional processes (Smith, 1987, p. 164). This broad scope of engagement is integral to understanding how the ‘social regime’ is accomplished (Diamond, 1992, p. 129). Secondly, it requires an analysis of the ‘ideological codes’ (Smith, 2004, p. 159) which are constantly generating procedures, shaping syntax, categories, vocabulary in the writing of texts, producing talk and interpreting sentences, written or spoken. For the purposes of this research the production of visual representations are also integral to the social regime. Smith uses the example of describing someone as ‘mentally ill’ as a local moment where one is drawn into the discursive relations of psychiatry (Smith, 2004, p. 158). These ideological codes generate the same order in disparate locations such as legislative, social scientific and administrative settings as well as television, advertising and popular writing (Smith, 2004, pp. 158-9). The final stage of IE involves analysing the sequences of local processes and their links to multiple sites.
Importantly, it recognises that individuals are engaged in processes which ‘produce’ social relations. At the same time they are also ‘ordered’ by social relations. Understanding this dynamic is integral to institutional functioning, for when people make decisions and take action they are coordinated within a schema of policies, professional practices, and organisational communications which are a combination of text based, informal and casual interactions (Campbell and Gregor, 2004, p. 100).

The Travails of Ethnographic Inquiry

In deciding to take up Smith’s approach to ethnography and her central question about the role of critical sociology I was informed in part by my past experiences in conducting ethnographic research. Ethnographic research remains one of the most challenging and messy forms of research. Messy because life is messy, leaving the ethnographer to find an ethical and ‘truthful’ way to witness, record, analyse and communicate these events to multiple audiences (Brogden and Patterson 2007, p. 223). The complexities of faithfully representing the lives of others reflects an ongoing debate within anthropology which began in the 1970s and still occupies an important place within practice and theory today. Schepher-Hughes adopted a compromise when she suggested a ‘good enough’ approach to the practice of ethnography given the often ‘perilous’ reality of her participants lives.

We cannot rid ourselves of the cultural self we bring with us into the field any more than we can disown the eyes, ears and skin through which we take in our intuitive perceptions about the new and strange world we have entered (Schepher-Hughes 1992, p. 28).

Wolcott’s reflections on ethnographic research had resonated with me in drawing attention to the peculiar nature of ethnography and the need to be
aware of ‘how one is seeing’ rather than merely producing an ‘inventory’ or ‘descriptive piece’ (Wolcott 1999, p. 66). Wolcott’s assertion that ethnography allows for the gaining of understanding about how we come to know something and the ‘organisation of our lives’ stands at the core of the ethnographic project (Wolcott 1999).

With this project I wanted to find a theoretical and methodological approach to the research which generated new academic knowledge but also met my scholarship obligations to produce work which could be viewed as ‘useful’ to the agency. I was also beginning to question the validity of a traditional ethnographic path which categorised and theorised the experiences of participants, effectively silencing them within the research. This was in part a reflection of my intellectual curiosity but also my concern that staff would not necessarily participate in the study if I could not communicate a purpose for the project which had some meaning for their work. I also recognised that my presence was a result of senior leadership and Board decisions and this had an effect on perceptions about the purpose of the research.

Smith has contrasted institutional ethnography with ‘extended case method’ and ‘grounded theory’ to illustrate how sociology had become focused on theory and theoretical discussion and displacement of the subject to an instance or example within a theory. The goal for institutional ethnographers is not to produce an account ‘of or from’ the insider perspective but to understand ‘how’ their experiences are organised. For instance, Rankin’s institutional ethnography about nurses in the Canadian health system explicates how nursing care work has been re-organised around a managerial agenda to reduce costs and increase efficiencies. The discomfort nurses felt and discussed in relation to their work were connected to the implementation of policies and practices which often detached them from care work (Rankin 2004, p. 185). Other studies such as
Campbell’s study on the use of assessment forms by community nurses reveals the way in which the standardisation of eligibility criteria reinforces a particular way of providing services which reduces costs, but in the process, undermines ‘professional knowledge’. The actualities and needs of patients become secondary to documentation which standardises information to meet institutional priorities within organisations (Campbell, 2001).

Institutional ethnography proceeds quite differently from other critical approaches such as grounded theory. Foucault’s conceptualisation of ‘discourse’ provides the basis for Smith’s concept of ‘ruling relations’, particularly the identification of ‘systems’ of knowledge as imposing an ‘interpretive order’ is central to understanding individual subjectivity (Smith, 2008). It does not seek to ‘transpose’ a researcher’s impressions or intuitions into sociological concepts which universalise phenomena, rather IE seeks understanding by identifying the linkages between individual actions and other sites of activity (Smith, 2005, p. 160). Where grounded theory uses an interpretive lens to produced new theory IE seeks to unravel how ruling relations organise and shape individual experiences.

Ethnography may start by exploring the experience of those directly involved in the institutional setting, but they are not the objects of investigation. It is the aspects of the institutions relevant to the people’s experience, not the people themselves that constitute the object of inquiry (Smith, 2005, p. 38).

The role of discourse is central to IE. As such Foucault’s emphasis on discursive events, in written and spoken accounts, demonstrate influential and distinctive forms of power. Within linguistics the notion of ‘streams of text’ is significant but, Foucault extended the concept to the identification of ‘conventions and patterns’ within textual forms (Smith 2005, p. 224). However, integral to Smith’s conceptualisation of discourse is recognition of
a ‘systematically developed knowledge, morality, and set of values that are expressed in definite ways of writing and speaking’ (Griffith and Smith 2005, p. 33). These are reflected in a range of textual forms.

The notion of discourse that we work with here shifts from discourse conceived as simply forms of signification or meaning to emphasize discourse as the local practices of translocally organized social relations… as we use the concept here, discourse is people participating actively and embodied in a conversation mediated by written and printed materials. Each discourse has its own distinctive organization of authorities, means of dissemination, educational and knowledge-producing sites and production processes (Griffith and Smith 2005, p. 34).

**Ethics Approval and Informed Consent**

In my application for approval to conduct my research from the Human Research Ethics Committee (HREC) I described how I intended to protect the identity of participants to the best of my ability, and my efforts to protect the organisation are an additional step in this process. The plain language statement included a caution that it is impossible to ensure complete anonymity given the unique status of the organisation and its small number of employees. To provide as much anonymity as possible, throughout the thesis I have employed a pseudonym for the name of the organisation and only use generic terms such as ‘education support worker, senior staff member, hospital employee and so on. The eventual decision to remove all identifiers within the main body of the thesis including the name of the state in which the study was conducted, the name of the hospital,
government departments and the University was taken to further protect the participants.

Furthermore, given that the bibliography contains internal and confidential documents as well as hospital documents, these will be de-identified once the thesis has been through the examination process. This additional step is to protect those working within the agency and the confidential nature of some documents which I was given permission to use during my research. This is an interesting question for ethnographers conducting research within organisations, namely, can a line be drawn between protecting the anonymity of an individual and that of the organisation. Organisations are not people but, they have people within them. To reveal the organisation, particularly when it is a small affair, is to reveal the people involved, especially when the research has occurred in the recent past.

_Institutional Ethnographic Stages_

This inquiry did not begin within professional or academic discourses about inclusive education rather it begins with the actual work and practical reasoning people apply on an everyday basis. Taking this approach to conducting ethnographic research required a considerable rethink on my part about the purpose of research and its relationship to the lives of the participants, as there are a number of differences between IE and more established forms of ethnographic research. However, if I had undertaken the project utilising a theoretical approach, that is where a theoretical proposition is predetermined, which would have theorised the experiences of participants to the point where it was only written for an academic
audience, then I believe an important opportunity to learn more about this complex setting would have been lost. For the purposes of my university ethics application I did formulate a range of questions which sought to gather information about the agency and the work done by ESWs, however, I did not want to begin with a pre-determined focus. Beginning with the actual work of ESWs and applying an expansive definition involves investigating ‘work’ in its ‘totality’ by exploring what is essential to the operations of the organisation yet, not always readily recognisable to those engaged in such activities (Smith, 1987, p. 166). Smith is not concerned with what is or isn’t work but more importantly what is done under ‘definite’ conditions and situations (ibid. 166). In exploring work from this perspective the researcher is able to identify how common sense understandings within work processes ‘dovetails’ into state apparatuses and existing stratifications (Ng, 1990, p. 110). The ‘extraordinary’ capacity of large-scale organisations and institutions to retain meanings and recognition across locality and time in order to co-ordinate people’s work and achieve particular outcomes raises significant questions. Smith argues this demands the study of the ‘institution’ be taken beyond focusing on ‘cultural norms’ and collective knowledge to seeking understandings about the scope of their power and agency in contemporary society (Smith, 2001, p. 164, 164, n.2).

Understanding how the agency is situated in this area of education is potentially a far more useful outcome for the research informants than for instance, focusing on the organisational culture of the agency or exploring the applicability of change theory in this organisation. IE is time consuming, often not easy to explain and the benefits are not readily identifiable until considerable time has elapsed. Questions of the relevance of research to informant lives are perennial and basing ones findings within theory often does little to console them. Whilst IE raises uncomfortable questions, it does stay within the lives of the informants and although the findings may
be confronting it goes to the heart of understanding how we engage with power.

Whilst it is important to enter the field with a set of questions in mind, the key to beginning to unravel how informants work in the way they do, is to hear what informants are saying and watch what they are doing, whilst bearing in mind what has been said in the literature or in departmental guidelines. Education is replete with policies, guidelines, pedagogical terminology and processes for categorising students and families. It took me some years to understand the language and mechanics in this setting and hence, identify what I was actually seeing and hearing. This caused some confusion, scepticism and concern within Integrate as it was difficult to explain to participants where the study might end up. To add further complications to this situation I had a number of extended absences from my fieldwork due to illness. These absences not only delayed my research but unintentionally, extended the duration of the study which fortuitously enabled a more extensive and expansive study to happen. In the end, the fieldwork was conducted over a two year period, however further exploration of information such as policy documents, academic literature, web documents and media coverage occurred over an extended period of a further five years as I continued to analyse my data.

On reflection it is clear to me now that informants in professional settings, even education professionals, are often no better informed about the intricacies or difficulties of conducting research than any other group in society. To complicate things further, in a health and education setting research is predominately viewed as an activity which is undertaken for very specific purposes such as to attract funding, demonstrate the efficacy of a new measure or policy or seek out a collaborative opportunity. This meant that ‘research’ is most often conducted over very short timeframes with specific goals. During the course of the research I witnessed a workplace
undergoing considerable change with people experiencing a great deal of uncertainty and concern about the direction the Board and management were taking the agency. As the research project progressed and my focus shifted to examining the complex of social relations beyond Integrate I was able to begin to understand how the interplay of interests were critical in reshaping localised decision making and actions, including research activities.

Analysis of Institutional Procedures and Ideological Practices

Smith's characterisation of discourse as an active textual constituent within everyday institutional activity offers a unique and powerful conceptualisation of the 'ideological force' exerted by discursive texts and how they come to influence our knowledge and actions in local institutional settings (Griffith, 1995, p. 110). Categories such as 'delinquency or mental illness' originate in bureaucratic, legal and professional spheres of activity. However, they also become 'substitutes' for what actually happens between people and the ordering of work processes which 'synthesize' accounts from diverse experiences (Smith, 2004, p. 160). Systems of accountability and reporting used in institutions render some things invisible whilst others are brought into focus. In this regard, Peter Grahame (1998) has argued recognising the objectification of experience is critical in enabling the 'imperatives' of the organization to be realised by establishing the formal definitions and procedures which control its functioning. Sociology 'has routinely concerned itself with objective constructs tied to practices of the formal organization rather than expressions which originate in the actualities of everyday life' (Grahame, P. 1998, p. 349). Institutional ideologies introduce codes which replace actual experience, work processes and local knowledge and hence deny the 'economy of material conditions, time and effort' instead producing sociological accounts which conform to 'institutional process and discourse' (Smith 1987, pp. 163-4).
**Social Relations as Synchronised Courses of Action**

Smith argues that social organisation and social relations are critical concepts. However, sociology has often used them in ways which pluck ‘phenomena out of time and place’ and in doing so, separate them from actual people and their activities (Smith 2004, p. 7). In proposing that social relations are the actual practices and activities through which people live their lives, Smith differentiates them from ‘relationships’ between people and from what is ‘done’ to people. They are instead something in which people are actively and proficiently participating – knowingly or unknowingly – in order to coordinate an outcome which conforms to particular standards, expectations or organisational rules (Campbell and Gregor, 2004, p. 31). For IE social relations become the lens through which to see, with ‘texts’ acting as the ‘sutures’ connecting the social at a local and extra-local sites of activity (Smith 2001, p. 175). The constancy of texts not only makes them replicable and recognisable across time and place but draws attention to their ‘standardising’ effects (ibid., p. 175).

**Institutional Ethnography as a Methodology**

Conventional approaches to gathering ethnographic data are shaped by concepts such as culture, symbols and rituals which direct the type of seeing and knowing employed by the ethnographer. Not only is data ‘tested’ for accuracy using techniques such as ‘triangulation’ but ‘abstraction’ is used in approaches such as ‘Grounded Theory’ to demonstrate meaning in participants lives and ‘solve problems’ by presenting theory as offering an understanding of experiences. Institutional Ethnography proceeds differently by seeking to identify ‘connections’ through ‘explicating the ruling relations’ which organise and coordinate the localised experiences of
their informants. Smith does not argue against abstraction, rather she is concerned with examining and explicating how they are put together with ‘concepts, knowledge, accepted facts, as socially organised practices’ (Smith, 1992, p. 90). The critical reason for conducting an institutional ethnography is to investigate how local settings come to be the way they are. The analytical goal is to ‘explicate’ the social relations of the setting by mapping and tracing the local to the ‘trans-local’ (Campbell and Gregor, 2004, pp. 88-90). Smith contends that despite sociologists having the best of intentions to be ‘oppositional or progressive’, if they begin with standard methods of inquiry and thinking they will simply import the ‘relations of ruling’ into the texts they produce (Smith, 1992, p. 91). By beginning with a ‘standpoint’ which is informed by the ordinary and everyday as people talk about and do their work, institutional ethnographers are able to look for the connections which organise these experiences. The researcher, by accompanying people, hears and sees how informants use ideological concepts and categories to explain the actions they take in order to complete tasks and in doing so, provide clues about the social relations in which they are caught up.

**Data Collection**

The diverse range of data in this thesis was collected over a six year period. The data included in-depth interviews and participant observations, as well as an extensive range of documents including national and state government education policy documents, funding agreements, legislation, a range of material on specialised programs and guidelines for schools. I also collated a range of internal and public documents produced by Integrate, including academic papers, research findings, as well as hospital and university publications.
The research encompassed a longer period than planned after a number of absences from the project due to personal reasons. The initial interview data and fieldwork observations were conducted over two years where I held formal interviews with twenty-one participants in various positions within Integrate. The interviews were with twelve ESWs, four senior managers – including the past and present executive directors – and three interviews with members of the board of directors. I also recorded a further five in-depth interviews with regional support staff in student support services. Other informal interviews and conversations with friends and associates working in education policy, nursing and other areas of education were important sources in building my knowledge.

My participant observations were conducted at Integrate and in the hospital over a period of two and half years. I attended the agency up to three days each week varying the days and hours spent there depending upon what was occurring. I prioritised the weekly morning staff briefings and fortnightly afternoon staff meetings as these were often when managers made announcements and feedback was provided by staff about the changes being implemented. If I could not attend meetings I was often able to access minutes and audio podcasts of proceedings. The content of these became important in compiling questions for further interviews with participants. My field notes incorporated observations and conversations as I accompanied ESWs during their working day and attended a range of events organised by the agency. The fieldwork was not continuous but broken into blocks of time with the most intensive period occurring in the early part of 2008 and then later in 2008. The next most intense block of observations and interviews occurred in 2009 with only a small number in 2010. These breaks in fieldwork were unplanned but due to personal reasons.

Over a longer period of time from 2008 until 2014 a range of public documents were collected. These were available on the hospital and
government websites or were issued as publications by Integrate and the hospital - some in collaboration with academic institutions. At the same time I developed an extensive collection of documents produced by Integrate. These included annual reports, web documents, research publications, a limited number of ‘internal’ policy and funding documents, as well as minutes from a range of internal meetings. These texts were important for beginning to map the ways in which the work of ESWs was changing and how the educational needs of children were being assessed as the management of Integrate implemented its new approach to education support in the hospital.

The participant observations involved being present for different types of activities. In the first instance it involved me accompanying ESWs in the hospital and spending time with them in their offices. When I began my research ESWs were not situated in the hospital on a full time basis but they would spend up to 2 hours a day in the hospital providing support to children. During 2008 and 2009 if they were agreeable I would stay with them at their desks whilst they checked for new referrals from their managers, answered email and phone inquiries from students, families and schools, hospital staff and others. I attended meetings with them including those to plan events in the hospital. On arriving at their designated hospital ward or area they would seek information from medical staff about children and families who had been referred for support. I observed as they provided learning activities and offered advice about a range of issues facing students seeking to continue their education in the hospital and those returning to school. On other occasions I would observe special events where activities were planned for children to promote education in the hospital. Furthermore, I attended team building activities, seminars and conferences where Integrate was working in collaboration with university research teams.
My observations were an important opportunity to record the actual work of providing education support at a time when it began to change its focus. This included ESWs being relocated back into the hospital on a full time basis during 2009. The majority of interviews were conducted between January 2008 and September 2009 with a small number of interviews conducted in 2010. The interviews varied in length but the majority were less than one hour. However, a few interviews extended for longer especially if an ESW wanted to show or explain a particular work process. Interviews were largely recorded on a digital recorder but if they participant preferred I would write notes and check with them if I had correctly understood and recorded their comments and descriptions.

The majority of interviews were conducted within the offices of Integrate or in the hospital. Formal interviews were held in meeting rooms or offices. Informal conversations where I took notes were very important within the study and often led to participants agreeing to later being formally interviewed. These opportunities usually arose as ESWs worked in the hospital, after meetings, or informally when they were discussing their work at lunch or taking a break.

The recruitment of participants began initially with an open invitation to all ESWs to participate in the research via email followed by an information sheet provided to each staff member. However, the recruitment process was challenging not only because some ESWs had formed the view that the Board of directors had ‘recruited’ me to report on them but, they expressed unhappiness about not being consulted or informed about the project before it began. This challenge was resolved with most participants by offering more information to them about the origins and the purpose of the project. With respect of those participants in senior positions there were a different set of concerns about whether the potential findings might reflect poorly on the agency. To allay some of these fears I attended a range of
meetings where I fielded questions from ESWs about the research project. I also had meetings with senior managers where they too were able to ask questions about the research and voice their concerns. Gradually I was able to address issues about the independence of the research and its goals. For participants who agreed to be interviewed I provided a letter explaining the project and informed consent including their right to withdraw from the research at any time. I provided my contact details and they signed the consent form.

The majority of ESWs who did participate in the research had an extensive working knowledge of education support in this environment, as well as experience of teaching in schools and other non-traditional school settings. This meant that they had not only been teachers in the school system for considerable periods of time in the past, but they been employed at the agency for a lengthy period in various roles, in some instances since its establishment. Three had worked with adolescents in the mental health system, whilst another had worked in rehabilitation area. I began the interviews in early 2008 and built a record of interviews over a two year period until my fieldwork in the agency ended in 2010. The interview questions initially focused on how ESWs came to work at the agency, the types of documents and policies which informed their work, understanding the types of issues that confronted the children, families and schools they supported, what they found challenging themselves in the work and how they assessed the educational needs of children in the hospital, including who should be referred to external services once they returned to school. Over time I focused on the introduction of processes to assess the educational needs of children and the types of strategies employed by ESWs. In interviewing senior managers and board members I focused on the reasons for establishing Integrate, its role in the hospital and what was influencing its planning and development.
Throughout my fieldwork I attended many staff meetings at the offices of Integrate where I took extensive notes. These occasions provided discussion points which I used later in interviews to further explore how the work was changing. Further to this I had access to the minutes and audio recordings of meetings and staff briefings. Other events organised by Integrate such as information sessions in the hospital, conferences or events held in the hospital. These were critical to documenting the changes and initiatives being implemented by the organisation and for understanding its new role within the hospital. Documenting the type and scope of these meetings/events were important for developing a chronological record of the changes being implemented by the new director of the agency over this intensive 2 year period. These types of data enabled me to begin to recognising the gaps or puzzling aspects between the work of ESWs, and experiences of the children they supported, and the new directions the agency was taking. Thus I was able to begin to identify the links between funding models, education department policies and programs, as well as within the burgeoning research agenda of the agency.

My collection of documentary data was integral to the development and realisation of the project. Institutional ethnography is by definition an expansive research process whereby it begins with localised experiences using them to identify clues and raise questions. This inevitably leads to the exploration of ‘texts’. In this area I was able to collect an extensive range of documentary material over six years as my research was extended due to a number of unplanned absences. However, quite serendipitously, this actually enabled the study to become more expansive and in the process enabled a wide ranging mapping of the changes and complex relations shaping the work of ESWs at the agency. The documents were both of an internal and external nature. Those ‘internal’ to the agency were provided
with the permission of the management of Integrate whilst an extensive range of additional material was open sourced. The documents were selected on the basis that they provided details about the history of the organisation, its role within the hospital and connected to funding bodies. They also provided information about the broader policies and types of programs being implemented by the Education Department, as well as the types of research being sponsored and funded. My selection of these items was guided by the types of language, images and wording in the documents.

The collection of photographic images displayed in the thesis are all publicly available on the internet and have appeared in Education department, hospital, university and publications by Integrate. These images became increasingly important texts for understanding the social organisation of education support work as the thesis began to take shape. As I began to gain more clarity about my research focus I began to recognise the considerable similarities between the documents produced by Integrate and the categories and language used in new reporting processes being implemented by ESWs. The use of images in such publications were presented as powerful evidence of the success of a particular policy or initiative. The textual analysis of interviews, observations and documents identified the ways these discourses reinforced each other and how education support work is shaped by social relations beyond Integrate. The analysis reveals the way ‘inclusion’ and ‘educational engagement’ were applied within a health care environment by multiple players. The identification of key discourses and ideological codes such as ‘child at risk’ and 'child as learner' became a major focus in the textual analysis.

**Validity**
Institutional ethnography situates itself theoretically from an ontological position which questions how the social exists and how to make it readily observable to all. To investigate the research problematic, IE does not engage in substituting the investigation of the sociologist with either the analysis or the perspectives and the views of informants (Smith, 1987, p. 160). The collection of data is focused on developing an in-depth knowledge of the setting as well as the external relations and processes which shape and organise it (Smith, 1987, p. 122). The aim is not to identify ‘typical features and variations among a class’, rather IE is concerned with how the everyday world is put together through relational determinants which are often invisible yet, generalised across settings (Smith, 1987, pp. 160). Smith employs ‘ethnography’ as a lens which foregrounds ‘how things work’ by focusing on actual practices and relations, and by utilising observation, interviews, accounts of work, conversations, as well as documents including visual and written materials. For IE:

Questions of validity involve being able to reference back to those processes themselves as issues of ‘does it indeed work that way’? (Smith, 1987, p. 160).

For Smith an ontological perspective is the starting point: it is about how the social exists in order for us to describe in a way for it to be traced back to ‘how it actually is’. The notion of ‘the actual’ in Smith’s writing presents as an arrow which says ‘you are here’ and pointing to the ‘text to a beyond-the-text in which the text, its reading, its reader and its concepts also are’. This demonstrates where ‘discourses happen and how they constitute reality’ (Smith, 1997, p. 393). Smith argues that it is possible to reach this point of understanding because of the very character of ‘the social’ itself, which is situated in the ‘ongoing active recreation of a world in common’ (1987, p. 122). For IE, validity is about whether an account can be ‘checked back’ to its actualities (Smith, 1987, p. 122).
Fieldwork and interviewing by the institutional ethnographer is propelled by seeking a fundamental understanding of the connections between people and work processes which implicate them within the ‘institutional complex’. The ‘rigor’ comes not from techniques - such as sampling or thematic analysis - but from the constant checking throughout the investigation which results in the development and continuous correction of the ‘map of social relations’ (DeVault and McCoy, in Smith, 2006, p. 33). The research problematic of the everyday world, according to Smith, arises at the ‘juncture’ of particular experience with ‘generalizing and abstracted forms of social relations organizing a division of labour in society at large’ (Smith, 1987, p. 157). This enables institutional ethnographers to investigate even from a ‘single case’ because it provides a ‘point of entry’ to discovering their location within a wider network of economic and social processes. This approach contrasts with sampling techniques which feature in conventional sociology and apply sociological concepts to a generalised population or groups and require a credible sample for extrapolation. However, it is not the intention of IE to demonstrate the entire social relations through one experience. Rather, a study will focus on particular work processes to provide a manageable project. The focus for my research concerns processes for identifying school aged children diagnosed with long term health conditions for educational support whilst hospitalised. The research takes up a number of viewpoints in order to bring the ‘complex of relational processes into view’ enabling a broad view of the institutional complex into which informants are hooked (DeVault and McCoy, in Smith, 2006, p. 18).

**The Research Entry Point**
For this study, the research developed as I worked through the interviews, observations and textual analysis. The interviews and observations specifically took place over a two year period from 2008 to 2010. However, over a longer period of time from 2007 to 2014 I was continually engaged in identifying key texts which were important for understanding the social organisation of education support activities being undertaken by Integrate. These included legislation, education policy documents and departmental guidelines, as well as drawing upon an extensive collection of internal and public documents produced by Integrate and public documents related to the hospital. Further texts including literature in this area and articles in the media were gathered over a much longer period right up until I completed the first draft of my thesis.

The study explores the way in which institutional processes and practices of workers within Integrate – particularly those which focus on encouraging/promoting educational engagement – regulate and organise the work of providing education support to school aged children in a hospital setting. School inclusion and educational engagement regulates and organises education work because of the complex of practices across legal (anti-discrimination and rights), administrative (resources and funding), pedagogical (all children can learn) and policy (education engagement) spheres of activity. The array of practices and decisions which are implemented by people working in Integrate, including formal policies and procedures in the hospital, working with schools and various divisions within the Department of Education, directly intervene into the lives of families and school age children with long term health conditions seeking to continue their education. These interventions have significance for the way long term health conditions are understood in schools and for what comes to pass as inclusion or successful educational engagement. The question of school engagement is also one which occupies education policy makers,
politicians, academics and schools. Formal policies concerning the inclusion of students with a range of diverse educational needs – including those with health issues - involves a set of practices and decision making which shapes the work of those employed in support services such as Integrate.

The research proceeded in two parts (McCoy, 2006, p. 124). The first part started with the interviews which I conducted with informants at Integrate over a 2 year period, which were transcribed and then analysed, along with fieldwork observations. The second part explored what I will call the ‘educational engagement apparatus’ which shaped the work in this setting. These steps comprised different qualitative and data gathering techniques. The first step involved conducting in-depth interviews, open ended reflexive interviews, serendipitous conversations and observations as well as reflections on my own experience. The second step involved archival research, textual analysis of policies and procedures of Integrate and a limited number of interviews. These techniques are known within other qualitative approaches but how institutional ethnographers approach and interrogate the data is quite different. IE treats the fieldwork, participant observation and other ‘informal’ research techniques as an ‘entry point’ into the social relations. An example of the way this happened in my research was for instance, when an informant mentioned a key policy document such as The Blueprint for Education in Government Schools or if they used a particular phrase such as ‘educationally at risk’ or ‘child as learner’, I would then seek to map the interconnections and meanings which are being transferred across sites of activity. Smith’s conceptualisation of ‘institutional capture’ is important in this regard. The researcher literally conducts a dialogue with the data, re-thinking ‘what is said’ with an awareness of the ways in which institutional discourses displace and colonise experience in order to produce particular outcomes and conform to particular readings of experience. Liza McCoy (2006, pp. 122-3), for instance, found institutional
capture useful in unpacking what ‘treatment decisions’ actually meant for patients and health care professionals. Medical professionals used the category of ‘treatment decisions’ as a form of institutional shorthand to meet their requirements. However, in the process they obscured or wrote out patients’ understandings in preference for professional discourses. Thus, my role as researcher was not to treat ‘institutional language’ as a descriptor, instead I began to call into question what is taken for granted by participants when they rely upon institutional categories (Tait, 2013, p. 559).

Consequently, I began to problematise notions of education engagement, including the notion of ‘education for all’, which, whilst related to ‘inclusive education’, entailed distinct actions and processes. This also involved examining policies and guidelines which informed the actual processes for identifying which students had the capabilities to succeed without ongoing support, as those that didn’t.

**The Research Problematic**

The ‘problematic’ is a conceptual research tool which enables the discovery of the social organisation of the setting. Smith (1987) argues it should not be ‘confused with the concept of problem, rather it is a new way to connect the sociologist and the sociological inquiry to the ‘knowledgeable’ experience of members of society in actual lived situations (1987, p. 91). Identifying the problematic is critical to framing the ‘interests represented in the research and is the basis for conducting the inquiry’ (Campbell and Gregor, 2004, pp. 48-49). This is done by listening to the concepts and categories spoken by informants – and used within the literature – revealing connections to the ruling discourse and institutional language, although they may not necessarily think of it in this way (DeVault and McCoy, 2006, p. 28).
Within this study I was fortunate to document a changing setting where new and old educational discourses were employed, and intermeshed with charity, medical and professional discourses which were used to represent the needs of children and young people with long term health conditions. Tracing the work of providing education support to policies to promote school engagement and inclusion requires examination of the 'relevancies' of those experiences to an ‘institutional order' (Griffith and Smith, 2005, p. 124), an order which is invested in segmenting education across professional and sectional interests, but importantly, maintaining the status quo. Inclusive discourses are the creation of professionals, although they have been shaped by the work of disability activists and other vested interests. However, what occurs in the sphere of everyday practice, where what is actually done or said, reveals further complexities.

**Beginning with the Everyday Lives of Education Support Workers**

Taking an ‘insider’ standpoint is key for conducting an institutional ethnography in which people are recognised as ‘experts’ in conducting their lives through ‘work’. Smith’s methodology begins with experience in order to explore the social processes which construct and organise individual actions. The focus of an inquiry is the ‘social organisation of experience’: how we act, speak, listen and actively produce social groups, and the social relations which make up society (Griffith, 1998, p. 369). Being present at Integrate during a period of rapid change gave me the opportunity to observe and record how the language around education support began to incorporate new terminology and reflect dominant discourses within education policy. My attendance at weekly staff meetings became important for understanding how ESWs were incorporating and at times resisting such discourse in their practices.
The social organisation of education engagement which functions as part of an institutional order within education discourse itself is present in the work of support workers, although this is not necessarily visible to them from the inside. Illuminating the discursive ordering of this work is essential to understanding how it is done in the way it is. ‘Experience is a method of talk’ which for Smith is a ‘language game’ where what is said ‘struggles dialogically to appropriate language layered with meaning even before the moment when one speaks. Thus, experience gives ‘direct access to necessary social character of people’s worlds’ including that which is taken for granted and what they are able to talk about (Smith, 1997, p. 394). The social organisation of providing education support to students who are hospitalised with health conditions requires more than simply keeping them up to date with school work or connected with their peers. The role of the institutional ethnographer depends upon understanding that knowledgeable and skilled professionals engage in talk which is ordered in a way which reflects the social order of which they are part.

**The Research Process**

The research for this project was a process of discovery, beginning with the accounts of those providing and managing the delivery of education support. The next phase of the research involved transcribing interviews conducted with ESWs and analysing them to uncover how education support is organised beyond the workers ‘direct’ experience. Events can often seem ‘disconnected, incoherent or lacking sense’, but Smith argues that an order exists outside the local setting which disorders or orders the lives of people which conforms to a logic, for example, the logic of the labour market or state agencies (Grahame, P. 1998, p. 351). This ‘organising “logic” is located elsewhere than in an individual's own activity and experience’ (Smith, 1997, p. 97).
The final part of the research is focused on textual analysis (words and images) and concentrates on the various organisational processes and practices within Integrate. Particularly, it identifies students for education support in the hospital or when they return to school. The accounts of education support workers who provided support, advice and teaching within the hospital are analysed and explicated to extend my knowledge of how Integrate functions within the wider education support system. A large part of this final stage also involved examining scholarly literature and research around educational engagement and social inclusion policies which informed the language in annual reports and representations Integrate made to funding bodies and submissions to government. I examined various reports and audits which had been conducted by the Victorian government in relation to school support systems including those for students with disabilities. I also conducted formal interviews with other staff involved in supporting students in the government school system to gain a better understanding of ‘how’ the work of Integrate is linked to support systems beyond the hospital and administrative processes which regulate the way in which educational engagement and inclusion are enacted. In this phase the institutional procedures and ideological practices of the state education engagement apparatus within the Education Department, acting in conjunction with the services provided by Integrate, are integral to understanding how the actions of support workers are concerted within an ‘institutional order’. The experiences of education support workers and importantly, the ways in which educational engagement is typified for school aged children living with long term health conditions, becomes visible by conducting the inquiry in this way. My analysis demonstrates how the institutional order is inextricably linked to the experiences of support workers in this local setting.
**Interviewing and Transcribing**

The interviews I conducted were opened ended as I wanted to familiarise myself with an expansive and detailed knowledge of the work involved in providing education support to school aged children inside and outside the hospital. A number of interviews were audio recorded with the permission of the informants and these were later transcribed. Other interviews with informants were not recorded and instead I took written notes with their permission. The interviews gave me a point of entry to the experiences and work involved with supporting school aged children in a hospital setting including how they ‘do’ support work. Key features of this included what they knew and understood about the children they worked with, what they expected from children and families, what difficulties arose in providing support and the kinds of solutions they offered, and who they worked with in negotiating solutions. They talked about the emotional and challenging aspects of their work, the resources they could access and the ‘troubles’ they encountered.

When analysing these interviews I was not conducting an evaluation of Integrate’s work or comparing it with other agencies, nor was I comparing the different work processes or strategies employed by individual workers or the teams in which they worked. By focusing on the actualities of the work – which Smith identifies as the material conditions of work – and then seeking to identify those which they do not control, I gradually developed a fuller picture of the work. Other sources of important data were my fieldwork observations and the on-going conversations I had with informants where I saw and heard about the full scope of their work in the hospital and back in their offices as they answered emails and phone calls, and attended meetings.
These personal accounts provide what Smith considers a fuller picture of what people do in their lives by recognising ‘a generous concept of work’ (Smith, 2005, p. 129, pp. 151-2; Campbell and Gregor, 2004). Work in this sense encompasses a range of activities, some recognised and some not, but all of which contributes energy, time and thoughtful consideration to what in this setting was called providing ‘education support’. Taking this approach considers all their actions as data worthy of analysis irrespective of how informants name and view their work or how professional and organisational discourses frame them. Seeking to deconstruct professional language requires moving beyond assumptions about what is actually involved when an informant says they are ‘making an assessment or referral’ or ‘updating case notes’. These activities have an administrative and ideological function which require work by the informant to overcome particular tensions and difficulties in order to make decisions about what information do they record or exclude, and draws upon their extensive knowledge and skills (Campbell and Gregor, 2004, p. 72). The data from the fieldwork interviews and texts provides the basis for exploring the links between local activities and the social relations which operate at different levels. Local experiences are the jumping off points for a more extensive exploration of what is occurring by following the clues provided within the data. The role of texts is pivotal in this step in moving beyond experiential accounts to understanding the full picture.

**Textual Analysis**

The concept of the social directs a focusing of sociological attention on how people's activities are coordinated (Smith, 1999, p. 11).
Smith proposes that ‘textual technologies’ are significant for sociological inquiry because they co-ordinate how people do their work (Smith, 2001, p. 174). Understanding how ‘texts’ enable institutionally standardised messaging to occur across sites of activity is possible if one examines the interaction between people and texts. Texts are one ‘point of reference’ and the reader the other. The text is fixed in time whilst the other is mediated by speech and other forms of interaction and information occurring in real time (Smith, 2001, p. 175). The coordination of social relations is shaped through the interactive dynamic of the reader with the ‘readable’ text; recognising the materiality of texts across sites is important for recognising how standardised categories, words and images are taken up in everyday practices and affect decision making in diverse locations. The institutional ethnographer seeks to identify in what ways texts ‘hook’ local work into ‘centralised regulatory and decision processes’. The researcher accomplishes this by questioning who texts are written for and how they inform particular organisational sequential processes and actions (Smith, 2001, p. 174).

**Conclusion**

In this chapter I have described and discussed how I understand the research strategy of institutional ethnography to explicate the social outcomes and experiences of those working to support the educational engagement of children with health conditions in the school system. In the next chapter I begin to describe how I conducted my analysis by discussing how the needs of school age children with on-going health conditions became part of the broader strategies to promote school inclusion and educational engagement. In describing the administrative apparatus which manages school support, what also comes into view are the practices which also ‘manage’ students by ‘fitting them’ within existing processes. In exploring the seemingly ordinary features of its everyday activity I aim to
show how these are implicated to wider sets of relations which are integral to the way ‘ruling’ occurs.
Chapter Three: The Organisation of Education Engagement

This chapter provides a brief history of Integrate utilising a combination of ‘internal’ documents including funding applications and planning documents and a larger number of ‘public’ documents, such as annual reports, web documents and publications. The documentation provides important clues to the institutional interests shaping the work of the agency and its links with the Education department and the hospital.

It then explores the actualities of the work that is the focus of the agency and the interplay between institutional processes which merge into apparatuses across multiple sites of activity. The final section of the chapter identifies the research problematic which brings to the fore the difficulties arising in the work of ESWs as they adopt new processes to tackle pre-existing issues concerning the provision of education support in schools.

My intention in this research is to make transparent what was organising the institutional interpretation of children’s experiences and needs and reshaping the work of the ESWs. This chapter will provide both background information about education support work and specific aspects of working with school age children who have health conditions. This type of education support is differentiated from what is termed ‘special education’ or support for students with disabilities. It is more often framed by discourses which are concerned with students who are identified as ‘at risk’ of leaving education or experiencing poor outcomes. My aim is not to compare health conditions with disabilities or to evaluate the efficacy of the decisions or professional judgements made by education support workers at Integrate in supporting these students. Rather, I am interested in the social organisation of local processes concerned with encouraging educational engagement.
Establishing Integrate: Educational Engagement for Children with Long Term Health Conditions

In 1998 the governing board of one hospital ‘special school’ in Australia made a decision to close the school and instead sought funding to establish a new type of service to support the educational needs of children with health conditions. The most commonly adopted approach to supporting the educational needs of school aged children in hospital is by funding teachers and classroom facilities as a ‘special school’ within the hospital. For instance, one Victorian hospital school indicates on its website that a nurse unit manager will refer a young person when they are well enough to benefit from educational activities, and/or if their period of hospitalisation is likely to impact adversely on their education. The young person will then on a daily basis attend a school room staffed by qualified teachers.

Integrate opened in 1999 after successfully obtaining a contract to supply a ‘unique’ range of services funded by the Education Department (Education Department General Purpose Contract, 2005). It was evident to the school board and the teachers that increasing numbers of children were spending less time in hospital and a much larger number were returning to their local school often whilst continuing their treatment. The 1992 annual report of the school had already noted these kinds of developments, commenting that there was a ‘noticeable trend of recurrent but shorter admissions’ for treatments such as chemotherapy’, whilst 20 per cent of teacher time in areas of the hospital (e.g. surgical units) was being spent on ‘re-integration programs and organising Visiting Teacher Services’ (Hospital School Annual

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5 Under the Education Act 1958 a ‘special school’ was defined as being a ‘night school, a school for special handicapped children, truant school, hospital school, institutional school, prison school and experimental school (Education Act 1958:1117).
Furthermore, as the Principal of the school also noted, ‘severe financial reductions and restraints’ within the Department of School Education at that time were considered likely to have a negative effect on building plans for a library and that this would likely lead to the ‘rationalization of resources and staffing at the school (ibid., 1992, p. 3).

When I interviewed one of the founding board members of Integrate she commented that the school at that time had been too ‘reactive’ to individual requests from parents for support and questioned whether the ‘one to one’ teaching model that was adopted was effective. She later added that often the ‘squeaky wheels’ gain the most support, rather than those children who were most in need (Interview July 2009).

The funding submission for the establishment of Integrate which was put forward to the Education Department identified two aspects to the service. The first, was to provide ‘direct’ educational services to children in the hospital and the second, to supply ‘indirect’ services to students returning to government schools after medical treatment in the hospital (Tender document, 1999). The submission compared the level of services Integrate would offer to those within the 1998 Department of Education ‘Framework for Student Support Services in Government Schools’ which promoted the development and provision of ‘preventative, early intervention and other primary health care products and functions’ involving children and families in the government school (ibid., p. 4). In the framework document additional funding had been identified by the government as supplementing existing services including guidance officers, educational psychologists, social workers and other agencies (Department of Education, 1998, p. 5).

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6 The Visiting Teacher service is a state government funded service. Service available to students whose ‘access to curriculum has been interrupted due to physical disability(e.g. cerebral palsy, spina bifida) health impairment(e.g cancer, cystic fibrosis) or wellbeing/mental health ( e.g. eating disorder, depression).
By 1999 Integrate had appointed 16 staff. The inaugural director of Integrate described the change from the hospital school to the new model, or from teacher to education support, as ‘an operational shift’ from the traditional role of teacher to a ‘support and liaison’ role between the school and the child (Integrate Report 1999-2002. NAME OF AUTHOR AND ORGANISATION REMOVED TO MAINTAIN ANONYMITY). The hospital did not contribute any funds to the operations of Integrate, but after a 6 month service agreement had been fulfilled Integrate was successful in gaining a three year contract with the state Education Department.

In 2001-2002 Integrate began to extend its strategic relationships within the education and health communities by establishing connections with the Catholic Education Office and with a leading centre in the area of adolescent health, as well as clinics and research centres in the hospital concerned with specific areas of child health (Notes from report covering 1999-2001). The annual review by the agency in 2001 reported that it had received over a thousand referrals seeking education support from a range of specialty areas in the hospital including Oncology (cancer), Haematology (blood disorders), Respiratory and Gastroenterology, Orthopaedics and Adolescent Medicine. The majority of these patients were admitted to the hospital for periods of one to three weeks with an increasing number referred from ‘outpatients’ (Integrate Annual Review, 2001, p. 11; 1999-2002 Change and Impact Summary Report, p. 4). By 2002 Integrate had moved into premises to a location nearby but outside the hospital. The Board of Directors indicated that they anticipated the physical move would strengthen the identity of Integrate (Integrate Annual Report, 2001-2002, p. 1).

There are a number of ways in which the differences between the new organisation and the old hospital school can be explored. The first of these concerns the conceptualisation of the child. The second concerns
identifying what constituted educational support. The Strategic Plan of the agency in 2002, for example, specifically referred to the United Nations Declaration of the Rights of the Child (1959). It also reinforced the importance of working in collaborative partnerships within the health and education sectors, providing ‘professional development’ for teachers and education providers, and offering direct and indirect support to children and young people. Information technology (IT) was viewed as having the potential to provide ‘virtual education’ and was identified as an important emerging element in education support work. The agency had made efforts to establish ‘on-line’ assisted learning initiatives and itself conducted research to find ways to link students to their school of origin over the internet. Laptop computers were also being provided to students at their bedside. In addition, Integrate had the use of the Adolescent Education Unit in the hospital which opened for two hours each day for students to complete homework or engage in other activities (Integrate Annual report, 2002, p. 8).

By 2007, 75 per cent of Integrate’s funding was provided by the Education Department and 25 per cent from a philanthropic donation to be used exclusively to provide education services to young people being treated for

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7 Principle 7: The child is entitled to receive education, which shall be free and compulsory, at least in the elementary stages. He shall be given an education which will promote his general culture, and enable him on a basis of equal opportunity, to develop his abilities, his individual judgement, and his sense of moral and social responsibility, and to become a useful member of society. The best interests of the child shall be the guiding principle of those responsible for his education and guidance; that responsibility lies in the first place with this parents. The child shall have full opportunity for play and recreation, which should be directed to the same purposes as education; society and the public authorities, shall endeavour to promote the enjoyment of this right (http://www.un.org/cyberschoolbus/humanrights/resources/child.asp)
cancer. Integrate had originally begun its operations as a single service. However, due to a philanthropic funding arrangement it was now required to operate two separate services. In 2007 Integrate had two teams with seven ESWs in the cancer specific service and six in the generalised service.

A 2006 review of the government funded service found that — despite Integrate identifying its main focus as the empowerment of schools to support students with chronic or long-term health conditions — it was continuing to respond primarily to individual students, their families as well as schools with ESWs often acting as ‘intermediaries’ and ‘advocates’ when problems arose. Not only was this recognised as unsustainable, but Integrate had not been able to meet the wider objective of improving the capacity of the education systems to respond to the needs of these students (Integrate Internal document, 2006). Therefore, while the notion of working with schools had seemed the most logical step it was apparent that this was not easily achievable. This was perhaps best summed up by ESWs which I quoted in my introduction, who acknowledged that they had little power to influence the decisions made by schools about whether to have a child back at school, irrespective of the legal requirements or what the parents or Integrate may suggest or ask.

By early 2008 the Operation Plan of the agency identified its service delivery goals as being developed in accordance with the National ‘Disability Standards for Education 2005’, the Commonwealth Disability Discrimination Act 1992 (DDA) and the principles of ‘inclusive practice’ in education. It also drew upon state and federal legislative reforms including the ‘Education and Training Reform Act 2006’ for quality education and the Equal Opportunity Act 1995. State education policy was also shaping the direction of the agency including the official launch of a proposal for reform within government funded schools in 2007 and a revising of the ‘Program for Students with Disabilities (PSD)’ which was administered by the
Education department Wellbeing branch. The key principles expressed in the 2008 Operation Plan of the agency released early are particularly pertinent for the present discussion. These are listed as:

- All students have the potential to learn.
- Students with disabilities and additional learning needs have the right to access services and participate on the same basis as other students.
- Delivery of an inclusive education system must be supported with a commitment to quality services provision at all levels of the system.
- A greater focus on early identification and appropriate interventions can significantly improve the life opportunities for all children in this cohort.
- Parents should be able to feel confident that their child is receiving the best possible education in state funded government schools (Integrate Operational Plan 2008, pp. 4-5).

The policy environment of the late 1990s, as well as a substantial restructuring of the Victorian government school system in 1992, saw the introduction of new accountability frameworks which sought new cost efficiencies in education spending. This not only resulted in the closure of schools and reductions in teacher numbers and support staff, but saw the devolution of authority and decision making to local schools (State Auditor General report, 1995). These were critical to the major shift in direction taken in this state’s education in terms of the provision of educational support for young people. As noted, the closure of the hospital school and the establishment of Integrate reflected a very different vision as to how ‘education’ could and should be provided and facilitated. This involved a rejection of the traditional model of school within a hospital setting, and the embrace of a more advocacy and liaison role. However, this model proved, to some extent, to be short lived. In the next section, I provide an overview
of some of the key changes which occurred within Integrate over the course of my research project, particularly during the years 2008-2009. What follows is an overview of many of the important aspects of these changes. Often these were raised in the interviews which I conducted and the issues raised are drawn upon more fully in subsequent chapters.

**A New Approach**

In late 2007 the Executive Director of Integrate announced her intention to retire at the end of that year and a new director was employed in early 2008. This meant that the 2008 Operation Framework was no longer applicable. For the next two years a number of changes were implemented under the direction of a new management team. Two of the key changes included ESW’s being required to re-apply for teacher registration and plans to present the hospital as a place of learning for children. In addition ESWs were to be permanently housed within the hospital rather than located in off-site offices. After a review of the referral processes a new strategy was adopted in 2009. Nurse Care Managers and other hospital staff, as well as parents or carers, were no longer able to make on-line requests to Integrate for education support. Instead, ESWs would identify which children to support after conducting an assessment of their educational needs, which included consideration of whether any risk factors for disengagement from schooling were apparent. The creation of a new role was also announced whereby a ‘regional liaison worker’ would seek to activate on-going support for a child once they left the hospital by making a referral to ‘external networks’ of student support services.

The focus of these changes was foreshadowed to some degree in a discussion paper written by three members of the Board of Integrate in 2007. It raised concerns around funding issues and the need to clarify the
direction of the organisation, as well as how Integrate could extend its profile. The paper also emphasised the importance of seeking out collaborative partnerships especially in the area of research. Interestingly, the Board specifically noted that whilst ‘very few children’ needed in-hospital support there had been ‘concerns’ expressed by the hospital that this service was no longer a priority (2007).

It was within this rapidly changing context that much of my research took place. In the next section I delve into the experiences of informants in the study which flesh out in more detail the general changes I have just briefly described. The experiences of the ESWs provide the entry point for understanding both the shifts that were taking place at an organisational level, and the effects of this in terms of the actualities of delivering education support in a hospital setting.

In concluding this brief summation about the establishment of Integrate, its initial focus and the changes being proposed during 2007, a number of important points are apparent. It is clear that the agency is positioned between its funding body, the Education department, and the hospital which has majority representation on its Board of Directors. Its goals reflect particular universal principles regarding access to education, as well as commonwealth and state legislation concerning the right to access ongoing education in government schools. However, providing a specific service in the hospital and seeking to provide on-going support once children left the hospital was not sustainable given the resources available to the agency. This became apparent when Integrate began to evaluate its services and question how to navigate the needs of children returning to schools whilst maintaining sufficient presence in the hospital to satisfy all its stakeholders.

It was through this period that I became increasingly aware that the experiences of ESWs were shaped and organised by a range of interests
beyond the immediate needs of the children and families they supported. My research began to focus on gaining an understanding of how the interplay of internal and external institutional interests contributed to particular ways of responding to educational needs.

**Education Support Work in a Hospital Setting: the Research Informants**

After obtaining approval from the University Human Research Ethics Committee, I conducted in-depth interviews with twelve women who were ESWs. I also interviewed one person in an administrative role, another who was an information technology support worker, three members of the board of directors, and four senior managers. The ESWs I selected were not chosen as representatives of all staff within Integrate but as knowledgeable informants who could tell me about their experiences in providing education support to children in the hospital, and about the history, funding, policies, management and operations of Integrate. I also had numerous conversations with other ESWs about their experiences supporting families and children and working with staff in the hospital. These were part of my fieldwork observations. In this inquiry, my point of entry was concerned with the everyday work of delivering support in the hospital and the steps taken to set up education support once a child left the hospital to return to school. Informants talked freely about the types of information, activities and troubles they encountered when supporting children and families, as well as the information they provided to schools. They spoke about the difficulties of closing cases after many years of contact with a child and family when children were discharged from the hospital. They also talked about the emotional impact of children dying.

Most of these women had children of their own, some with health or learning difficulties. Each of the ESWs and the senior managers had
trained as teachers, although most were no longer state registered teachers\(^8\) as this had not been a requirement for their employment with Integrate. After the appointment of a new director in 2008, all ESWs were required to renew their registration as required under the Education and Training Reform Act 2006. All had completed tertiary qualifications in education, some in special education, whilst others were qualified in specialities such as languages or music. Others had worked in a health related areas, such as rehabilitation or mental health, before being employed at Integrate.

ESWs described and showed me how they worked to negotiate outcomes with schools and medical staff in the hospital in order to obtain additional support for children returning to school. Each ESW had their own understandings about what contributed to a successful educational outcome for a child or what constituted evidence of a school acting inclusively. The conversations and interviews with informants were laced with references to procedures and policies for delivering education support as well as different categories of need and medical diagnoses. The daily tasks they undertook involved responding to referrals and assessing children in the hospital wards, fielding telephone inquiries from schools and families, providing documentation to schools about the educational needs of children, conducting information sessions at the hospital for schools, attending internal staff meetings and medical team meetings in the hospital, answering emails, providing computers and a range of other learning materials to children in the hospital. ESWs working in the cancer specific service also visited schools to make arrangements for students.

In the course of these interviews informants raised issues which were consistent with themes in the scholarly literature about the difficulties

\[^8\] Section 2.6.8(a)(i) of the *Education and Training Reform Act 2006* requires that in order to be registered as a teacher, a person must obtain registration or permission to teacher from the [Name of State] Institute of Teaching before they can be employed in any school.
confronting children with long term health conditions. These included the invisibility of some health conditions, poor educational outcomes, lack of cooperation between medical and teaching professionals and the reluctance of schools to enrol or accept students with health conditions (Ashton and Bailey 2004; Asprey and Nash, 2006; Dempsey and Conway, 2005; Keeffe-Martin, 2003; Shui, 2004, 2004a). Their motivation for working in this field was often expressed in terms of concerns about these children’s access to education and the sense that communication between these children and their school community provided ‘a sense of hope’ and ‘social connectivity’. There were, however, other aspects of the work which were also shared but often couched as ‘internal’ challenges, some of which have not been raised within the literature. These issues included the differential funding of the cancer specific service and the government funded non-specific service, and the fear expressed by some schools about dealing with children with ongoing and sometimes serious health conditions and the difficulties that resulted from this for both children and their families, and for ESWs themselves.

My fieldwork and interviews began in early 2008 when ESWs were still responding to referrals from the hospital when a request for educational support was lodged. Referrals could be made at this time by ESWs themselves, doctors, nurse care managers, the rehabilitation service, parents, and multidisciplinary teams. These were received by email, phone and in person. ESWs followed-up once they were allocated a case by their manager and this entailed them talking with the child, the family and possibly the child’s school. The process involved deciding what type of issues the child was having, how much support the child needed, the type of support, identifying what work a school would need to provide in the hospital and what might be needed when the child returned to school. The other aspects of their work were concerned with seeking support for and improving the
profile of Integrate within the hospital, as well as in schools and in the broader health and education sectors. One might call this ‘networking’ in order to access additional resourcing and funds. At that time Integrate was part of The Office for Government School Education which managed, coordinated and implemented government school education in the form of services and support across the state and assisted in the implementation of government education policies. This included ‘developing innovative strategies to assist the learning process’ (Fieldnotes 2008).

**Working at Making Educational Engagement Visible**

In addition to the everyday work of providing individual tutoring and advice to children, families and schools, ESWs also performed work which was particular to presenting Integrate as an exemplar for supporting educational engagement in this setting. The retired Director had drawn upon inclusive discourses to promote school inclusion and had sought to develop a distinct identity for Integrate which was separate from the hospital. However, this was difficult, not only because they were employees of the hospital but Integrate was also facing cost pressures while funding had remained static. Despite efforts to operate a generalist service, in 2005 Integrate became the recipient of a large philanthropic donation from an organisation funding cancer research. This differentiation between medical conditions and providing ‘specific’ services in the hospital effectively split ESWs into two teams. This arrangement remained in place until 2010 when the philanthropic funding ceased and Integrate reverted to one service.

In 2008 under direction from a new management team all ESWs were reminded about the importance of improving the profile and awareness about Integrate within the hospital, as well as the broader network of education support services in government, catholic and independent schools.
and in the philanthropic sector. One of the most obvious ways to achieve this was for ESWs to utilise spaces within the hospital. Another was the use of photographs showing ESWs working with children, engaging them in learning activities and using resources such as laptop computers.

The contrast between the two different approaches to providing support to children in two different time periods to continue their education can be reflected in a number of ways. One of these included the increasing use of photographic images (see figures 2 and 3) in presentations and publicity. In the past children in the hospital had not been a major feature within the publications produced by Integrate. The following images illustrate some of the ways in which the work processes of ESWs increasingly included visual documentation and representation of successful education engagement.

Figure 2
Figure 3
Integrate had begun to utilise photographic images in its documents, echoing the format and design of those produced by the Education Department and which were similar to those produced in hospital publications. They were brightly coloured, cheery and glossy pictures, usually of children, families and professionals beaming at the camera, deeply involved in an activity and obviously enjoying whatever activity they were undertaking. Whilst this is perhaps not surprising, the images did, however, reinforce a particular view of educational engagement and reinforce the positivity of participating in education as a means to overcome the rigours of hospitalisation, illness and trauma.

However, there were occasions when the use of these images were at odds with the realities of children living with health conditions and what it was like being in the hospital or going back to school. I witnessed the considerable and taken-for-granted power of such images at an event organised by Integrate during the time when its new leadership team was
implementing significant changes. These changes included seeking the cooperation of education support networks within the government and independent school sectors in order to follow up the educational needs of children once they returned to school. The event brought together bureaucrats from the Education Department, Student Wellbeing staff from schools, Visiting Teachers, and a range of professionals from Education Department Regional Student Support Services. The purpose of the event was the announcement of a new ‘referral system’ with participants at the forum asked to provide feedback on key elements of the process. The data generated by the system was designed to update Education Department regional managers and those in the Independent and Catholic sectors with monthly reports on the numbers and types of children who had been serviced by Integrate and importantly, indicate which students required follow-up support.

A key element in this process was the identification of ‘educationally at risk’ students which would be managed by a newly created ‘regional liaison teacher’ who would coordinate communication between the different services and schools, as well as the medical and ancillary professionals and the family/carer and student. Integrate was hopeful that such a process would not only eliminate the need for ESWs to have ‘cases’, but importantly, reduce the numbers of children who were overlooked within the current networks of support. In this way Integrate could rationalise which children it supported in the hospital and refer children to external services.

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9 At the time I conducted this research the state Education Department had nine regions which were overseen by The Office for Government School Education. It is responsible for the management, coordination and implementation of government school education across the state. The nine school regions support schools to improve and respond to the government’s education policies. The Department website lists the responsibilities of the regional offices in the following way: evaluating key educational initiatives; developing the capacity of schools and school leadership; promoting increased community involvement and commitment to improving student outcomes; leading or participating in innovative programs to achieve government goals for school improvement and student outcomes.
support services when appropriate. The initiative was described by the Executive Director of Integrate as a ‘significant and rare’ meeting of a broad cross section of representatives from the government, independent and Catholic education sectors.

During the day’s proceedings two case studies were presented to participants in order for them to workshop the possible solutions for each of the children to continue their schooling. One of the children was an ‘outpatient’ who visited the hospital regularly for treatment but no longer needed to stay in the hospital. The other child was still an ‘in-patient’ on a ward in the hospital. The facilitator of the workshop emphasised that the girl had the capacity to read before her cancer was diagnosed and treated. She was described as having ‘complex health and educational needs’. The supportiveness of her family was also stressed and their desire for her to attend a locally based mainstream school as she was ‘cognitively unimpaired’ by her condition. The photograph on the page below (Figure 5) accompanied the power point slide which described her health condition. [Note: Figure 6 is a colour photograph of the same girl in Figure 5. I found the photograph by chance in a hospital publication produced in 2008. The girl is not identified. By contrast, in other photographs appearing in hospital publications, patients, families and staff are usually named].

Figure 5 and Figure 6
The girl is happily smiling at the camera, lying on her tummy with her arms supporting her, and her blonde hair falling over her shoulders. There are no discernible signs of a health problem and the picture was very engaging and pretty. Yet, when reading the description of her health condition it was not at all consistent with the picture. She had been diagnosed with a brain stem tumour when she was 6 years old and the surgery had left her with a number of significant physical impairments. Not only could she no longer speak but her legs and arms were paralysed, she required a nasogastric tube for nourishment and was unable to swallow. She also had a tracheostomy tube to enable her to breathe and relied upon a ventilator when she slept and at various times during the day. Her medical care was managed by two teams and her family were described as ‘complex’ although no details were provided as to what this meant. The plan for her education included her commencing primary school in 2010, although she had not been able to attend a full year of kindergarten – her preparatory year for the first year of schooling.

Once the details about the girl had been provided to the participants they were then asked by the facilitator to collaborate in small groups and brainstorm the kinds of resources the girl would require and then report their suggestions back to the entire group. At the table where I was seated participants began listing the types of resources the girl would need in order to begin her schooling. They acknowledged firstly, that the girl would be eligible for the Program for Students with Disabilities (PSD)\(^\text{10}\) and she would need communication devices, wheelchair ramps, arrangements for

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\(^{10}\) The PSD program utilises seven key categories of disability to determine the level of resources allocated to support students. These include Intellectual disability, Autism Spectrum, Physical disability, Severe Behavioural Disorder, Hearing impairment, Visual Impairment, Severe Language Impairment with critical education need. The key indicators determining the allocation of additional resources includes ‘mobility, fine motor skills, cognitive skills, self-care, behaviour and expressive and receptive language’ (Auditor General Report 2007; PSD Handbook 2009). Health impairments are within the category of Physical disability.
toileting and additional classroom support. I asked about transport to and from school and it was agreed this would be important too. During these discussions there was a noticeable absence of discussion about any difficulties in obtaining particular equipment or funding or that the family might encounter difficulties in gaining access for their daughter to attend a mainstream school given her health issues and medical needs. Furthermore, it was suggested that the capacity of the child to ‘read’ would markedly change the expectations of classroom teachers about the types of support she would need at school. The ESW at our table knew the child and the family and she reinforced a number of times that the child was ‘very, very bright and could read’ and participants agreed this would be a significant ‘asset’ in her beginning school. The emphasis on the ‘brightness’ of the child and the ‘capacity’ of the family were presented as counters to the considerable physical health issues facing the girl. At no stage were any questions raised about the school where her family intended to enrol her and the consensus of the participants was that it would be entirely possible for her to begin her schooling in a mainstream school. At the end of the workshop participants were congratulated by the facilitator for their knowledge of the appropriate resources which would enable her to successfully attend a mainstream school.

It seemed obvious that the child met the requirements within the criteria for the PSD and her entitlement was acknowledged. Yet, something was unsettling and the workshop session had left me with a feeling of unease. It seemed to me that the medical condition of the girl had slipped from view and was framed only by the reference to the eligibility criteria within the government funded program, and the kinds of support she would require. Her considerable health issues were not discussed, instead particular aids such as a wheelchair or communication board became the focus. She had a ‘tracheostomy and a nasogastric tube, and couldn’t speak or swallow, and
she was reliant upon a ventilator throughout the day. Reflecting on the events of the day I later realised that no-one at the forum, including myself, asked about the photograph of the girl (Figure 5). There was a glaring difference between the photo and the written description. This omission seemed strange the more I thought about it. It was also more concerning because I had interviewed an ESW who described the difficult situation for a boy with a tracheostomy who was seeking to return to his school. However, the school had made the decision ‘not to take him’ despite extensive consultation between the school and his family. The ESW explained:

She had accompanied the Rehabilitation Team from the hospital to the school with a 12 year old boy and it was the first time she had been back since he had become ill. He had been in hospital for 6 months and still had a tracheostomy tube. Now the school has decided not to take him as it is too complicated. His mother and grandmother are in a custody case. She also was handing the case over to another worker as she was leaving (Interview notes ESW 2009).

The role of photographic images and their connections with the actualities of living with a long term health conditions had also arisen on other occasions, for instance, when Integrate hosted activities timed to occur during the week in which International Children’s Day took place. The hope was that this type of week-long education based occasion would become a yearly event. The organising committee had booked guests who would run activities, workshops and demonstrations for the children. They included authors, magicians, dancers, and jewellery makers as well as groups from the community such as the Metropolitan Fire Brigade who would visit children on the various wards. ESW’s had mixed feelings about the event largely because staff numbers were low at that time and the number of referrals they were dealing with was quite high. The hospital had an official
photographer but increasingly ESWs were being encouraged to take their own photographs. Organising photographs provided an important opportunity to build an archive of images for Integrate to use on its website and in various forms of publicity and documents. Once a photo was taken an ESW would then need to gain the consent of parents/carers of the child before it could be used in the future. When I was observing one ESW who was accompanying a magician who was performing for children she asked a parent and child during the routine for permission to take a photograph and then asked them to sign the appropriate paperwork. However, in the moments when the ESW was asking the child and parent to pose for the picture the child lost interest in the entertainment.

This was one of the many disconcerting moments during my fieldwork. It seemed apparent that the process and reasons for taking the photograph overtook the purpose of the entertainment and diversion from the everyday realities of being ill and in hospital. On another occasion an ESW had expressed frustration about the hospital public relations people calling ESWs asking for children to appear in photographs. She spoke of a public relations person from a cancer charity asking for ‘a child with cancer’ who could be photographed accepting a donation. But, they often wanted a particular kind of child for instance, from an ethnic group or a child who was attractive. She understood the necessity of fundraising but saw these types of requests as invasive and insensitive to what children and families were going through. It entailed the ESW having to approach families often at very difficult times to ask for their cooperation in participating in these activities. While she accepted, she says she would have liked to have refuse, saying instead:

No we don’t. Why don’t you come over and spend a day with the kids instead of ringing for a made to
order attractive child with a hopefully young, attractive mother for the photo shoot (Interview ESW3 January 8, 2008).

Yet it was recognised that this was part of the work. Integrate needed to work with philanthropic organisations as they provided potential opportunities for additional funding and resources. Importantly, it complied with requests from the hospital too, which had a high public profile and of course it was where the children were located.

Just as the photograph used in the workshop had been incongruous, so too did these requests for a particular child to appear in a photograph for the cancer charity. Both instances failed to take account of the actualities of children with cancer and their families, whilst the photo of the girl rendered her reality and identity completely invisible.

The final account I offer is one which occurred when the Minister for Education visited the hospital to present a significant donation to Integrate. Interestingly, as it turned out, it was the hospital CEO who accepted the new resources. On this occasion concerns had been expressed by the Minister’s office that very few children or families had taken up the offer to attend the event. In conversation with a colleague on the morning of the visit there had been some alarm the previous evening, when it was suggested that the Minister might send a replacement to make the presentation if more children could not be found. The question of numbers of children was strange given that it was a children’s hospital. Yet the unwillingness of children to be part of such event was perhaps not so strange.

My observations involved two aspects of the Ministerial visit: the first concerned events which took place on the ‘ambulatory care’ ward where children receive medical treatment such as chemotherapy or dialysis over a number of hours or the whole day. When I arrived on the ward I could hear
loud screaming from one of the rooms, the reason being that a young child was undergoing a medical procedure. As it happens it was the same room where it was intended that a mathematics lesson between a child in the hospital and an external school would take place using the internet. The Minister would be there to observe the virtual classroom and the use of the new computers which would enable these kinds of activities. It was unclear how the demonstration could occur in such circumstances.

The other situation concerned a boy in his teens who was being prepared to attend another item on the Minister’s agenda, which was the presentation of the new Netbook computers in a newly outfitted ‘learning space’ in the hospital. The boy’s medical condition meant that he was unable to walk. However, the nurses were not able to find a wheelchair which could comfortably support his leg. They were concerned as the boy was in pain and the wheelchair was not suitable for his needs. Yet, at no stage did anyone – including the nurses, the ESW or the boy himself – suggest that the preparations should stop, although the ESW did comment that ‘people forget this is a hospital and these are sick kids’. I again wondered how the realities of living with a health condition became secondary to other institutionally driven imperatives from the hospital and the Education Department.

In order to understand how textual representations, including photographic images, come to feature in the work of ESWs, one needs to consider what type of educational engagement they depict, including those which encourage self-advocacy by children and families when they did not meet departmental criteria for risk or disability. This excerpt from an Education Department publication featured an article about the work of Integrate emphasises the personal qualities of the child and the normalising effects of education in a hospital environment. The magazine is published monthly by the Communications Division for the Department of Education. The
images (Figures 7, 8, 9 and 10) within the magazine are very positive and show innumerable photographs of children and adults smiling. The images below provide a sample of these.

The theme for that particular issue was ‘Gifted Education: Special Education’. It included an article about the work of Integrate. The headline read: ‘Brave teen a true inspiration: With a bit of help, even the most unwell children can achieve their dreams’. The article read:
[The boy] is a truly amazing young man who is determined to achieve academically and always makes school a priority, even while he is undergoing chemotherapy and radiation treatment,” Ms Donaldson said. “His positive attitude towards life is an inspiration to us all”....“For our school-aged patients, keeping life as normal as possible and helping them catch up on school work and connect with their friends is very important. It’s encouraging to see principals and teachers supporting students with complex medical needs and giving them every opportunity to reach their full potential (2009, p. 43).

Did such pictorial representations act to reassure schools and the broader community, leaving the uncertainties and diversity of children’s experiences when they are ill or recovering from trauma, isolated and largely hidden from view?

Figure 11

Is this a manifestation of the disjuncture between policies or processes which aim to be inclusive but are in fact are driven by a different set of institutional imperatives which emanate from the Education Department and the hospital. The Education Department seeks to ‘manage’ the needs of children within ‘normalised’ notions of child development and progression (pathways) within the mainstream school system. The hospital on the other hand seeks to reinforce its ‘child focused’ profile and its insatiable need for funds, with education becoming another facet of the services located within its walls. Families and children become the stories and images to attract community support and the receipt of more resources and donations.
Identifying the Research Problematic

The accounts and descriptions which I drew upon in the previous sections of the chapter were critical to me identifying the research problematic. They were significant because they were puzzling moments which drew my attention to gaps between the organisational responses of ESWs and their managers and the actual needs of children who were returning to schools or seeking to continue their education whilst in the hospital. Concentrating on the tension between what was known about the barriers to re-entering or maintaining connections with schooling and the development of standardised or institutional responses, became an important element in understanding how education support comes to be delivered and presented in particular ways. The research utilises accounts by participants – what they said – along with my observations to begin to interrogate what informed their decision making. I began to consider how the categorisation and codifying of particular educational needs or health conditions and what constituted actual educational engagement, was being shaped by discourses and interests beyond the workings of Integrate. This entailed considering the ways in which ‘normalised’ notions of educational engagement were being adopted and the manner in which technology was being presented to mitigate the isolation children experienced when they were not able to attend school.

Accepting the proposition that policy is made at all levels (Fulcher, 1989; Slee, 1993) I became curious about how an assessment of educational need, as means to achieving inclusion, is understood and interpreted on an everyday basis in this non-school setting. Furthermore, what does inclusion and diversity mean within education when working with children and young people who have a range of medical conditions which are not necessarily categorised as a ‘disability’, but may require special arrangements in order
for them to continue their education? What discursive steps contribute to the labelling of a child as educationally at risk or as a ‘school refuser’? What happens when they do not fit such criteria?

**Conclusion**

This chapter began with a brief overview of the establishment of Integrate in 1999 and the types of issues and changes which reshaped and shifted the focus of its work over a short period of time. In many ways its beginnings drew upon a more integrationist approach to education by seeking to encourage and support the inclusion in schools of children who had ongoing health conditions. However, in order to achieve this it was relying upon other parts of the education support system to respond. However, as the chapter shows Integrate was not able to respond to competing demands for its services from the hospital, families and schools. The lack of power experienced by the agency and ESWs in many ways mirrored that of children and families who also rely on schools and government regional support services. Drawing on fieldwork conducted in that setting it identifies early clues that emerged about the way the actions of ESWs dovetail into apparatuses within the hospital and the Education Department. Importantly, these reinforce particular images and normalised views of educational engagement. The chapter identifies the research problematic by demonstrating how ruptures occur between the way education support is delivered and the actualities of children who are seeking to continue their education. Institutional processes transform individual experiences into textual forms which serve a variety of purposes. As such, photographs, case notes and patient notes which document educational activities and educational needs are objectified using codes which translate across sites of institutional activity. In the next chapter I will delve more deeply into the
processes within education support work and the interconnections between the hospital and Education department shaping this work.
Chapter Four: The Everyday Experience of Normalising Education and Identifying ‘Risk’ Within in the Hospital

This chapter describes the way Integrate began to change its model of service delivery. The most significant aspects of these changes were the creation of a new system to identify and refer children to external support systems once they left the hospital and attempts to improve the profile of the agency in the hospital (‘Internal’ Board Discussion Paper 2007). These changes were being implemented at the same time that the Education Department had commissioned a review of Integrate, which had been triggered by the Executive Director seeking an increase in funding for the agency. The education consultant conducting the review addressed a staff meeting where he strongly suggested that they needed to clearly identify ‘who’ they were supporting and clarify ‘what’ they were doing. Notably, these needed to reflect the current education policies of ‘all kids achieving and succeeding’.

The release of a new Business Plan by Integrate in 2008 provided insights into the changing role of the agency and strategies to improve its visibility and position – relative to other external support systems – and how these goals could be addressed operationally. Interestingly, it demonstrates how the organisational priorities of the hospital and strategic activities related to education are united in one document to create a template for the work of Integrate. When interviewing a senior manager at Integrate they described the role of the Plan in the following way:

The business plan and the individual departments in each division [of the hospital] were asked, we didn’t need to, but I was going to do it anyway ... so there is a line of sight from this [the Business Plan] back to Clinical Support Services, back to the hospital strategic plan. Equally, I would hope that anything
we do, and it’s not quite of line of sight, the other sort of policy context I believe we should operate within and this the Education Department’s Blueprint for Education and Early Childhood Development. They are our funders after all and I’ve got a great commitment to it ... Not only that we’ll leverage off it, it will work for us in the end. So they are the two strategies that inform how we’ve got to this (Interview senior manager March 2009).

These are curious developments given that the original reasons provided for establishing Integrate were related to the increasing numbers of children with health conditions returning to school and the relatively low numbers remaining in hospital for extended periods of time. Whilst ESWs no doubt provided valuable services and support to children and families, they were also subject to a dominant set of social relations concerned with educational engagement and inclusion which shaped the establishment of the new approach being implemented by Integrate. In focusing on the criteria for determining ‘who’ to support, it appeared that those who did not meet specific criteria were excluded. Further issues that arose included whether some children had an unfair advantage and questions about what counted as evidence of authentic teaching and learning experiences. When combined with key texts which were used to inform decision making around the support of children in schools, one can begin to see how inclusion was on some occasions selectively applied. Importantly, the document provides an entree into understanding how institutional accounts of normalised educational engagement in the hospital and the discourse of ‘at risk’ for those returning to school compartmentalise and camouflage the actualities of children living with long term health issues.
Assessing the Risks for Disengagement

The Education department was reviewing all aspects of Integrate’s work and is effectiveness in meeting key aspects of education policy at that time. The consultant conducting the review stressed the following points in a staff briefing, suggesting that the agency needed to reflect on whether it had the capacity to:

Enable children to regain time lost from learning ... overcome illness but also keep the learning happening ... [given] the incredible diversity of age, individuals, family. Support therefore has to individualise the learning. What the department is looking at is ‘are you correctly resourced to do that? Everything i.e. [means] the teacher. Not enough teachers at Integrate. A formula [funding] will look at child numbers and nature of child as learner then needs for learning. Anything that impedes: poverty, illness, adverse environment, a child with mental illness. [They’re] not in a group but to deliver services you have to include them [children with mental illness] ... Patterns of kids identified to show resources needed immediately. Match support to the nature of needs and aspirations of children (Notes from staff briefing June 2009).

The consultant then talked specifically about Integrate being ‘unique’ in the world and different to the most common approach which is a ‘hospital school’ model. He encouraged them to use their ‘intuition’ and identify what is ‘best practice’, but also warned them that what they choose to do will not necessarily be agreeable to everyone.

Defining the Educationally at Risk Child

The regional seminar which had announced plans by Integrate to seek more involvement and support from external student support systems also sought to have ESWs prudently apply the concept of ‘at risk’ to children within the
hospital. This delineation in needs was especially being emphasised by managers, as some ESWs had expressed the view that ‘all their kids were at risk at some stage’ (Fieldnotes, 2008). Clarifying the notion of risk entailed staff utilising a consistent definition in their work, but importantly one which would enable referrals to be taken up by ‘outside’ agencies within the education system (Fieldnotes, Staff meeting 2009).

The staff were increasingly being reminded about their role in establishing ‘evidence’ of the existence and needs of a specific ‘cohort’ of children. It was stated by managers at staff meetings:

Be mindful of which families you support, that builds a picture and story of the work (Minutes September staff meeting, 2009).

The establishment of a ‘conceptual framework’ to illustrate what factors contributed to educational risks had two dimensions – factors impacting on children in the hospital and those factors which broadly impacted on a child’s wellbeing and health beyond the hospital. The hospital factors included for example: whether the child identified as a ‘learner’, whether they possessed ‘a culture and knowledge of education’ and if the family had the ‘capacity’ to communicate with the child’s school. Beyond the hospital, those factors which impacted on a child’s well-being and health included for example: social conditions, strong family and social relationships, and access to ‘high quality education’. Figure 12 (p. 85) which was shown at the regional seminar, shows the continuum of risk identified by Integrate at that time and shows a full range of factors inside and outside the hospital.
Towards a conceptual framework for children and young people educationally at risk

Factors impacting on children & young people at The Royal Children's Hospital

Pre-admission
- School & community disadvantage (e.g. SFO, AED)
- Knowledge of education support & learning culture on admission
- Family capacity for school-family communication

Communication with health team (e.g. risk assessment)
- Child's identity as a learner (e.g. strengths & interests, learning plans, school reports)
- Length & frequency of admission
- Health status during admission

School-family communication on discharge

Post-discharge
- Information to family on discharge
- Liaison with education infrastructure for children at risk

School-aged children & young people at RCH

Risk & protective factors determine everyday health, growth & development

Social conditions shape children's life chances (Graham 2002)

Strong family & social relationships benefit children's health & reduce school dropout rates (AIHW 2009)

Factors affecting children's health, development & wellbeing at a population level

High quality education system from birth to adulthood (DEECD 2008)
The application of the conceptual framework of ‘at risk’ began to shape and re-organise the work of ESWs in particular ways, informing how they assessed the capacity of children and families to communicate with schools.

In 2008 an information pack was developed for distribution to families or carers with a child in the hospital. The pack included the following items: an introductory letter addressed to a Parent or Carer, a letter which was addressed to the child’s school principal and an information sheet about Chronic Illness and various types of useful resources and Education department and contacts.

The introductory letter stressed the importance of keeping young people engaged in learning and in contact with other students. It reinforced the ‘positive impact’ on health of continuing schooling and learning. The letter encouraged parents or carers to consider ‘the importance of education as part of the journey towards better health’. The remainder of the letter suggested ‘early contact’ with their child’s school principal is important for managing a child’s ‘health condition’ but acknowledged the sensitivities around sharing private information. They were encouraged to work with schools to develop a ‘plan’ for supporting their child and access a laptop from home or school for their child to use whilst they are in hospital.

The second letter for the school principal had blank spaces for the child’s name and health condition to be added, along with the signature of the parent or carer. It reinforced the importance of the school in providing strategies to improve the ‘journey to better health’ and indicated that the school would be contacted by the parent or carer to discuss ‘strategies’ for maintaining open communication, enabling ongoing connections with peers, teachers and curriculum, accessing a laptop computer, and lastly, accessing support, resources or funding (quotes from the Information Pack).
The new packs had been developed as part of a strategy to persuade parents and carers to directly contact schools about their child’s educational needs, rather than solely rely on ESWs. I spent a number of occasions on wards with ESWs as they visited children and families and provide them with the new information packs.

However, the way ESWs assessed the risks of educational disengagement for children within the hospital was not always straightforward. Talking to parents in the hospital brought to the fore the difficulties in reconciling institutional imperatives about directing children and families to outside support systems once they left the hospital, and strategies to rationalise with actual support work done by ESWs in the hospital.

**The Role of ESWs in Assessing Educational Risk**

On one particular day as I joined an ESW she explained the ‘tentative and delicate process’ involved in raising questions about education with families. It was apparent that the ESW had to ‘weigh up’ whether a family would be receptive or not. Three families were approached on this morning and each one was at a different stage in terms of their child’s diagnosis, treatment and recovery. The first boy had been in a traumatic accident and was still heavily sedated. The ESW introduced herself to the boy’s mother and gave her a pack but left relatively quickly as his condition was still very serious. Another child was recovering from recent hand surgery and on speaking with the girl and her mother, the ESW was reassured that the school was assisting by providing school work and the family were well equipped to support their daughter. The third child was recovering from a horse riding accident and had been in hospital for over a week. However, the interaction between the ESW, the child and the family was less straightforward.
The ESW suggested to the girl that school work could be provided by Integrate or by a teacher volunteer from the hospital. She emphasised that:

You don’t have to work or it can just stop you feeling bored (Fieldnotes July 2009).

After asking the child’s mother for the name of their daughter’s school and her year level she explained that they can assist with work either obtained from the school or the ESW could create some specific work for her. She asked the girl about her reading. Her mother answered saying that her daughter was ‘fine’, adding ‘she likes books’. It was at this point that the girl’s mother said that she was ‘dyslexic and had trouble reading’. The ESW did not offer any comment when the mother said this, but instead asked if the family is in contact with the school because the girl will miss the rest of the school term.

The ESW says she will ‘keep her [the girl] in mind’ and then asks the girl’s brother to ‘take a note to the teacher and bring home materials for his sister’. Apparently they are twins. An information pack is then given to the mother. The ESW asks the girl if ‘she has heard from her school friends?’ The mother replies that ‘she hasn’t’. The ESW suggests to the mother that she ‘ask the girl’s teacher to organise cards and letters from other students in her class’. Her mother replies that she would be ‘too embarrassed to ask’. The ESW responds by saying that she needs to ‘update the teacher’ and points to the letter for the school principal in the information pack. The ESW decides at this point that organising a laptop computer is not necessary. But once again she reinforces the importance of contacting the school and once more encourages the girl’s mother to call school saying, ‘don’t be embarrassed’. But the mother repeats ‘it’s too embarrassing, especially asking for cards and letters’. The ESW suggests again the parent call the school saying:
It’s what you are comfortable with.

Afterwards I asked the ESW about the information pack and whether it was significant that the mother had identified she was dyslexic and why the girl’s father had not been brought into the conversation. She replied:

They have two other children at the same school ... She has two kids, one a twin at the school. She has to ask for her daughter. Not my job now. I could have offered but she should do that.

We then talked further about how difficult it is to decide when to talk to families. She admitted it is ‘not easy’ especially when they have little information to go by other than a name and a medical diagnosis. The conversation ended with her saying:

I have to be sensitive to individual families to judge what is appropriate and also when to leave an information pack.

On other occasions ESWs also described difficulties in making assessments about a child’s educational needs and what counted when identifying a child ‘at risk’. For instance, an ESW was informed by one of the medical staff that they had ‘deep concerns’ about the mental health of a child’s mother. The doctor had already called the child’s school to discuss these concerns. Apparently, one of the issues contributing to this worry was that the child needed glasses but the mother had not organised an eye appointment. It was suggested to the ESW that the mother was ‘not able or unwilling’ to do this. However, the severity of the illness was not apparent to the ESW when she had met with the mother. The ESW ‘upgraded’ the risk assessment of the child based on the new information provided by the doctor about the mother and the level of uncertainty about her ability to support her child adequately (Fieldnotes, August 2009). However, she did not have a conversation with the mother about the change.
These decisions seemed to be even more contentious and complicated when children had a disability. On another occasion the same ESW had made a decision not to highly prioritise the educational needs of a girl with cerebral palsy. She made this decision because she had at least nine other children to support and many of those children were described as ‘falling behind academically’. She expressed some guilt as she knew the girl was entitled to the same level of support as other children, but wasn’t sure about how to engage with the girl as she was ‘not a special ed trained’ teacher. The ‘at risk’ category in this instance was unclear for her – should she ‘teach or consult?’ (Fieldnotes, August 2009).

Other ESWs gave examples of the difficulties when medical conditions became life threatening or were life-long or talked about the ‘risky times’ for children who were making ‘transitions’ during their education, or transitions across different schools or even hospitals. But these situations were also complicated by the ways in which their illness fluctuated over time, shifting from moments of wellness to illness and back again (Staff briefing notes May 2009). The question of ‘what counted’ was becoming obviously an important one in the framing of ‘risk and need’.

The accounts of ESWs about assessing educational risk factors provides important insights into understanding how organisational pressures in the form of new processes shape professional practices in particular ways. Inevitably, standardised definitions and categories which rank educational needs will never cover all the complexities which children and families experience when a health condition is present. Indeed, Corman’s (2008) research demonstrated that professionals were often conflicted and expressed frustration about who misses out when they apply diagnostic criteria which then determines a child and family’s access to additional resources and funding. In such circumstances workers come to know their clients in bifurcated ways – one which is abbreviated into a textualised form...
and then in another way which is much more nuanced and emotive form with many shades of grey. Smith argues that we often ‘unconsciously’ ignore what we know from experience when it is subverted by practices which demand particular outcomes or solutions.

Thus, what comes to pass as knowledge about a particular group of people or a problem is often subordinated to a ‘solution’ where the right boxes can be ticked, and a remedy identified. This produces a technical outcome which is institutionally consistent with the implementation of processes or meeting performance indicators and other managerial criteria. It also is compatible with institutionally driven imperatives which depend upon standardised language and communication across diverse institutional sites. The Department of Human Services for instance, identifies ‘at risk’ as describing:

> Young people who are vulnerable to, and affected by a range of factors to impede their transition to a fulfilling adult life ... Risk can be conceptualised on a continuum from minimal to extreme, whereby an individual’s skills, supports and belief systems can all impact on likelihood and consequence of harm occurring (State Government Department of Human Services, 2003, pp. 11-12).

The document goes on to identify a number of key protective factors which foster resilience, including ‘strengthening family relationships, minimising stress through creating positive relationships and promoting school belonging’ (ibid.12).

The notion of ‘child at risk’ is used in many spheres, but its power as a concept for Integrate was in its ability to act as a red flag or trigger within the Education Department. It was also part of a strategy to initiate a range of actions or responses from parents to advocate for their child, as well gain a response from schools and external student support services in the
government, independent and Catholic school sectors. In that way ESWs could then be asked to focus more closely on the needs of children within the hospital. As one senior manager commented:

There’s a whole structure out there that hasn’t been utilised (Interview 2009).

Clearly, for Integrate the notion of establishing a category of risk for the children to whom it provided education support was linked to the social organisation of education support services in the Education Department and to a lesser extent systems within the hospital. This also had direct implications for the funding and resourcing of Integrate.

The processes, created to manage children who were identified as at risk, were also important in the design of a new database which could generate reports to the regional offices of the Education Department, the Catholic Education Office and Independent Schools. These reports had a dual purpose, not only did they refer children for ‘follow up’ but they provided a record of the total number of children who had been given education support by Integrate in the hospital. The importance of establishing a process around contacting external support systems had culminated in the regional seminar where the case study of the girl (described above in Chapter 3) had been presented. The case study had been used as a working example of how Integrate could encourage more communication between families, regional services and schools.

However, there was an obvious difference between how processes ‘should’ work when families sought to have their children enrol in school, as opposed to how they ‘actually’ worked. Issues were not so straight forward as evidenced in the accounts of ESWs. The identification of factors contributing to the risks for educational disengagement performed two significant roles in establishing Integrate within state apparatuses for
providing education support. One part of this was to distinguish a specific cohort of children with educational needs. The second dimension of the ‘at risk’ category was the ‘sieve’ it would create to enable Integrate to identify those children who were most in need. In this way ‘at risk’ helps to establish a body of evidence by which the funding for the agency can be justified and provides a way to manage and rationalise the referral system and the provision of support in the hospital.

The next step in the process was creating a method for referring children once they were assessed as ‘at risk’ of disengaging from education.

**A New Database**

The new database had been designed to establish criteria which would be used by teachers within the agency to refer young people for additional follow up by a regional liaison worker. ESWs had been asked to suggest the types of categories which could be incorporated into the database. ESWs input was part of a consultative approach by management but it is also fair to say that the categories which were ultimately included were also consistent with many of the dominant themes and key issues which were the focus of State Education Department programs and policies. For instance the ‘Effective Schools are Engaging Schools’ student engagement policies and guidelines (2009) used many of the same classifications. Categorisations such as ‘school attendance’, ‘mental health’, ‘behaviour’, ‘cognitive decline’ or ‘family complexity’ are codified concepts which are used to communicate across institutions. They also reduce complex problems into accounts which are institutionally manageable texts.

The new database recorded a range of information about children who had been assessed by ESWs. This included: why they had been hospitalised, why additional support had been requested, as well as details about the family.
Additional details were also recorded about the types of information, support and educational activities conducted by the ESWs in the hospital. What’s more, this information also formed part of an ‘evidence base’ to demonstrate the value of the agency to its funding body – the Education Department. It was intended that the database be updated on a weekly or even daily basis depending upon changes to the child’s health condition and other information which became available.

The database provided further information, including data on how many children were being supported in the hospital and the types of support being provided by ESWs. It focused on collecting key information, including the name of the school and location, their diagnosis, the year level of the student and the student’s personal details. The data entry form also identified ‘key issues’ which had sparked the referral for ‘additional education support’ once the child left the hospital. These included:

- Academic Progress
- Behaviour
- Complex health
- Family complexity
- Learning needs
- Mental health
- Transition
- School attendance
- School support
- Cognitive decline

Whilst ESWs were responding to a wide range of issues in the hospital it was these ten which featured in the majority of the referrals made to the
regions, Diocesan and independent schools. ‘Academic progress’ was the most commonly identified issue in the reports and it was often combined with ‘Behaviour’ and then less so with ‘School Attendance’ or ‘Transition’ issues. Interestingly, these categories overwhelmingly focused on the individual child with few referrals concerned with systemic issues in schools or identifying problems with accessing external support systems.

‘Health issues’ were rarely selected as an ‘issue’ on their own in the report, but the medical diagnosis of each child was provided often with just the initials of the condition and no further explanation. For instance, MS & CIDP (a nervous system disease) or Sclerosing Cholangitis (liver condition which affects bile production) were both cited, but it was not clear how they might contribute to an issue with school attendance or academic progress.

The majority of children listed in the monthly reports were identified as having ‘issues’, however, few were referred for regional support. In fact, in the period from October – December 2009 less than one third were referred. Interestingly, the report provided a list of all the students Integrate had been ‘associated’ with the hospital. It was not clear to me what ‘associated’ meant but it suggested that in the process of making assessments which would form the basis for a referral to the regions, ESWs were clearly making distinctions in their assessments and how they supported the children in the hospital, and those they deemed ‘at risk’.

The database information formed one part of a suite of strategies and types of information which was being collected and provided to the Student Wellbeing and Support Division in the Education Department. When in conversation with a senior manager, he identified critical information which needed to be documented to secure the ‘on-going funding’ of the agency. The information needed to demonstrate three things in particular: ‘the work of Integrate’, ‘the worth or value of the agency’ and to ‘show why the
funding needed to continue’. Furthermore, recording ‘what actually worked and how’ was also considered critical information.

This was made very clear by a senior manager in a staff meeting in 2009 when she observed that the types of comments being entered into the database were ‘not sufficiently comprehensive’ or directly addressed the ‘conditions for Education department funding’. It seemed that the terms of the funding agreement was based on two things – the ‘numbers of children’ and ‘key teaching and learning tasks’ that were consistent with and appropriate to the ‘developmental stages of children’. She emphasised the point that:

If there is no evidence then there will be none or reduced funding. The evidence for funding is now an explicit part of the contract with the [Education] Department (Fieldnotes October staff meeting, 2009).

The Changing Roles of Education Support Workers

Identifying ‘at risk’ was neither easy nor always recognisable to ESWs when interacting with children and parents. Another of the terms used by ESWs was ‘complex cases’, although what distinguished them from ‘at risk’ or whether it was contributing factor was somewhat unclear. A manager explained in relation to a ‘complex case’ that:

It is still to be defined ... the criteria were unclear although literacy and numeracy, parental involvement are key areas. The role of the social work department is key to providing more information and the school they [the child] attends, early learners and post compulsory groups, types of medical conditions are important and SES (socioeconomic status). All this sort of information will then be given to the Student Support Services in
the regions so they can notify the schools (Interview 2009).

When discussing the question of identifying what ‘at risk children and families looked like’ his comments focused on different kinds of medical treatment and health conditions as being important indicators:

We probably all know, even you, but we still need to demonstrate this ... for example the child who is in for a bone transplant for six months is at risk of disengaging from school or kids with eating disorders and mental health issues are often disconnected from families (ibid. 2009).

Another senior staff member indicated that ‘at risk’ was being informed by ‘assessment tools’ such as the HEADSS which was used by the Adolescent Team in the hospital. HEADSS is used to perform ‘risk assessments’ and ‘screening for risk issues’ and is an acronym for the key areas to focus upon when interviewing young people. They include: Home-information about their living situation, Education, what Activities they engage in, whether they use Drugs of any kind, questions about their Sexuality and risk for Suicide. Another senior staff member indicated that ‘at risk’ was being informed by ‘assessment tools’ such as the HEADSS which was used by the Adolescent Team in the hospital. HEADSS is used to perform ‘risk assessments’ and ‘screening for risk issues’ and is an acronym for the key areas to focus upon when interviewing young people. They include: Home-information about their living situation, Education, what Activities they engage in, whether they use Drugs of any kind, questions about their Sexuality and risk for Suicide.

It seemed that ESWs were including as much information as they could in the database to demonstrate how they determined a child was at risk, however, accommodating this amount of data was proving problematic. At

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11 The HEADSS adolescent psychosocial risk assessment has been recommended by The Royal Australasian College of Physicians for use in primary, secondary and tertiary care, and is commonly used in Australia. HEADSS helps health professionals to develop rapport with a young person, while systematically gathering information about their world, including family, peers, school and intimate matters. It helps to identify areas for intervention and prevention, and develops a picture of the young person’s strengths and protective factors. The HEADSS is a framework of a conversation. It provides a semi-structured format for conducting a comprehensive, bio-psychosocial assessment of a young person (http://www.rch.org.au/clinicalguide/guideline_index/Engaging_with_and_assessing_the_adolescent_patient/).
a staff meeting a manager noted that there still seemed to be confusion about who was being referred, that being between the ‘potentials and those actually at risk’. This created a lot of follow up work for the regional liaison worker as they would have to contact each of the parties to obtain further information about a child and/or family, including the region and doctors in the hospital. The amount of information could become extensive as often a child could be treated by multiple medical teams, especially if they had complex health needs. ESWs were being reminded to carefully choose what to include and which information they recorded, as well as what they selected under ‘education needs’ and the ‘reason for admission’ to the hospital. In this way ‘at risk’ was being defined by the parameters of the database. The database itself was shaped by the kinds of information which was required by the Education Department in order for Integrate to meet its funding requirements (Fieldnotes Staff meeting September 2009).

The 2008-09 Business Plan of the agency specifically identifies the Department of Human Services ‘Framework for Vulnerable Children 2007’ policy as informing the agency’s actions in ‘identifying children and young people at risk’. It sought to do this through utilising a number of points of reference. These were identified as:

- Collaborating with schools across education sectors to identify children and young people at risk
- Use the Australian Early Development Index (ADEI)
- Develop a risk assessment form

They were linked to strategies which would enable Integrate to introduce processes to assess the needs of the children with whom they worked, and importantly, manage the way ESWs interacted with children, families and
This shift in focus for the agency differentiated it from approaches it had taken in the recent past. It is fair to say that in many ways the previous management had been more focused on adopting an ‘advocacy’ role seeking to inform education department policies around the needs of children with health issues and at the same time developing specific programs which would inform schools. The new approach being implemented by senior management and supported by the Board became one of a ‘broker’ seeking to build relationships across the education sectors, as well as with the hospital. The identification of a ‘target’ population or establishing a clear cohort of ‘at risk’ students was a key strategy in justifying the funding and resourcing of the agency in the hospital by the Education department. At the same time the database enabled the generation of reports which acted as a reminder for these external systems about the existence of the agency. Integrate sought to identify a range of social and individual issues which placed a child at risk, but overwhelming the ‘issues’ identified in the reports to the regional support services emphasised the child’s behaviour. However, the experience of living with an ongoing health condition and being disengaged from school was codified under the guise of ‘at risk’. This administrative characterisation camouflages the complexity of such experiences, relegating them to issues of ‘school attendance or academic progress or behaviour’. In this way being at risk of educational disengagement comes to exist within an institutional category detached from the actualities of the child or family.
Baker (2002) observes that assessing risk has increasingly become part of ‘normal practice’ for teachers, special educators, psychological and medical experts, as well as parents. This invariably involves focusing on the behaviour or disability of a child and presenting them as a ‘problem to be solved’. The difficulty, however, is that whether the child is identified as a problem or not, often a solution is not forthcoming (Baker, 2002, p. 674). Furthermore, as DeVault (2008, p. 21) argues, there are undeniably complex issues associated with objectifying young people with additional learning needs. ‘Labelling’ is often not desirable but, as Corman’s (2008) research demonstrated, it is also often the only way any support can be accessed. This tension creates considerable pressure for professionals to produce evidence which meets eligibility criteria to obtain additional support for children and families.

When ESWs were conducting risk assessments they also knew, from their past experiences in dealing with regional student wellbeing services, that children identified as needing additional support may not be followed up once they returned to school. ESWs described the ‘mixed responses’ they received from the regional support services and the lack of clarity around questions of who takes responsibility for students not attending school. The account below describes such experiences:

I have had mixed experiences … if you were to say overall good rating, I would say no, um, I think the problem is the same with schools, regions can only bluff to a certain point and then really they have no jurisdiction, you know parents of kids in that situation in the first place it’s because their street smart because they know how to work the system, so really what can the region do, apart from you sending letters to tell them it’s their legal and moral responsibility blah, blah, blah. I don’t really know what they can do apart from that so I think regions realise that too. I met good people but I haven’t had
great responses a lot of the time ... Its taken a lot of follow up, a lot of pushing and a lot of hand holding whereas I expect when it goes to the regions it should be that they take your hand and they guide you. You know, so I have found that really interesting (ESW Interview 2009).

I sat with one ESW who was making phone calls to inform families that she would no longer be their key contact under the new processes for making referrals. She had been in contact with some of these families for many years. She remarked:

It is very difficult and upsetting ending close ties with families and not being sure who will look after them. I rang up a school for a kid who had had no contact from a school yet. He was about to start Year 10 and he had not seen his timetable or had been given any information. I still don’t understand how this all works (ESW Interview February 2009).

Another ESW suggested that ‘two out of three’ things needed to work together – the parent and child, or the parent and school or the school and child – if these relationships were not happening then the educational outcomes were often poor. Interestingly, the regions were not mentioned in the equation although they were clearly the key component if a problem emerged when families sought support from school and assistance was not forthcoming.

The extent and origins of some of these problems became clearer after reading a 2010 state Auditor General report which had investigated the effectiveness of Student Wellbeing Programs and Services. The report by the Auditor General was timely as these were the very systems which Integrate was seeking to rely upon to provide on-going support to children once they left the hospital. These were also the services which families were
being encouraged to directly contact. However, the Auditor found that there was:

No clear and current overarching policy framework for student wellbeing. Moreover, there is no single document that integrates all of the [Education Department] student wellbeing programs and services and shows how, for example, school nurses, student welfare coordinators and student support service officers align with other wellbeing staff in schools (State Auditor General report, 2010, pp. vii-viii).

In addition, the Audit report is critical of lack of data which had been collected within a report which detailed the wellbeing of state’s children conducted in 2008. The report identifies 35 outcomes of health, safety, learning, development and wellbeing, along with 150 indicators quantifying these outcomes. The Audit notes that if used in conjunction with the state data on outcomes for children and adolescents, the combined data showed that the influence of ‘family and community, and the supports and services in the wider society’ should be given consideration.

Nonetheless, the Audit is critical of the available data because of missing key elements and the absence of indicators related to physical health relevant to student wellbeing. It used an example of Type 2 Diabetes in children, a key indicator of physical health, yet data on this illness was not available. The Audit goes on to say that:

Schools have only a limited capacity to influence the physical health of their students ... Student wellbeing programs and services have the potential to have a positive impact on student lifestyles (ibid.p,16).

The difficulties highlighted by the Auditor General are concerning as the identification and support of children who are ‘at risk’ is often left with schools, although the Auditor indicates that Student Wellbeing Programs
and Services have the most ‘potential’ to have a positive impact on the ‘lifestyle’ of students. The lack of coordination between systems and services leaves agencies such as Integrate and schools in an invidious situation. They are compelled to identify students ‘at risk’ but the programs and services they are relying upon to respond are not coordinated. This leaves teachers, families, students and ESWs with a limited range of options and resources for addressing educational needs in schools.

A further issue in applying the concept of ‘at risk’ were the doubts which arose about those who did not fit such criteria but were still seeking ongoing support. These kinds of doubts were expressed in accounts by ESWs and managers who had misgivings and some suspicion about the motives of some children or families when they sought particular dispensations concerning undertaking school examinations. This was emphasised in an interview with a senior manager who was concerned that some children may be seeking an ‘unfair advantage’ by virtue of being in the hospital and therefore opting not to sit exams, when other students who do not have a health condition did not have such options (Interview 2009).

The other concern was in relation to ‘who’ EWS or hospital staff were selecting to work with and refer for further assistance.

In fact we probably spend the most amount of time chasing the least important one’s because once they come in [the referral from the hospital] you have to do something with them. You have to ring somebody or provide some information to somebody. So those [referrals] come in and we have to try and sift. As an ESW sitting in the referral seat I do try and sift out the ones that are not going to be assigned to an ESW (Interview ESW 2009).

The suggestion that an ‘unfair advantage’ is sought by some families and students was also characterised by the reference to the ‘squeaky wheels’.
Who is getting support? I suspect it’s the squeaky wheels not the kids that really need it ... The family that asks for support, [or] the ESW likes to work with, [they] get noticed and assisted. The too difficult are ignored (Interview 2009)

Jung (2000) argues the fixation upon capturing ‘true’ target populations contributes to over-emphasising individual deficits in assessment processes. This investment in the deficit side results in a focus on ‘substantiation’ and ‘verification’ in order to prove entitlement or deservedness (2000, pp. 110-11). As Jung asserts, the institutional imperative organises individuals in such a way that whilst the assessor does not intentionally act with suspicion or scepticism, they are often left with little option other than to take up the ruling relations in which they are situated. In this case, identifying an ‘at risk’ cohort became central to demonstrating to the Education Department the legitimacy of the funding it was already providing to Integrate and importantly, justify any further increases. The ramifications for those who are being assessed, and for those doing the assessments, meant that the experiences and intimate knowledge of what it actually meant to live with a long term illness and remain within the school system, is only rendered visible when presented in an institutional context.

The distinction being made between those who are ‘actually’ in need or at risk and others who do not meet the criteria encourages a focus on proof of entitlement with ESWs acting as ‘gatekeepers’ (Slee, 2006, p. 115). The role of gatekeeper is pivotal to understanding the way resource allocation is acted upon by those working within local settings. Professionals such as psychologists or teachers implement assessment processes, utilising categories including ‘at risk’ or applying diagnostic criteria (Corman, 2008) for particular disorders, at the same time they are also overseeing the access
of children and families to additional funding and resources. Slee and Allan (2001) offer the example where in:

The Australian states of Queensland and Western Australia, elaborate ascertainment schedules have been created, in which statements about the nature and severity of disability are used to calculate the resource provision for regular schools in which disabled students are seeking enrolment. Consequently, inclusive schooling is reduced to pitched battles for apparently scarce resources (Slee and Allan, 2001, p. 179).

The documented proof of being at risk of disengaging from education or having an ‘actual’ need becomes the official account which then passes for the ‘embodied experience’ of the child, in much the same way as the photographic images symbolise a successful medical outcome or a child being educationally engaged.

Earlier I referred to a workshop organised by Integrate which had been unsettling. The imperative to identify a technical solution for the girl with significant health issues relied upon a shared knowledge and understanding, albeit unstated, between participants about how to proceed. Hence, it was relatively easy to reel off the various services and programs which might be available to the girl and her family. Pivotal to this was a tacit agreement that the regional support systems had the solutions and would provide the support necessary for the child to begin primary school despite her considerable health needs. The ESW stating that the girl could read and her parents were supportive reinforced the notion that a successful outcome would be possible. In speaking afterwards with some of the participants who I had been seated with during the workshop, I inquired if the case study of the girl was unusual. Their reply was instructive because not only had they encountered worse cases, but often these children leave school
completely. Yet, they did not raise these issues within the workshop (Fieldnotes regional seminar 2009). The power of identifying a problem and offering a solution is deceptively simple and a standard way of proceeding. Acting in this way provides an insight into why nobody during the workshop questioned the photograph or the solutions which were presented. It also shows how the child became an object of a ‘text based’ process related to the funding of the agency. The solution is foregrounded rather than the actual needs of the child.

This dynamic creates a tension where what we know to be true from experience is displaced by the institutional imperative to identify a solution. Such bifurcation creates significant distress and personal conflict for people. These are often the moments when power and powerlessness is played out in everyday life. ESWs know that schools are often reluctant to enrol children with significant health issues and they also know that families can be under extended periods of financial and emotional pressures supporting their children, many who will live with a health issues for their entire lives. Yet, the systems upon which ESWs were increasingly being asked to rely on and the way in which the concept of ‘at risk’ was being applied, masks the complexities of remaining engaged in education whilst living with a long term health condition.

**Conclusion**

Clarifying the role and purpose of Integrate for its funding body – the Education Department – whilst seeking to develop processes which would link into external student support systems in government, diocesan and independent schools were key elements in a series of changes implemented by the management and Board of the agency.
The identification of ‘at risk’, the categories in the new database and the issues identified in the new regional referrals provide ‘evidence’ of what comes to be known as the actual reasons children with long term health conditions disengage from education. These are the verifiable and legitimised reasons which are consistent with an objectified professional conception of risk and need. ESWs are obliged to comply with processes which delineate between legitimate claims for assistance and the ‘squeaky wheels’ or those gaining an ‘unfair advantage’.

I take the view the very best advocates for the children are the parents. Parents need information, support, skills and confidence to play that role. Again, to a greater or lesser extent dependent upon the parent or family for that matter. So in our context it’s about the ESW being able to make a quick assessment of where the need is through conversations and adapt their responses accordingly. For instance, adolescents and young people, there should be a lot of work around them being advocates for themselves (Interview senior manager March 2009).

The changing role of ESWs can be viewed as one which shifted them from case manager and advocate to that of gatekeeper. These changes reflected the funding issues confronting the agency and its need to differentiate a cohort of children with specialist needs and develop a higher profile within the Education Department and the hospital.

In the next chapter I concentrate on the changing role of Integrate and ESWs in the hospital as they seek to promote educational engagement. This included strategies to present the hospital as a learning environment and the child as a learner, rather than exclusively being a patient. Through observing and hearing the accounts of ESWs I will argue that a default position emerges for those children who do not fit the criteria in the ‘at risk’
category. Such normalising discourses overtly focus on individual capabilities, encouraging self-advocacy and individual responsibility.

Encouraging educational engagement masks the complexities and actualities of schooling for children with long term health conditions and the deficiencies within the school system. These complexities and actualities are masked in much the same way as the colourful photographs of smiling children engaged in educational activities (See figures 13, 14, 15, 16).
Chapter Five: The Hospital as a Learning Environment

The previous chapter explored how education support work was increasingly being organised around the ability of Integrate to demonstrate to its funding body – the Education Department – that the agency was identifying and supporting an educationally ‘at risk’ cohort of children within the education system. Since its inception in 1999 Integrate had been specifically funded to address the lack of awareness in schools about the needs of children with long term health conditions. By the end of 2008 Integrate had developed new processes to identify and refer the ‘educationally at risk child’ to external support agencies within the education system. Integrate was relying upon regional support services within the government and independent school systems to respond when alerted to those children who needed ongoing support when they returned to school. In turn, the families and carers of those children not identified at risk were being asked to initiate the cooperation of schools with minimal support from ESWs. This could be characterised as a shift from an advocacy to gatekeeper role for ESWs and the agency.

However, this was only one strand in the social relations which were beginning to re-organise and shape the delivery of education support by the agency. This chapter explores how the hospital was increasingly becoming the focus of the agency. Most particularly, the chapter examines how the notion of the hospital becoming an alternative learning environment, with children being viewed as ‘learners’ instead of only being patients, began to shape the activities undertaken by ESWs. Throughout this period a noticeable discursive shift toward notions of flexible learning environments, the ‘talking up’ of the capacities of children to engage in educational activities and the role of new technology all featured in publications by the agency and in new research projects being undertaken in the hospital.
A quote from a university publication perhaps sums up the shift in thinking about the role of Integrate and its re-orientation towards the hospital. The booklet featured a number of research innovations from a range of research institutes, including Integrate, covering projects in neuroscience, energy, sustainability and the use of broadband technology. A collaborative project being trialled by Integrate in the hospital was researching the use of an ‘ambient orb prototype’ connected to a laptop computer and controlled by a wireless sensor (see Image 13 and Image 14). The article exemplifies subtle but significant shifts in language and activities concerned with the presentation of educational engagement and reconnecting children to schools. The article says:

The ambient orb can alert teachers and schoolmates to a child’s desire to connect with their classroom and peers, without requiring the need to establish communication (University publication, 2011, p. 34).

The comments of one of the children quoted in the article are also instructive.

I reckon it was good ... some of my friends said when it changed colours it reminded them of me and I liked it ‘cause everyone would think of me’ (ibid.)
Presenting the ‘desire’ of a child to connect with school but not having to actually ‘establish communication’ provides an clear indication of the way in which gaps or disjuncture’s occur between institutional responses, in this case to a child being separated from school, and the realities for the child and those delivering education support. Importantly, it controls the amount of direct intervention on the part of ESWs or the agency, whilst also offering a device which promotes the visibility agency within the hospital and in schools. The device was not designed for ‘rich communications’, rather it was devised to offer a muted form of contact, one which managed the type and amount of contact whilst limiting interruptions for the classroom teacher. The research findings on the hospital website wrote:

The use of the tablet and the presence app was appropriate for classroom use, however, in the home context its low-bandwidth modality is less appreciated. Parents want direct and timely connection with their child and are not concerned
about being interrupted by them (Posted May 23, 2013).

The use of the word ‘interrupted’ is again instructive because it suggests that the device provided a way for schools to manage contact without it being too disruptive, but it is not clear how this meets the actual needs of the child who is absent from school. In fact the findings showed that children who gained the most benefit were those who were already well connected with their local school and these children were the ‘most likely’ to use the new devices’ (ibid.).

Returning to the work of ESWs and the reasons for the establishment of Integrate, one can begin to unravel a subtle but significant shift in the way education support work was changing.

**The Changing Role of Support Worker: Advocate to Evangelist**

In order to understand the scope of the changes which were re-defining the work of the agency it is worth recapping the original reasons for the establishment of Integrate. The hospital school had been closed because of the significant decrease in the number of days children were remaining in the hospital for treatment. This has continued to be the case with the average stay being as little as four days for the majority of patients. Instead, the largest number of children are being treated and monitored in day clinics and outpatient units, as well as in home by hospital community care services. Advances in paediatric medicine has meant that children are living much longer with medical conditions as well as surviving trauma and treatment in larger numbers than had been possible in the past. For instance, in 1963, when the hospital was first opened, the average length of stay for patients was 10 days. By 2011 the average stay had reduced to 2.8 days (Hospital Annual Quality of Care Report, 2010-11, p. 14).
Consequently, children are returning to school sooner, seeking to continue their education throughout their treatment and contemplating a life beyond their teenage and schooling years. Before 2008 Integrate had focused on seeking to influence education department policy around school inclusion as well as informing and assisting schools to better recognise and support the needs of children living with on-going health conditions. This often involved ESWs directly informing classroom teachers in regular schools about supporting students who may be recovering from trauma, surgery and the side effects of treatment.

Integrate, under the previous directorship, had also sought to establish a profile largely independent from the hospital because its funding was derived from the Education Department and not the hospital. However, such independence was never fully realised. The reasons for this are attributable principally to the status of the agency as a ‘controlled entity’ of the hospital. This meant that the majority of Board members were derived from the senior management of the hospital. Other factors which made such autonomy difficult was that Integrate’s staff were employees of the hospital and its client base were situated in the hospital. A further connection with the hospital concerned the agency’s receipt of a large philanthropic donation in 2005 which had funded the provision of specific education services to children being treated for cancer in the hospital. The previous Executive Director described the relationship she had developed with the hospital in the following way:

I work really hard to maintain the independence of this organisation because you know the majority 75 per cent of the funding now comes from the Education Department which it always has and 25 per cent from philanthropic sources, the hospital ... doesn’t contribute a cent so we must be quite independent and represent education (Interview March 18, 2008).
However, the considerable prestige and power of the hospital also made such independence difficult to achieve. The hospital was an institution in which a large number of charitable organisations were directly or indirectly established for the purposes of fundraising. The hospital itself had its own extensive fundraising foundation which supported various streams of research and philanthropic work to assist patients and families. The combination of the considerable power and cachet of the hospital, the deep regard in which it is held in the community, as well as the role Integrate was beginning to play under the new leadership was described by one board member in the following way (this was in 2009 after ESWs had been reinstated as teachers in the hospital):

The hospital is the ‘jewel in the crown’ of stand-alone hospitals in comparison with others in [the state].

The [hospital] staff are happy as Integrate is responding and Integrate is seen as doing something by addressing gaps. For example, eating disorder kids sitting in bed with nothing to do. It’s [Integrate] demonstrating its profile and role within the hospital (Interview September 2009).

Clearly the hospital was viewed as a desirable place to work for many people, including ESWs, in spite of and because of the opportunities it provided to work with children who were experiencing illness, trauma and death. For instance, one ESW who had a background in mental health and had worked as an English language teacher overseas had always wanted to work in this particular hospital. She described how she and her family had celebrated with ‘champagne’ the day she was notified that she had the job at Integrate. Working at the hospital was a ‘dream come true’, although she later found that working at Integrate hadn’t been as fulfilling as she had expected (Interview February 2008). These types of experiences were alluded to in other interviews, including one with the former Director who
commented somewhat sympathetically about the experiences of ESWs in the hospital:

It is difficult to resist the demands of working in such an emotionally charged environment, and the allure of working in a hospital with a high level of prestige and cachet in the wider community (Interview June 2009).

ESWs and the majority of the senior management were all trained teachers, although this had not previously been a requirement of their employment until the change of leadership in 2008. In fact, ESWs had been specifically asked to think of themselves as independent from the hospital and to also shift away from ‘thinking like teachers’ in order to facilitate an independent identity. The complexity and indefinable quality of their role was described by ESWs in the transcripts from the Keeping Connected focus groups:

ESW 1: Because it goes outside the hospital walls, so many of the people that we work with, you know their jobs start and finish within that hospital ward. And their role is much more kind of, tick the boxes, I think this is what’s hard about educating people about what we do because we can say look we do this, this and this but really it doesn’t show a true picture of what we do.

ESW 2: You can’t show a true picture of what we do. I think these are hysterical (points to pictures on the wall of the meeting room at Integrate displaying staff), groups of people standing, important groups of people but how do we show a picture of what we do? (Keeping Connected focus group, 2007)

The accounts of ESWs indicated they found the role difficult to describe given its breadth and complexity. Yet, their managers had often focused on ESWs needing to ‘stop being teachers’ as it was also seen as contributing to
children and families in the hospital becoming overly dependent on the agency.

[There are] No ‘warm and fuzzy’ moments once you leave the teaching role behind. [But] Some like that a lot and can’t let go. The workload issues relate sometimes to staff not willing to let go of the personal contact with students and families. It’s time consuming and labour intensive (Interview February 27, 2008).

Contrary to these views about the role of ESWs, when the agency management changed in 2008, ESWs were required to renew their registered teacher status, and to some extent this change did clarify their role within the hospital.

The intensification of the role of the agency within the hospital was affected in large part by the new Business Plan announced in 2008 using the key goals of the hospital to set its agenda. The basis for this was to reinforce the position of the agency as part of a ‘division’ within the hospital and working to meet the organisational goals of the institution. These included: ‘Excellence in Healthcare; Leadership in Research and Education; Quality and Safety; Partners in Paediatric Care; and Improved Organisational Environment’. Each of these goals included components and strategies which set the operational parameters for Integrate’s staff within the hospital.

This became evident in the types of services ESWs began to provide on the wards, its deployment of new technology funded by the Education Department and the types of research projects it was initiating to promote education and learning in the hospital. Such activities even extended to the development of ‘compulsory’ learning activities for particular groups of children within the hospital and enabling ‘work experience’ for students in their senior years of secondary education within the hospital. As mentioned earlier, these activities also entailed the collection of documentation which
fed into Education Department reports and formed the basis for the agency’s evidence base. These texts were in the form of patient notes, database notes, photographic images, stories and providing real time demonstrations of technology as a positive tool for continued learning.

‘Learning Happens Anytime, Anywhere’

Integrate had reverted to using the hospital logo during 2008 and had gained approval by the hospital for a discrete ‘education’ section in the patient notes by 2009. These developments were identified by senior executives of the hospital as particularly important for signalling the merging of education into the overall strategy to establish ‘education, creativity and learning’ as ‘fundamental to the healing process’ (Integrate Annual Report. 2009, p. 7). In addition, ESWs and other Integrate staff were allocated distinctively coloured lanyards inscribed with ‘teacher’ (2008 and 2009 Fieldnotes). These developments were symbolically important in demonstrating Integrate was part of the hospital and in re-defining the work of ESWs who would eventually be situated on a full time basis within the hospital. The agency was throughout this period also seeking to secure spaces in the ‘new’ hospital complex when it opened in 2011 (Interview notes 2009).

ESWs and other staff also began compiling information and providing documentation about the children they supported and how they were using the resources provided by the Education Department. The contrast between the Annual report of the agency at the end of 2008, compared with excerpts from the 2009 and 2011 Annual reports, offers accounts which demonstrate how education support was being refashioned into hospital based services. The report in 2008 particularly emphasises the relationship with the Education Department and its role with schools.
[Integrate] is committed to ensuring continuity of learning and ongoing connectedness to school for children and young people ... The major funding source is the [Education Department] which has as a goal improved education, health and wellbeing outcomes for all young [people]. [Integrate] plays a significant role in supporting the [Education Department] to achieve this (Integrate Annual Report, 2007/08, pp. 1).

Within a year the major theme within the 2009 Annual report had shifted on to showcasing opportunities for ‘education’ within the hospital, and reshaping the work done by ESWs.

When they [children] come to the hospital for treatment they become patients, but they are still learners. Our teachers work to create vibrant and dynamic learning environments where children and young people are engaged, interested and curious ... just as they would be if they were at school (Integrate Annual Report, 2009, p. 6).

The planning and rollout of all education based activities were also now done with the cooperation and approval of senior hospital executives in Clinical Support Services and Home and Community Care, as well as Care Managers across hospital departments (Field notes, Staff meeting July 3, 2008).

The 2011 Annual Report presents the hospital as a showcase for education, equating the quality of experiences in ‘out of school environments’ with what can be expected to be found ‘in’ schools:

Our teachers, [the] Hospital is more than a hospital, it’s also a potentially rich learning environment, not in a traditional sense, but much more exciting than that ... Out-of-school learning environments like the hospital can provide opportunities to maintain children’s learning identities during school absences ... What they find when they get here is not only
outstanding health care, but an environment that increasingly speaks to them as ongoing learners. It is a place that has teachers, education support officers, teacher volunteers, books, netbooks, iPads, interactive whiteboards, etc.; in fact, all the things that they would expect to find in their schools and early childhood settings (Integrate Annual Report, 2011, p.18).

The comparison being made between schools and the hospital as learning environments in effect ‘talks up’ the capacity of schools to support children with a range of medical needs by working on the assumption that all schools are equipped similarly and are able to effectively utilise new technology. At the same time the role of the hospital was being talked up as a place which could mitigate issues for some children. This was despite some areas in the hospital, notably Outpatients, being significantly under-resourced although that was where the majority of children were situated. The unevenness in the distribution of resources in the hospital also to some extent reflected the pre-existing arrangements with different hospital departments dealing with different medical conditions and how ESW were deployed. An ESW explained this in the following way:

ESW: I worked across neuroscience so student support meetings are important. I did sixteen up to June this year and I only work three days a week so I was pretty much churning out assessments for students with brain injuries who were going back to school. I think the need for students with brain injuries is a high needs area because it is an invisible illness and it’s really easy to interpret a child’s behaviour as not being related to a health condition but being personality defect, a naughty boy or an acquired brain injury? What is it? It doesn’t matter how many times I go out to a school and explain about the 16 year old, that this is a brain injury and this is how it manifests itself the teacher will say to me, “I’ve got a whole class of boys like that, their adolescents”. So you know, those student support
meetings are very important and one’s not enough, and it might be different for a child that’s had a nasty car accident coming back with a badly injured foot. So I would say you don’t need a school visit for that. But some staff members create or encourage a school visit or minimise a school visit. I did so many at beginning of year. Some more driven by my role in the Rehab team because we are contractually bound to the Rehab[ilitation] team to do those, they like to do school visits.

Researcher: What do you mean contractually bound?

ESW: We have one full time staff committed to the rehab team to the state Paediatric service and they deal with all ABI kids and there are actually three staff members working on that team. And I think we are going more than our one full time equivalent, but we didn’t actually measure the time we spent there, um, now two of those team members are not available at the moment, so rehab are getting a lot less [from Integrate] and it’s hard to fill them (ESW Interview 2009).

However, it was unclear how these responsibilities might change given the heightened focus on presenting the hospital as a better learning environment than what had been described as ‘traditional’ forms of education.

ESWs were increasingly being asked to not only assess which children they supported in order to identify those at risk of disengagement, but importantly, to also document what kinds of ‘learning and teaching’ they were engaging in and how they were using the new resources in the hospital. Resources including Netbook computers and new electronic whiteboards had been ordered for use in the hospital. Such resources represented a significant further investment by the Education Department in the hospital. The Education Departmental review of the agency had stressed the importance of Integrate being able to demonstrate that it was working with
an identifiable cohort of children using strategies and initiatives that were effective. This was essential because as one manager stressed at a staff meeting:

The Deputy Secretary, in the Office of Government School Education wants to know how they are being used or we can forget about that funding (Fieldnotes, Staff meeting August 2009).

Demonstrating how such resources would be used and the types of situations which arose raised some difficult dilemmas for ESWs and the agency. In the next section I discuss some of these using the accounts by staff at Integrate.

**Netbook Computers and Education Engagement**

In 2008 significant changes had been implemented which sought to capitalise on Education department initiatives around the use of IT for remote learning and accessing additional funding and resources to introduce education as part of the ‘normal’ structured activities of children within the hospital. This was experienced by ESWs in a variety of ways. The varied aspirations and goals young people and families had about their education, and demands from within the hospital to ‘occupy’ or provide distractions when patients were bored or distressed, presented challenges for ESWs and the children and families they supported.

These challenges arose in sometimes surprising and unsettling ways for staff at the agency. The account below involved a staff member who had been with the agency for six years providing technical support to enable the use of laptop computers as part of the education support service in the hospital. His account offered another insight into the role of the hospital in shaping not only perceptions about the use of technology, but also the role of the
agency. When I spoke to him he was still visibly upset by a situation he had confronted a few days earlier.

He had received a phone call asking him to come to a hospital ward with an ‘urgent request’ for a laptop computer. A young, adolescent girl was threatening to commit suicide and the medical staff on the ward hoped the computer might act as a diversion. He was very worried about the situation and the amount of emphasis being placed on the laptop. When he arrived on the ward she was on the balcony, and although there were barriers she was threatening to jump.

Ridiculous … the uncertainty of technology … anything that can go wrong, usually does. This creates enormous difficulties where it is positioned as the answer for such a complex situation. What if it hadn’t worked? What if I hadn’t been able to make it work? What if the system went down? What if she had reacted badly? What if she had jumped or injured herself?” (Interview 2009)

His account demonstrated the way the agency was being viewed by the medical staff within the hospital, and the unexpected and unrealistic ways in which technology was at times being promoted. This was not the only occasion where the laptop computer was offered as a short term panacea to a range of problems facing young people. Indeed IT had become the ‘go to’ solution for complex issues involving connectivity and delivery of ‘education’. Further issues around IT arose from research conducted by a university team in the hospital working with Integrate. These researchers found that despite efforts by the agency to establish links with local schools to support young people using new interactive technologies, there was a clearly some way to go before teachers in schools had the skills and confidence to use such technology (AUTHORS NAMES REMOVED TO PROTECT ANONYMITY OF ORGANISATION. 2008, p. 10).
In the next section I refer to other research which was conducted by Integrate to establish an ‘evidence base’ for its work. I use this research example in order to further explore the types of discourses which were framing the delivery of Integrate’s educational support.

‘Researching’ Education in the Hospital

The findings from a small research project conducted by Integrate in 2009 provide another opportunity to view the way in which education support was increasingly being socially organised by the needs of the hospital. The study also provides insights into how particular education policies and pedagogical approaches were being employed to engage children who were regularly absent from school.

My interest in the results of the project are not concerned with evaluating or critiquing the research itself, rather I am interested in reading from the view of an institutional ethnographer, how the experience of delivering education support and the value of education in a health care setting are framed by ruling discourses. Taking an institutionally ethnographic approach, one can read the research findings from different standpoints by giving consideration to which voices feature in the report. Within the project, interviews were conducted with ESWs working on the adolescent ward as well as a ‘project reference group’ which was composed of staff from across the hospital, whilst young people and their parents or carers completed a survey to elicit their views.

The project was investigating the merits of establishing a dedicated learning space for adolescent patients in the hospital. ESWs were interviewed by the project team. Within the design of the project a range of educational activities were assessed, including the frequency and type of use of the newly
acquired Netbook computers, the use of the space itself and the usefulness of Individual Learning Plans for children and young people. The separate learning space was established on a twenty-two bed ward that received 484 admissions in 2008 providing medical care to children and young adults between the ages of 12 to 20 (Integrate Research Project Final Report 2010, NAMES REMOVED TO MAINTAIN ANONYMITY). The researchers had identified a ‘developmental cohort’ which would help establish an evidence base for the work with adolescents who had been assessed as being at significant ‘risk’ of disengaging from school because of prolonged and/or frequent absences from school.

The re-introduction of organised and targeted teaching and learning toward particular groups of children within the hospital also reflected the agency’s goal of delivering services which were consistent with Education Department policies around improving school engagement. ESWs and the reference group participated in individual semi-structured interviews and a focus group about the ‘value of the space and if they were ‘engaged and supportive of the learning space, bedside learning and teaching’. The children and young adults, parents and carers were asked in the surveys about the ‘usefulness of the resources provided in the space’ and ‘how many of them used the space’ (2010, p. 20).

The feedback from the interviews with the ESWs and the reference group concentrate on the benefits of having a designated school-like space operating within the hospital. This included, morning ‘start times’ and ‘compulsory’ participation in activities for eating disorder patients, both of which were presented as positive strategies for educational engagement.

Initially when I introduced this whole school idea to them, they were apprehensive and they weren’t sort
of sure … Now they know that 9 o’clock comes that the kids need to be in the space … They [ward staff] are very encouraging… if there’s any new kids they sort of explain what’s going on and try and get them up and out of bed, if they [young people] haven’t already done so themselves … So they’re right onto it, which really helps, coz it really helped in the beginning to establish the space. To be able to … work around kids, you need everyone on board (ESW, 2010, p. 39 Integrate Research Project).

Psychiatrists, physios, everyone knows that school runs in the morning. While the kids are over here [in learning space] learning and developing their education their health needs are a priority. If we’ve missed a kid in the morning because a doctor was talking to them, we’ll often have nurses bring the child over as soon as they are available or as soon as they have done a few procedures. The student will often be brought over by the medical staff here [learning space] (ESW ibid. p. 40).

It’s part of the deal. When you come in, you go to school (Focus group participant, ibid., p. 14).

It’s [education on this ward] been a huge development and really great I think it’s awesome and it’s occupying their time and taken their minds off their disease for a little while and I think it’s been really good (Reference group member).

The project collected a range of demographic data, the child’s year level at school, how frequently they used the space and what resources they were using. Perhaps unsurprisingly the project findings supported the notion of a traditional model of timetabled education sessions, yet, we do not really know if that in turn produced good outcomes for these young people when they left the hospital and returned to school.
The comments by young people themselves are far less detailed within the findings of the project.

Since the compulsory learning space was introduced, keeping up with school work is a lot more achievable. There is also more distraction from dull ward life (Survey participant, ibid. p. 14).

It has been a great pass time. At times it has helped keep my mind off pain (Survey participant).

Great to see how seriously it is taken by teachers and this motivates the kids. Very impressed (Survey participant).

We think it’s great as it gives the kids that have long stays at the [hospital]... an education (Survey participant).

I was very impressed by the teachers and the facilities provided. Also [I’m] very grateful for maintaining her education providing distractions and engagement in constructive learning activities (Survey participant, ibid., p. 38).

It is not clear from Integrate’s project findings for instance, how the children felt about being taken to the learning space by medical staff or about the times of day when the space was open, as this was not covered in the research report.

These comments are of interest because they demonstrate how the experiences of being in the hospital for young people are translated into the notion of a learning space being a distraction from the ‘dullness’ of ward life. The learning space also alleviates the ‘boredom’ remarked upon earlier in an interview with one of the hospital managers, as justifying the role of Integrate in the hospital. The research reports universal enthusiasm by ESWs and the reference group members for the learning space within the ward, and support for the idea of adapting it for other wards in the hospital.
However, the project was conducted at a time when the majority of children and young adults had finished school for the year and had little school work to complete. This accounted for few of them having ‘individual learning plans’ and the space was largely used for recreational purposes, such as playing pool. The issue is not that they were using the space to play computer games, pool or just to hang out with friends. Rather, it is unclear if sufficient attention was given to exploring the difference between how professionals valued the space and how young people experienced education inside and outside the hospital. It could be argued that the findings reinforce the benefits of establishing a ‘learning community’ that replicates a conventional notion of learning. The space addresses the concerns of professionals within the study, and draws upon professional discourses about the values associated with education. The voices of the children and young adults are secondary in shaping how the space operates and its role in supporting their education beyond the hospital. The following quote is from an informant in a focus group about the dedicated learning space.

“This is obviously a lot more evidence-based ... we’ve got program aims and there’s a lot more structure then there ever was ... it’s more outcome driven now (Focus group participant (2010, p. 37)).

Institutional ethnography provides another way of considering how Integrate engaged in ‘research’. The production of research findings becomes an organising text for the work of ESWs by shaping official accounts of education support and educational engagement of children within the hospital. Research exerts a powerful influence through the presentation of expert opinion and relaying codified language which translates across institutional spheres. In this setting it reinforced notions of ‘developmentally appropriate education support’ and characterisation of the value of an education culture within the hospital. However, what is far less clear is whether children in the hospital value education in the same way and
whether the dominant discourses framing discussions around school disengagement sufficiently acknowledge the systemic barriers in schools, which in turn contribute to issues of alienation and detachment for young people.

‘Education’ within this project was presented to children and parents/carers in a particular textual form, for instance, becoming part of a treatment plan, or an individualised learning plan, or by using particular resources such as computers. Thus, in seeking to investigate education at the same time, it becomes embedded within the institutional practices of the agency and the hospital. It also contributed to the ‘evidence base’ which the education consultant conducting the departmental review had impressed upon the agency, as ‘critical’ for its continued funding. In other words, the research data assists in making the case that Integrate is needed because it targets a particular cohort of children within the system who have an irregular attendance record.

The research project began with concepts and discourse which are comprehensible across multiple institutional settings from the local to the extra-local – from Integrate, to the hospital and the Education Department. The research project introduces an explanatory schema which displaces the ‘actual’ experiences of being disconnected from one’s school and peers to one which replicates a ‘sense’ of connection, in much the same way as the ‘Orb project’ mentioned earlier. Educational and health experiences are re-written through the lens of in-hospital learning, while at the same time offering a solution for the ‘dullness’ of ward life or, as in the case of the Orb, of being ‘remembered’ by friends and teachers. The actual issues facing children when they return to school slip from view in such representations.

The research commitment is identified as seeking ‘knowledge’, but one can ask knowledge of what? It would appear the goal of ‘knowledge’ focuses on
how to reinforce institutional priorities which re-interpret young people’s experiences of educational disengagement through the workings of the hospital and Integrate. The issue of disengagement is explored through the concept of introducing a ‘culture of learning’ via more structured activities within the hospital. What the notion of creating a ‘learning environment’ in the ward meant to young people and families is not so apparent from the research findings. However, it is clear that it had benefits for the medical and other staff on the ward as well as Integrate. The background and context for the study is instructive because the researchers identify the hospital goal of ‘child centred, family focused’ as informing the design of the project so they can:

Build the capacity of both adolescents and their families in managing learning and understanding the importance of maintaining connection to education during periods of health care (2010, p. 3).

The presentation of education as a ‘normalising’ activity for children and families (Ashton, 2004, p. 26; Tregaskis, 2002, p. 462) is not new, neither is the perennial issue of how to respond to children and young adults who are, for a range of reasons, disengaged from or are considered ‘disruptive’ to, the normal functioning of schools.

The emphasis in education policy on alternatives to traditional teaching and learning by relying upon new technologies through the provision of computers and web-based resources, has important implications for the way education is being presented. These ‘solutions’ and alternatives are also more cost-effective than traditional forms of teaching in schools. Importantly, they further reinforce individual modes of learning and presume a ‘level playing field’ in terms of access and capacity to engage with and access new technology.
Figure 19

The Informal and Formal Work of Providing Education Support

In the field of education, Lewis (1989) argues that historically teachers have often been conscripted to additional roles, such as instructing the morally and economically ‘inefficient’ or assessing students for specialised programs. For whilst teachers are ultimately responsible for teaching the curriculum, the broad umbrella of ‘teaching’ has become larger and larger in order to fit the institutional imperatives of government and expectations within the community. Even under the previous management, ESWs working in the hospital had been responsible for a broad range of activities, however, in reinstating their teacher status in the hospital, management were now adding to this extensive list with the inclusion of new formal responsibilities. This further differentiated the formal and informal aspects within education support work. The formal aspects were focused on contributing to the making of a ‘rich learning environment’ in the hospital, which included responsibilities to comply with new reporting regimes such as writing in a patient’s notes and documenting the use of computers and other resources which had been provided by the Education department.
The new database devised to assist in the identification of children at risk of disengaging from school included a list of the formalised roles and responsibilities of ESWs. It was also testimony to the way education support was focused on roles within the hospital. These responsibilities included:

- Deliver group teaching
- Deliver 1-1 teaching
- Develop authentic personalized learning projects
- Develop individual learning plan
- Develop medical support plan
- E-learning professional learning
- Handout generic information pack
- Handout diagnostic specific info packs
- Identify student learning needs
- Prepare lessons
- Refer to community support groups
- Refer to regional liaison teacher
- Special education assessments
- Support major educational events

Each of these activities involved the production of texts which linked the agency to the hospital and confirmed the necessity of the funding from the Education Department. Field notes from a staff meeting I attended demonstrated the way in which the priorities of the funding arrangements were shaping the role of ESWs.
Two important issues were stressed at the meeting—the first was that the new funding model was directly related to the number of children the agency supported in the hospital. The second concerned clarifying the role of the regional support worker. ESWs were instructed to stop approaching medical teams in the hospital or accessing medical reports in order to provide documentation to schools for funding applications for students with additional needs or disabilities. It was expected that doctors in the hospital were capable of providing this kind of documentation. This was a vexed issue for ESWs as doctors had little time and sometimes limited interest in these kinds of educational matters.

The other pressing issue raised at the meeting by the senior manager concerned the quality and amount of information ESWs were entering into the new database. The information was being scrutinised and it was considered ‘insufficient’ and not comprehensive enough or ‘directed toward Education department funding conditions, rather it was ‘too general’.

The manager reinforced that the funding agreement is now based on two things: The number of children and secondly, the key learning and teaching within the hospital which should be tailored to the ‘child’s developmental stage and key learning tasks’.

He emphasised that if there was no evidence then there would either be a ‘decrease in the funding or it might stop altogether’ (Fieldnotes 2009 staff meeting).

Two things were being reinforced in the meeting which directly shaped and re-organised the work of ESWs. In needing to record information which met the categories in the database the experiences of the child are sifted for key information which is consistent with the requirements of the Education department funding arrangements.
Jung (2000) makes the point that there is often a lack of ‘fit’ between experience and the way organisations frame such experiences. In this setting, despite the difficulties children and families faced when they had multiple interruptions to schooling and the issues arising in schools around supporting students when they had serious and ongoing health issues, or the fact that the majority of children were spending less than four days in hospital - these were not the experiences framing how education support was now being delivered. Clearly, the expectations of the hospital and the demands of the Education Department were reframing the delivery of education support. Under the new model the experiences of children facing multiple absences from school related to long term health conditions, were transformed into texts – these included research applications describing research cohorts, identifying categories of children and families which required departmental monitoring and targeted support, texts which featured stories and images for stories in publicity and appeals for funding or resources. In these processes the personal and complex work done by children and families or carers to remain in contact with schools and teachers, and the difficulties they faced, were re-written using language and concepts which were useful to a range of professional interests.

However, the intimate and deeply emotive aspects of the work in the hospital extended beyond its institutional confines. The work involved close interaction with families, children and schools. These informal aspects were movingly described by an ESW in the following way.

A boy now 15 years old has been ill with cancer since he was in primary school. He has had many critical hospitalisations where he has been on life support and when his mother was told he would die. But he has survived. His mother has four other children and is a single mother. Each time he recovers he wants to go back to school and I organise support for him so this can happen. I have
done this many times but this year I was not permitted to go out to the school to organise his return. I organised a meeting elsewhere where the boy and his mother, teachers and medical staff attended. The issue was ‘fear’ about toileting the boy and his health status. The boy was also fearful and embarrassed to toilet himself at school. He had had his toes amputated and is in a wheelchair after side effects from his treatment and complications which impacted on him. The meeting and resolution were successful and the boy returned to school. Recently he relapsed and it is not expected that he will recover however he has. He is bored at home and I will organise another re-entry to school.

She was very concerned and genuinely cared for this young person. She had known him, his mother and the family for nine years. She described how she had sat silently with his mother outside the cancer ward near the lifts and comforted the mother and waited.

She said: ‘There were tears pouring down her face but total silence, no sobs, just rubbing her back and we sat there. There is nothing you can say’.

He is back again. I have sat with him when he was so, so sick and just read to him. He was not expected to live. So this time I will organise for him to return. I don’t know if I can go out to the school or they will come here.

She acknowledges he will not have a long time to live but he is alive now but school is very important to him and everything needs to be organised (Interview July 2009).

These accounts by ESWs exemplify the bifurcated way in which they know children but where institutional decision making and vested interests framed the way a problem is defined and the type of solution offered.
In addition to their informal work what was striking about their formalised roles and responsibilities was the significant amounts of additional work ESWs and children had to do in order to fit the activities listed within the database. These formal activities often entailed additional or compensatory work to be carried out in order to keep the wheels of Integrate turning, as well as enable education support to continue in the hospital and ensure that the right kinds of referrals were being made to the Education department.

It was not straightforward supporting ‘major educational events’ or engaging in ‘one to one learning’ because children or families may not be receptive at a particular point in time and they were often only in hospital for a short time. In addition, seeking out children and families to participate in activities which could be filmed or photographed was not something ESWs always liked to do, but reluctantly they did approach families and children.

This difficulty was very evident in the account by an ESW of an event organised in the hospital with a burns patient who had sustained injuries in what are known locally as the ‘Black Saturday’ bushfires. The ESW who had been providing education support to the girl was troubled by the activity which had been organised by a ‘work experience’ student. I took notes as the ESW described the event to me:

The girl had been very seriously injured and all her family except her grandparents had died in the fires. The ESW described how the life of the girl had become a ‘daily struggle’. She recounted how it was the birthday of the girl’s dead sister and that this would be the ‘first of many remembrances’ she would have to cope with. She said: ‘every anniversary and birthday or celebration is a reminder of how much she has lost’.

The activity with the girl took place in the gardens of the hospital with a student who was doing work experience in the hospital. They were to play music together. The ESW described how the girl’s hands
had been badly burned in the fires and she had lost the physical capacity to do this. But it also became apparent that her memory had been affected and she could not remember how to play the piano. At that point the girl broke down and cried.

Another staff member from Integrate commented that ‘it [the performance] was too much for her’. However, the ESW saw it differently saying: ‘everything is too much. She has had to deal with, the loss of everything—physically and emotionally it’s all very hard’.

After the performance another staff member began to take photographs. But the ESW had to intervene and stop them because her grandparents had requested that their granddaughter not be included in any publicity for the hospital about the bushfires. She had suffered much scarring and hair loss and her appearance was altered considerably. She almost lost her hands and feet due to the extent of the burns.

The following day the girl decided that she would like at some point to visit her school. The same ESW had asked permission from her manager if she could accompany the girl on her first trip back to her school. The girl’s grandparents had requested her support on the day. The request was denied. The ESW had to tell the grandparents she was unable to go (Fieldnotes July 2009).

The complexities facing the education support of the girl and her attempts to re-engage with her education are difficult to fit within the parameters of official accounts of ‘age appropriate developmental stages or completing key learning tasks’. The incremental steps in recovering from such catastrophic injuries and personal loss are slow and painstaking. The attempt to take photographs to record her journey is an intrusive act at this early stage of her re-entry into mainstream life. Yet, somehow the imperative to record the event which is in keeping with the institutional priority to demonstrate the
value of education in the hospital overrides the actual experience of the girl which slips from view.

The emphasis placed on the use of resources and expectations on families/carers, children and schools around school engagement underscore the way in which Integrate was shifting away from an advocacy role beyond the hospital. Instead, ESWs increasingly talked up the individual capacity and responsibility of the child and family with regard to education outcomes. The role of children and family in gaining the support of schools had become pivotal. Yet, the systemic deficiencies within external support services and the reluctance by schools to engage with students when they had health conditions are not mentioned, although these are common themes in the literature.

**Conclusion**

Chapter four and five have sought to demonstrate how the Education Department and the hospital became increasingly important in shaping the way education support was being defined and delivered. It seemed that in shifting the responsibilities of ESWs to promoting the value of education within the hospital – and shifting away from the key role of the agency in raising awareness in schools about the needs of students with long term health conditions – Integrate was increasingly becoming an advocate for the hospital as alternative educational setting. This was ironic given that the original reasons for its establishment were to shift the work from a school and bedside tutoring model to one which focused on improving the outcomes for children in schools.

The role of education and health discourses in fundamentally re-shaping the work of the agency demonstrates how ruling relations shape work in localised settings. In particular, by showcasing education in the hospital,
Integrate was attempting to reinforce education policies that flexible learning using new technologies was achievable. Implicit in this approach was a notion of the individual learner and their family taking a greater role and responsibility for education. Whilst the merits of IT based solutions within schools are possibly important new tools for classroom teachers and are obviously seen by governments as a way of constraining education costs, there are still important and unresolved questions about the extent to which they can replace the social and academic experiences of being ‘in’ school.

Thus, whilst the social and educational benefits of being able to engage in learning activities within the hospital are commendable, they also reflect the ruling discourses within education which are seeking to gain improvements by shifting the costs and responsibilities. This entails placing greater pressure on individual teachers, schools and families to take responsibility for managing the health needs of children when they return to school, including performing quasi-medical roles.

Integrate works in an environment where the powerful discourses of education and medicine define and manage the lives of children, families and ESWs who work in these systems. I have argued that institutional priorities shaped the way educational support was delivered when vested interests re-defined what came to be viewed as effective and valuable within the hospital. Interestingly, in this setting the engagement of support workers, children and families as participants in research projects was one manifestation of the way the agency gathered evidence to support its case for having a role in the hospital. In order to achieve this Integrate utilised the organisational goals of the hospital as a template for its own business case for introducing discourses around improving health outcomes for children by offering educational activities across various areas within the hospital.
In the final chapter I will discuss what Smith names as ‘ideological practice’ and how this relates to providing ‘education support’. ESWs worked in a highly emotive and difficult environment, sometimes witnessing death and other deeply distressing events when supporting children and families. The provision of education within the hospital isn’t something one would argue against per se, however understanding the ‘actual’ reasons for its funding is necessary in order to explore the greater issue of the under-resourcing and inequalities within the education system. I will argue that the ‘student support apparatus’ including services such as those funded within the hospital, accomplishes a particular institutional purpose for the hospital and for the Education department, but at the same time this brings into question how inclusive goals are being met.
Chapter Six: The Ideological Practice of Education Support

Introduction

In the course of my research into a single education support service operating in a hospital setting, I have analysed the work processes and activities around referring and providing education support to a young people. I argue that support workers utilise a range of criteria, consciously and unconsciously, in order to make assessments to categorise educational risk and individual need. Some decisions are informed by the eligibility criteria in specific government programs and policies around school inclusion, whilst others are reflective of systems and demands from the hospital and various philanthropic organisations which provide additional funding and resources. This raises a number of questions, including how this service is shaped by developments in the broader education reform agenda around school inclusion; and secondly, despite the overall decline in lengthy hospital stays and significant issues arising largely when students return to school, how did the agency come to refocus its attention primarily on children ‘in’ the hospital?

By critically examining the deployment of education support services in this localised setting, significant issues emerge about the social relations organising the identification of students with additional educational needs within the broader agenda of school inclusion and the right to education. The intermingling of disability, medical and charity discourses with prevailing ‘normalising’ education discourses are important to consider when viewing how the risks for educational dis-engagement are assessed. Furthermore, but equally importantly, how is successful educational engagement actually judged? I argue that whilst support workers often utilise a normative pedagogical discourse to encourage educational engagement
and ‘inclusion’ they also reinforce the categorisation or ranking of educational needs. These categorisations became integral to the administration and management of requests for additional support.

**Texts in Action**

During the time that the old referral system was being evaluated and the departmental review was being conducted at the agency during 2008/09, a number of projects and activities were being undertaken by Integrate. The subsequent development of a new database and referral system which introduced the category of ‘at risk’ became integral to the production of reports which would be sent to regional education networks in the government, independent and Catholic school sectors. The development of a definition of ‘at risk’ informed the actions of ESWs when they assessed children and families in the hospital and became part of new systems which categorised and targeted the resources of the agency. These administrative projects were presented to ESWs as processes which would better identify and target support to those children who were ‘most at risk’. On the other hand, they also performed the role of separating the experiences of children and families into distinct and manageable parts. These administrative changes differentiated between the responsibilities of ESWs ‘in’ the hospital and set up a system to hand over responsibility of children to other support services ‘outside’ the hospital. The shift in focus provided a different plan for the way the resources and staff would be deployed by the agency.

ESWs were increasingly making a distinction between the responsibility of the agency and those of the family, child and school, as well as those in government regional support services.

It starts with the first conversation. We ask about whether they have a contact there [at school] and
how often they talk to them, how often they’re missing school and try and establish some contact that they have. Rather than we sort of calling them [the school] and doing everything for them we try and put it back onto the adolescent….Sometimes you will sit with them with the phone on the bed and you will just step through the conversation: what are you going to say; how are you going to say it; get them to write it down and they do and they go ahead…. They feel more comfortable after the first phone call to ring again… I think most of them are doing quite well (Research informant quoted in Integrate research project 2010).

The letters in the information packs directed the actions of parents/carers to communicating directly with the school and the regional support services rather than relying upon the agency to act as an intermediary. The overriding institutional purpose reduces the complicated and individual experiences into manageable and distinct parts enabling them to be directed to different sections of the education support apparatus. Thus, those children who had existing problems – not the maybe’s – that met the newly developed definition of ‘at risk’ were identified as having ongoing issues in the regional reports, whilst the larger remaining population of children and families, usually spending short periods in the hospital, were either encouraged to seek support themselves (self-advocacy using the template letters to schools) or were assessed as successfully managing their own needs.

As mentioned in Chapter Four, the reports listed the names and details of children who had been ‘associated’ with the agency, although what this actually meant was not defined. However, as they were not identified as ‘at risk’ there was no request from the agency for any follow up.

The process for referring children who were identified as ‘at risk’ of educational disengagement was consistent with the priorities of the Education Department in the Blueprint policy and associated guidelines for
student support services, as well as the Australian Early Development Index for assessing ‘developmental delay and risks’ (Integrate Business Plan, 2008-09). As described in Chapter Four, the hospital factors which Integrate identified as contributing to the risk of disengaging from school included: whether the child identified themselves as a ‘learner’, whether they possessed ‘a culture and knowledge of education’ and if the family had the ‘capacity’ to communicate with the child’s school. Beyond the hospital, the risk factors were defined as those which impacted on a child’s ‘well-being and health’ including: ‘social conditions, strong family and social relationships, and access to high quality education’.

Under the old case management and referral system the ESWs managed the case file notes of the children referred to them from the hospital. This meant that ESWs could be updating the notes of up to twenty children in the database, although many children and families might not be contacted again by an ESW until they were back at the hospital or a request for additional support was received from a family or school. It may have involved for instance, a school contacting the ESW to ask for advice about whether a student with diabetes would be safe attending a school camp or if a family had a concern about their child falling academically behind at school. Or the ESW might call a family once a year to check how their child was progressing at school. When the agency shut down the case files system it meant that the same ESW was no longer the key point of contact for schools, families or children when they sought on-going advice and monitoring once they left the hospital. This change in the ESW role from advocate to gate-keeper released a significant amount of ESW time which in turn enabled them to move away from ‘case management’ role to a teaching role. The work of the ESWs was articulated toward policies and strategies which promoted educational engagement in the hospital. In turn, children
and families visiting the hospital also became necessary to the realisation of this goal.

In order for me to demonstrate how the actualities of the work done by ESWs and the experiences of the children and families they support are re-conceptualised into an organisational action, I have adapted a ‘schema’. The diagram shows how categories and pedagogical/teaching discourses which Integrate implements are framed by Education Department policies and the strategic goals of the hospital. The diagram adapted from Jung (2000, p. 131) builds on Smith’s schema for understanding how texts work across multiple sites of activity but importantly, how lived experience is reframed by institutional imperatives. Smith argues that texts, such as case files, can be viewed in two ways: they are a ‘product’ of multiple institutional functions but, they also introduce ‘accountability’ which coordinates such functions. Smith emphasises the importance of recognising the selective way in which texts are read for different purposes. The analytical goal is then to identify and demonstrate how they are used in a setting (Smith, 2006, pp. 67-68). The diagram on page 147 seeks to demonstrate the institutional functions of texts at Integrate.

The flow of the arrows from A to E in the diagram is important because it indicates the sequence of ‘action-texts-action’ shaping the institutional practice. The interplay between ‘interpretive frame’ (D) and ‘decision making’ (E) indicates how standardised definitions of ‘educational risk’ and the emerging role of IT, flexible education and ‘personalised learning’ shape decision making in the agency – this interaction represents the text-action-text dynamic. The interpretive frame (D) informs the assessment of educational risk consistent with the Education Department guidelines and those within the research literature. Additionally, it informs the deployment of IT and the conceptualisation of personalised learning. The interpretive frame (D) then is constantly reframing and looping back to the ‘coding’ (B) of the lived of
ESWS and experiences of the children and families with whom they work (A). See diagram, Image 14, below).
<table>
<thead>
<tr>
<th>A</th>
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<tr>
<td>Lived Experience</td>
<td>Coding</td>
<td>Documentation</td>
<td>Interpreтив Frame</td>
<td>Decision making</td>
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<tr>
<td>Schools and regions not following up requests.</td>
<td>Disengaged/ ‘at risk’ – behaviour, school attendance, performance.</td>
<td>Risk Factors. Referrals to regions/ reports.</td>
<td>Vulnerable/at risk cohort identified (consistent with DEECD, DHS criteria, HEADDS criteria).</td>
<td>Which children to refer?</td>
</tr>
<tr>
<td>Children not ‘in’ hospital for very long. Multiple visits. More time in Outpatients/ Day clinics</td>
<td>Hospital place for learning</td>
<td>Use of Computers. Designated learning spaces in the hospital</td>
<td>IT in hospital = effective learning environment; personalised flexible learning, child focused environment (Dept Ed policies, funding for IT related projects and literature; compliments Hospital goals)</td>
<td>What educational activities and types of support to offer in the hospital.</td>
</tr>
<tr>
<td>Difficulties in returning to school; struggling to get back to or continue with education. Children bored, lonely and in pain.</td>
<td>Capable, academically ‘bright’ child</td>
<td>ESW utilising IT and other resources</td>
<td>Integrate’s policies are now designed to achieve three things: they secure its funding; they satisfy the Board of Directors desire for a higher profile within the hospital and create an evidence base though conducting research in the hospital.</td>
<td>What types of IT based learning to offer?</td>
</tr>
<tr>
<td>Lack of awareness and knowledge of children’s health conditions</td>
<td>Research and resources for learning</td>
<td>Success stories – pictorial and written. IT and engaged learning</td>
<td>Accountability systems: demonstrate value – who is using what and how?</td>
<td></td>
</tr>
</tbody>
</table>
The education support needed by children and families (based on the lived experience A) are reinterpreted and responded to, within the guidelines of the interpretive frame (D). In this setting, the Education Department’s definition of ‘at risk’ and its policies in regards to ‘educational engagement’, ‘personalised learning’ and the use of new technology combined with the hospital goals of creating a ‘child focused environment’ and being a centre for collaborative research, are adopted by Integrate to secure funding and elevate its profile within the Education Department, the Hospital and the research community.

Integrate draws on the experiences of children with long term health conditions in the hospital by featuring their stories and accounts – their lived experience – but only in selective ways. ESWs were privy to the details of the extreme difficulties and challenges children and families faced when seeking support in schools, irrespective of whether they were assessed as ‘at risk’ or not, yet only selective pieces of information counted. Jung found in her interviews with university students with disabilities that the ‘subjectivity of the students was cancelled out’, instead as ‘applicants’ for assistance they became instead discursively organised subjects (2000, p. 32).

This complex, lived experience is reduced to a number of highly generalised descriptors when children are included in reporting systems. For instance, Behaviour, Academic Progress, School Attendance or even ‘complex family’ can be interpreted in multiple ways. Similarly, the medical diagnosis e.g. ‘Burns, Brain tumour, Acquired brain injury etc., is presented in isolation without any contextual information that would link the diagnosis with the educational issues.

What is instructional about the development of the official Department reports, in regard to the regional services referral process, was that when Integrate issued the first round of reports it only included children who
were being referred for additional support, the agency suggested what kinds of responses were ‘required’ from the regions e.g. Follow Up, Monitor or Provide Information (Integrate Western Metropolitan Region, Regions and Dioceses Report September 2009).

However, this changed in the next round of reports to include ‘all’ children who had been ‘associated’ with the agency in the hospital and it no longer indicated the type of response required (Regions and Dioceses Report October-December 2009) This shift in the report content to the Education Department demonstrates the way the institutional priorities of the agency begin to mesh with ruling discourses within the interpretive frame. Not only did the number of children being referred to the regions decrease by nearly one third between the issuing of the two reports but, importantly, the report becomes a means to lift the profile of the agency by listing all of the associated contact with children and reduces the amount of follow up work the Agency is committing to, which in turn frees up ESWs for teaching work in the hospital. The omission of the Regional Response request highlights the transition from child advocate to gatekeeper. It also moves the responsibility to act onto the regions and away from the agency, which changes the nature of its accountability. Its accountability to the children is now confined to the hospital.

The experiences of the children are codified in a different way in order to highlight the work of the agency to the Education department by demonstrating the range of health conditions and issues the agency was dealing with, rather than focusing on the needs children themselves. The interaction between the coding and documentation processes translated the experiences of the children into an account which create an organisational action, but not necessarily one which would change the outcomes for the child or family when they sought support from schools.
The construction of an identity called ‘a learner’ also relied on coding lived experiences differently, in this case shifting from ‘patient’ to learner. In the same way that educational needs are assessed and the identity of the ‘educationally at risk’ child is produced, so too is the label of ‘learner’. Such labels are informed by the organizational policies and research literature, embodied in the interpretive frame and applied in a way which may or may not correspond at all with how children may view or describe themselves. For instance, on one occasion an ESW was visiting a girl who was in the final year of her secondary education. The girl’s mother was being discharged from hospital that day after undergoing surgery related to cancer. The girl was worried about what was going to happen when she went home as her mother had been the primary person who cared for her given that her father worked long hours. She was concerned about upcoming exams and asked about ‘special provision and whether she would qualify for a derived score’. A derived score meant she would not have to sit exams but would be assessed based on the work she had already completed and submitted at school. However, the ESW thought she would be ok as she was a ‘good student’. The ESW also explained that the only dispensations available to her would, at best, be ‘rest breaks and more reading time during the exams’. The actual circumstances of the girl’s health and her family situation were secondary to the rules that governed the assessment of educational need but, just as importantly, the fact she had been identified as a ‘good student’ overruled her subjectivity and right to ask for additional support from her school. In addition, being labelled as a ‘learner’ and a ‘good student’ meant she was not categorised as being ‘at risk’.

The legitimacy of the ‘learner’ identity in the hospital was, at times, also highly selective. This was apparent in the account I gave in Chapter Four.
when providing education support to a girl with a disability was a low priority in comparison to other children who were ‘falling academically behind’. The notion that not everyone could have the same level of support, just as in schools where teachers made similar decisions, disregarded the subjective experiences of the girl as a student who also happened to have a disability. It seemed in this account that being disabled somehow discounted the request to be recognised as a legitimate ‘learner’ beyond the confines of a special school environment. The shift from subject to object when the focus becomes the policy or the process yet again demonstrates how the interests of the child and family are supplanted by the ideological practice now framing the delivery of education support.

**Technology, Educational Engagement and Research in the Hospital**

A further activity which was shaping the way education support was being organised in the hospital was that of ‘research’. Research projects which recruited ESWs as well as children as participants were particularly focused on assessing the value of education utilising new technology in the hospital and establishing an ‘evidence base’ which cemented the bona fides of the agency.

The concept of the whole hospital becoming a flexible ‘learning environment’ which offered opportunities across the many departments and wards was initially introduced mid-way through 2008. This new approach reflected the views of the Board and the management of Integrate in wanting to build a greater profile and clarify its role within the hospital. Utilising new technology and seeking out collaborative research projects and partnerships were the signature aspects of establishing this new flexible ‘learning environment’ in the hospital.
However, the change in focus of the agency also served to highlight the way the experienced phenomena of children and families were displaced by another set of institutional imperatives and organisational categories. As the support of educational needs became increasingly focused on the deployment and testing of new technology for use in the hospital, the children and families become positioned as research subjects. Consequently, their experiences take on a different institutional value.

The use of IT in schools is a phenomenon which has been promoted universally by education departments, bureaucrats and politicians as a means to advance access to education, enabling more flexibility for students and schools and improving skills and performance. In seeking to establish the merits of IT for learning outside the classroom the Education Department has been trialling a range of devices, software and on-line learning in schools. In 2010 the hospital became one of a number of trial sites across the state with over 700 iPads being distributed. Integrate described the benefits of being included in the trial in the following way:

> The use of iPads has enabled teachers to create a sense of group and peer-support with students who are spread out across various wards in the hospital and in some cases confined to bed. The use of iPads has assisted [the hospital] to achieve its aim to be not just a health space but also a learning space for young people in its care. For young people returning to their classroom after an illness, this gives them a seamless transition in their learning (Quote taken from education department website reporting on the iPad trial in schools).

It is important to reiterate here that the aim of this analysis is not to judge the good intentions of those working at Integrate; rather the intention is to make transparent what was organising the institutional interpretation of children’s experiences and needs and reshaping the work of the ESWs. To that end the introduction of educational activities, including IT, in the hospital provided interesting and engaging and indeed enjoyable
experiences. However, it was not always clear how these activities addressed the ongoing issues children and families faced when they sought ongoing support from schools.

By presenting the experiences of children and families as research subjects and learners, Integrate could then propose that it is was acting in the educational interests of the child. Yet, when teaching and learning is introduced, as was the case with the learning space on the Adolescent ward (Chapter Five), the voices of the staff were more prominent than the young people and their families. For instance, only staff were included in the project reference group and they provided the detailed accounts in the focus group interviews, while the young people and families only completed a survey. The discursive organisation of the project was focused on demonstrating the efficacy of establishing a dedicated learning space, but it was unclear if this actually addressed the issues of most concern to the young people or only addressed hospital staff concerns.

The Circularity of Ideological Practice in Supporting Educational Needs

The final section of this chapter discusses an evident ‘circularity’ of ideological practice in supporting educational needs arising from the way in which problems are defined and seemingly solved. The text-action-text sequence described above demonstrates how the experiences of a specific group are reframed. They become ‘issues’ identified in research literature and by those with vested interests. In this case, the interests of the Board of Integrate, the Education Department and the hospital were all instrumental in reframing the lived experiences of the children and their families and shaping the role of Integrate in the hospital.
The changes implemented by management were connected to the departmental review which advised the management and Board of the agency. The review would ultimately make recommendations to the Education Department about the future of Integrate, based on its ability to identify a specific ‘cohort’ of children and document the efficacy of the approach it was taking in the hospital. In addition, the Board of Integrate had identified its goals. As the work of ESWs began to change, so did the way in which education needs were represented; the types of activities offered by Integrate within the hospital also began to change. In the process it became selective about which aspects of educational engagement it included in documentation and which experiences it focused upon. This contributed to a constructed reality which ordered the work of ESWs and the activities of the children. The Ministerial visit brought this to the fore when children were brought from the wards to attend the event, even when they were in pain. The official photographs show the Minister with one of the children on the ward although this particular child had not attended the actual event – making it a somewhat artificial reality. The photograph in the case study of the girl used in the regional forum announcing the new referral system, reinforced the notion that ‘support systems’ were working for children returning to school, even when ESWs knew families and children with significant health issues often faced considerable hurdles gaining entry to mainstream schools.

Furthermore, by Integrate aligning its business case, services and research projects with the objectives of the Education Department and the hospital, it no longer was acting as primarily as an advocate for children and families or issues emanating from schools. Instead, it became an advocate for the programs and initiatives of the Education Department in utilising devices such as computers, and for the hospital itself. The children become subjects providing important evidence of education happening in the hospital and
examples of educational ‘success stories’. The new identity of the ‘flexible learner’ overtakes the actualities of living with health issues and the difficulties within mainstream education, of supporting children with the associated range of educational needs.

The interpretive frame reflects ruling interests which are not necessarily addressing the issues facing children and families. For instance, the introduction of research funded by the Education Department to study the use of iPad computers in the hospital and the development of the Orb project, both had overt connections to education policies promoting the value of IT in education in the classroom and beyond. However, the presentation of technology in this way avoids the complex questions about the experiences of children with health issues accessing schools and the realities of being isolated from their friends.

In this way the circularity and self-reinforcing elements of Integrate’s ideological practice in delivering teaching and learning in the hospital becomes evident. By shifting the focus to the hospital the agency meets a number of key objectives. Firstly, it can promote its work as supporting the educational needs of children with health conditions, secondly, it has identified a ‘cohort’ of children who are at risk and therefore require specialist support. Thirdly, it has established a system of accountability consistent with Education Department processes by referring children it has assessed as ‘at risk’ to external support services. It has therefore met its obligations to its funding body and to its ‘host’ – the hospital. The imposition of categories such as ‘learner’ or ‘educationally at risk’ or ‘research participant and/or self-advocate’ selectively and artificially imposes a subjectivity upon children and families which ordered the way in which ESWs supported them. Most importantly, it fitted these lived experiences within a schema of education support which constructs a reality which suited the institutional purposes of the agency.
In considering how I was going to conclude this thesis, quite serendipitously, I read two newspaper articles which appeared in the same paper on the same day. They provided a stark reminder of the gravity and consequences of the issues which I have been trying to make sense of for seven years, but in reality they have haunted me for most of my life.

The article appeared on the front page of a metropolitan daily newspaper with the headline: ‘Ferals’ teacher payout’. The article claimed that the Education Department in one state could face a ‘wave of lawsuits’ after a judge awarded damages to a former teacher who had experienced depression ‘after he was forced to teach the worst behaved students in the school’. The school is located in the outer western suburbs and it had instituted the commonly known practice of dividing students into ‘streams’ called – accelerated, high achievers, medium achievers, low achievers and foundation. The children in the ‘bottom classes’ were identified in the article as those with ADHD, dyslexia, acquired brain injuries, disabilities such as Autism and whilst most of the other students were ‘very badly behaved’. They were all clustered together in what is called ‘foundation studies’. It seemed that the majority of teachers at the school had opted not to teach foundation studies, leaving this teacher with children who had significant problems and who needed the most intensive support. Interestingly, he said he had been given training at the school for ‘gifted children’ but nothing to prepare him for the ‘most challenging students’. The principal of the school commented that ‘parents sent their children to the school because of the streaming model, which had led to it performing higher than similar schools in the state’s Certificate of Education. He then added:
We no longer allow teachers to request to teach at only one level (Lee and Topsfield, 2014, p. 1, 6).

The article did not however, tell us anything about the students and what may have happened to them over the last ten years. We can only assume that their fate has not been good either, however, the failure of the education system toward them will not result in a million dollar payout as compensation. They are only know as ‘ferals, the badly behaved and dangerous’.

Interestingly, in a different article in another part of the newspaper on that day a feature piece appeared about an internationally well-known chef. One of his colleagues was asked in the article about this particular chef’s philosophy and his success in business – and his ‘exacting standards and perfectionism’. The former head chef replies:

They are perfectionists, yes, but if someone is not performing, the instinct is to lift that guy up. He says, Yotam is an extremely patient man and he has a great big heart (Wheatley, 2014, p. 10-13).

The two articles go to the heart of what is missing in education when the focus is on performance and standards, rather than equity and inclusion. In streaming students to get the best results for the school, what happens to those with health issues, disabilities and behavioural problems? Where is their place in a school? What are we to make of the way our schools function and of policies which repeatedly fail to provide the resources where they are needed most? How can a school proclaim having one of the best exam results in the state when it has students who are doing so poorly? Did we ever actually leave segregation behind or does it go under another name called ‘streaming’?

The professionals working at Integrate are situated in a children’s hospital where they encounter school aged children with a range of health issues and
education needs. Some of these children will be diagnosed with ADHD, Autism and dyslexia, or they may have experienced trauma leaving them with acquired brain injuries. Children are now living for longer with health conditions that in the past would have shortened their lives and they certainly would not have been able to go to school and continue their education. This trend will only continue to increase the number of children facing challenges in schools. Astounding successes in paediatric medicine have compounded pre-existing issues concerning the inclusion of children with a range of learning needs in mainstream schools.

Establishing Integrate was one response to the problem of bridging the gap for these children. Yet, when I began to trace the map which shows the social organisation of the work of this agency I find it has come in full circle – back where it started – focused on the hospital. In addition, it has become absorbed within systems which categorise needs, but has no answers for how children should be properly resourced and supported ‘in schools’. The kindness of the ‘one caring teacher in the school’ is simply not good enough. Confusingly the hospital, via Integrate, receives resources and funding to improve its services and further its reputation for putting the child first. Meanwhile what is happening in schools?

What happens when the camera shifts from the hospital to the school – which pretty and engaging pictures of students are being taken? More than likely, the photos are not of those in classes such as foundation studies. When the little girl with the tracheostomy tube, wheelchair, ventilator and who cannot speak turns up for class, where will she be placed? Who will support her and what will be the quality of her education?

Understanding how the work of educational professionals is organised within a complex of ruling discourses assists us to identify how the actual experiences of children with a range of educational needs are sometimes
rendered invisible or only partially revealed, in order to suit particular administrative functions. It is vital that teachers understand how their actions replicate disadvantage through the application of categories which marginalise children.

Dorothy Smith contends that people need to be able to see how their work is organised in order to consider how they might do things differently (Daniel 2008, p. 251). For those working at Integrate, providing services and interacting with two highly bureaucratic institutions – education and health – it is important to develop an understanding of how children’s actualities are re-constructed by a range of discourses. However, these discourses unintentionally undermine the democratising elements of inclusion when they disregard the specificities of the child’s experiences. The particular ways in which the experiences of children and families are reframed and deconstructed to suit a range of institutional purposes, reinforces dominant perceptions about ‘normalised’ learning and the extent that technology can ‘fix’ complex issues surrounding access and equity in education.

In labelling another cohort of children ‘at educational risk’, or nominating them as ‘successful learners’ and seeking them out as ‘research participants’, we focus on particularised facets of their lived experiences. In doing so the actualities of living with long term health conditions are fractured and on occasion rendered them totally invisible. Such incomplete accounts undermine efforts to encourage inclusive practices in schools – or even within a hospital environment for that matter.
Bibliography

Note to readers: The bibliography presented for public viewing has been anonymised in order to protect the identity of the agency in this study. The examiners of the thesis were given access to all references before this process of redaction was undertaken. This was done with the agreement of my supervisor and in consultation with the University, Office for Research Ethics and Integrity.


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Education Act 1958:1117(Vic).

Education and Training Reform Act 2006 (Vic).


Hospital. (2010). Annual Quality of Care Report. Melbourne, Australia. NAME OF ORGANISATION REMOVED TO MAINTAIN ANONYMITY.

Hospital clinical guidelines. Engaging with and assessing the adolescent patient). NAME OF ORGANISATION REMOVED TO MAINTAIN ANONYMITY.

Hospital School. (1992). Annual report. Melbourne, Australia. NAME OF ORGANISATION REMOVED TO MAINTAIN ANONYMITY.


Integrate (2002). Annual Report. Melbourne, Australia. NAME OF ORGANISATION REMOVED TO MAINTAIN ANONYMITY.


Integrate (2007). Board of Directors ‘Internal’ Future directions discussion paper. NAME OF ORGANISATION REMOVED TO MAINTAIN ANONYMITY.

Integrate 2008-09 Business Plan. NAME OF ORGANISATION REMOVED TO MAINTAIN ANONYMITY.

Integrate Constitution NAME OF ORGANISATION REMOVED TO MAINTAIN ANONYMITY.

Integrate: Change and Impact Summary 1999-2002. NAME OF ORGANISATION REMOVED TO MAINTAIN ANONYMITY.

Integrate (1999). Submission for Department of Education Tender: The provision of direct educational services to school aged students. NAME OF ORGANISATION REMOVED TO MAINTAIN ANONYMITY.

Integrate (2006). Internal evaluation document. NAME OF ORGANISATION AND AUTHORS REMOVED TO MAINTAIN ANONYMITY.

Integrate (2005). Victorian Education Department. General Purpose Contract Schedule 2: Empowering schools to maintain social and academic connections for students with ongoing health conditions. NAME OF ORGANISATION REMOVED TO MAINTAIN ANONYMITY.

Integrate (2009). Internal report. Western Metropolitan Region, Regions and Dioceses Report, September. NAME OF ORGANISATION REMOVED TO MAINTAIN ANONYMITY.


Integrate. (2013) Research Project- Executive summary: Posted on Hospital Blog. NAME OF ORGANISATION REMOVED TO MAINTAIN ANONYMITY.


University of Melbourne. (2011). Research Findings in collaboration with Integrate. AUTHORS NAME, TITLE OF PAPER WITH HELD TO PROTECT ANONYMITY OF ORGANISATION.

University of Melbourne. (2008). Research conference paper). AUTHORS NAME, TITLE OF PAPER WITH HELD TO PROTECT ANONYMITY OF ORGANISATION.


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Date: 2015

Persistent Link: http://hdl.handle.net/11343/50964

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