**Australian Association for Research in Education 2008
November 30- December 4th, Brisbane
Changing Climates: Education for Sustainable Futures**

Symposium Title: Schooling, identity and social connectivity: Sustainable futures for young people with chronic health conditions.

Paper 4: Schooling, identity and social connectivity

Abstract

This paper will report on the progress of a large three year Australian Research Council (ARC) grant awarded to a multidisciplinary team of researchers in Victoria, Australia. The research, *A multi-disciplinary investigation of how trauma and chronic illness impact on schooling, identity and social connectivity* commenced in 2007 and is known as *Keeping Connected* (2007). The research is a collaborative grant in partnership with the Royal Children's Hospital Education Institute, in association with the Melbourne Graduate School of Education, University of Melbourne and the Centre for Adolescent Health, Royal Children's Hospital. The research aims to investigate qualitatively, longitudinally and through multiple perspectives how young people construct/reconstruct identity and relationships with schooling following disruption associated with chronic illness. Using a mixed methodology, but with a central focus on longitudinal qualitative studies from the perspective of the young people, the study aims to identify key elements of disruption or continued connection, and will illuminate identity issues of people facing this disruption at different age and schooling points. The research outcomes will support education and health practices and provide a differently focused empirical contribution to the literature on education and social connection. The paper works at mixing methods qualitatively, rather than focusing on the overall mixed method design of the study. Assemblages of social capital theory and sociomateriality may be a useful standpoint for the development of our empirical contribution.

This research is ambitious at many levels. Practically we are working between a major hospital and linked education and health institutes and a large university graduate school in Melbourne, Victoria. Not withstanding the complexities of the research environment, the project is well supported financially and has a highly committed industry partner that has a genuine belief in research and its capacity to make a difference to the lives of young people with chronic illness. Our research about connectedness may have the potential to contribute to discussions and operationalising social capital theory more broadly, but we may also be simply sliding into Fine's 1999 analysis of social capital as a "catchall, ambiguous if not incoherent, and yet analytically selective" project (Macinko & Starfield p. 394). Fine's remarks remain in the background of my thinking as the first phase data analysis of the qualitative case studies begins.

Social capital in brief
Initially it is useful to remind ourselves of the broad affirmation of social capital and civil society that Putnam and colleagues concluded after their 20 year study of decentralisation and economic development in Italy. Regions such as Tuscany and Emilia-Romanga were found to exemplify strong social relations and higher levels of civic engagement which in turn leads to greater trust, enforceable norms and dense networks of association amongst citizens. Of interest to educators is that Emilia-Romanga, one of the 20 regions of Italy includes the province of Reggio Emilia. Reggio Emilia is an affluent town of northern Italy, and is well know in progressive education and early childhood circles for the substantive contribution to municipal child-care and education programs for young children. Reggio principles have been affirmed by educators working in the middle years of schooling and sustainable

education (Bolger & Behrenbruch, 2005).

Given Putnam's work and the importance of a civic culture and what happens in a society when civic culture declines, what is known of education in one of these provinces and recent interest in the utility of social capital research on health determinants and education (Mackino & Starfield, 2001; McGonigal et al. 2007) operationalising social capital theory may be useful to framing our research. Australian research, acknowledges the considerable body of social capital research that has accumulated, but points to the "considerable gaps in the literature that limit its utility for policy development purposes" (Spoehr, Wilson, Barnett, Toth and Watson-Tran, p.6). What is also neglected in the existing evidence base "is research into the negative influence of social capital, and particularly, the factors which can lead social capital to have an excluding effect thereby militating against social inclusion" (Spoehr et al. p. 16). Table 1 on page 4, provides a conceptual reading of an amalgam of the major theories of social capital, set beside explanations of social inclusion and social exclusion. The model framed through two conceptual categories, community and social level concepts is argued as a method to measure social inclusion.

Paper Presented at the AARE Annual
Conference, Brisbane 2008
Australian Association
for Research in Education

Table 1. Conceptual categories of social capital (Spoehr, Wilson, Barnett, Toth and Watson-Tran, 2007,p. 35)

Category A – community level concepts	Category B – social level concepts
Mechanical solidarity Social inclusion and cohesion based upon the likeness and similarities among individuals in a society, and largely dependent on common rituals and routines	**Organic solidarity** Social inclusion and cohesion based upon the dependence individuals in more advanced society have on each other. Though individuals perform different tasks and often have different values and interests, the order and survival of society depends on their reliance on each other to perform their specific task
Bounded solidarity Processes that facilitate the reciprocation of aid and produce norms that work towards the communal good.	**Aggregate social capital** The aggregate of the actual or potential resources that are linked to possession of a durable network of more or less institutionalised relationships of mutual acquaintance or recognition
Bonding social capital Bonding networks that connect people who are similar and sustain particularised (ingroup) reciprocity.	**Bridging social capital** Bridging networks that connect individuals from diverse backgrounds and which sustain generalized reciprocity.
	Linking social capital Relationships between people who are interacting across power or authority social structures, which leverage advantages for the owners of this form of capital.
Emotional solidarity Solidarity that binds groups together through the emotional bonds forged by collective activities. Can exclude those who have not shared the collective experience.	**Social exclusion** A subjective experience of inequality and unfairness as materially deprived people seek to obtain the unobtainable.

Foregrounding educational relationships in research on chronic illness

Whilst we have been able to specify in our initial research design that the study will investigate the experiences and perspectives of young people whose schooling is disrupted by illness and trauma, from the perspective of our partners, the research aims to produce guidelines for better practice by

health and schooling professionals and parents of such children, and provide better knowledge about the processes by which disconnection occurs. The research aims and outcomes include civic, social and educational aspirations.

In the research we asserted we would take an approach that foregrounds education relationships. We know that while leaving school early does not necessarily preclude pathways to further study or work opportunities, it does increase the likelihood of periods of unemployment, restricted options for employment, reliance on government income support and adverse health outcomes (MacDonald, 1999; Dwyer & Wyn, 2001; Lamb, 2001; Lamb et al., 2004). Students who experience (accident-based) trauma and chronic illness (TCI) are highly vulnerable in respect of their social connectedness and patterns of educational achievement, since disengagement from school is a process rather than an event (MacDonald, 1999; Osterman, 2000; Dwyer & Wyn, 2001; Lamb, et. al, 2004) and disruptions of social attachments during the early teenage years are well established precursors to mental health problems, depression, and persisting difficulties with peers (Monck et.al. 1994; Bond et.al, 2001). But how do these young people see themselves? The data for the research draws from quantitative and qualitative sources and includes visually constructed data (Bach,1998; Author, 2002; Rich & Chalfen, 1999; Rich, Lamola, et al, 2000) from case studies (Stake, 2005). We have recruited 30 young people aged between 13–17, to produce visual data from both digital and video sources. The first phase case studies, 30 in total, are nearing completion.

Data generation
In the first stage of the research, the following has occurred:

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1. Ethics, the production a 161 page document that included plain language statements and consent forms;
2. Survey distribution to young people with a current referral to the Royal Children's Hospital;
3. 30 phase 1 case studies, voluntary recruits from the survey.

Phase 1 qualitative data and the analytical issues

While these data are being returned for our initial analysis both as individual researchers and for cross case analysis as a qualitative research team, we have yet to face the issue of the way that we can in detail theoretically construct the analysis that offers fresh insights but also entangles the production of visual data. As an education provider our partner has attempted to disentangle their work from the highly medicalised models such as visiting teacher services, that surround the past history of support to students with physical disabilities and chronic illness. Rather the focus for our research partner, is to develop within schools an internal culture of sustainable support. Support services have a reasonably long history within education in Australia. Many of these services were developed during the late 1960 and early 1970s as visiting teacher services, school based psychology or student welfare teams, depending on the location of the school. Typically urban schools have had a greater concentration of these services as remains today. Support models have in common a lineage to guidance, educational psychology and special education services. One of the issues with these models are the inadvertent exclusionary properties these constructions of established support deliver (Author, 2002).

A number of arguments have been advanced in the literature on both the successes and failures of support models. For some time in the fields of inclusive education and middle schooling the struggle has been laid open to

develop heuristics that both provide and open up avenues inside schools the solutions to complex multidimensional issues, such as student learning support, vocational planning, health and well being. The international literature affirms that students with developmental disabilities do have a recognised system of service delivery, but students with chronic health conditions "do not have a service system designed to meet their health and educational needs at school" (Thies & McAllister, 2001). The literature on students with development disabilities is however highly contested and does not offer straightforward narratives of successes or liberation (Author, 2002).

Australian research overall is limited in the area of chronic illness and support services. The issues, or the evaluation of existing systems have not been conceptualised from the multiple positions of policy, student school experience and perspectives from the voice of young people and their social networks. Shiu (2001, 2004) has identified this area as one that needs further attention, and has surveyed parents and teachers in NSW about their perceptions of what is needed. Dockett (2004) has identified some particular friendship issues for young children returning to school, in a small interview study of parents and children with chronic illness. The educational and adolescent health literature emphasise the importance of flexible school policies built on partnerships between health and education systems at the community and state level (Thies & McAllister, 2001).

Identity, representation and connections to schooling
To produce the phase one case studies all researchers were required to make individual contact with the young person and seek their and their parent/s consent. This involved researcher presence in their home. Contact extends to 1–2 hours. In the qualitative case studies developed initially through the use

of visual and photo voice techniques, we have been struck by the ways these young people aged between 13–17 have constructed their stories. What they wanted to tell us was about wellness. Amongst the everyday clutter and sounds of siblings, the ensuing kitchen table conversations have provided through visual and interview data, thick and lively accounts of what it is like to be a young adult, living a life in twentieth first century Australia. Wellness narratives, friendships, social inclusion and exclusions in the community and at school, engagements or not with school and life aspirations converge. Students have produced anything from 500 to a handful of digitised still images from simple low cost cameras.

How then does this first stage of qualitative data support our partner in understanding the relationships with schooling following disruption associated with chronic illness? Allan indicates social capital theory "has the potential for strengthening community, by emphasising the value of connections between people" but "there is a difficulty with operationalising social capital and even the concept itself has been considered under-theorised" (2008, p1.). McGonigal et al. (2007) reporting from the *Schools and Social capital Network*, (part of the Applied Educational Research Scheme in Scotland) situates a collaborative review of existing theory of social capital, with a particular emphasis on its significance and value for school and community context. The review attempts to define social capital in relational terms through the seminal contributions of Putnam, Bourdieu and Coleman. Taking a focus that is relevant to schools, the group seeks to identify the different types of social capital – bonding and bridging – and the "social capital 'resources'" (McGonigal et al. 2007, p.77) brought to school by children, families and communities, and acted upon by the schools

themselves. Further, the Scottish *Schools and Social capital Network* investigated the particular relational networks within schools and the prevalence of trust, a key dimension of social capital.

In our qualitative data collection to date, we have been positioned inside the homes and lives of these young people. We have experienced this through the struggle of attending to our data collection where to all intents and purposes and the ethical guidelines it is the voice of the young person we were attempting to foreground. But our data sources appear to be getting all mixed up both through the visual data and ensuing memory work that is added through the photo elicitation method as we attempt to produce data with the young person in their own home through visual methods.

Visual methods are now making a greater contribution to educational and health research. Intertextuality is defined by Shirato and Webb (2004) as "the process of making sense of texts by reference to other texts, or to meanings that have already been made in other texts" (p. 196). Jennifer Mason (2006) shows us that these approaches are an important dimension to the recent developments of qualitative research.

> Yet, although it is fairly widely accepted that our theoretical orientations inform our methodological practice, it is perhaps less readily recognized that this process works in reverse too (Skeggs, 2001). Our ways of seeing, and of framing questions, are strongly influenced by the methods we have at our disposal, because the way we see shapes what we can see, and what we think we can ask. In that sense, researchers can fail to appreciate how methods driven are their questions (p. 13).

As a 'city' based organisation our project partners are spatially peripheral to the main game of the students' lives. They are in-between the students' school experiences and the medical services and geographically distant, even if a student lives in Melbourne. The partner organisation as an education based institute is dislocated geographically from the immediate community

networks of these young people and their families. The hardship, either economic, social or both faced by the young people and their families managing a chronic illness is ever present as are the disparate sets of relationships with professionals. When I call my case study participants, the query, "Who are you? We deal with so many people" or after a visit, the comment "Thanks for coming, we don't get many people up here", affirm the disjuncture of these lives. A key part of Bourdieu's analysis of capitalist society and social divisions is the extent to which individuals actively draw up on social capital, "taking advantage of community resources to improve their own economic position while in the process learning lessons of trust and reciprocity in their dealings with others" (Mc Gonigal et al. 2007, p.83).

Our research problem is centred on connectedness and schools and young people's lives. Our data sources of interest at this stage of the project are the case studies collected by 7 individual researchers. We intend to do cross case analysis, however at this point in time we are attempting to see how these visual data sources illuminate the lives of these young people, some of whom have continuing interruptions to schooling. Some of our 30 case study students are not able to attend school at all. Some attend government schools, others are enrolled at catholic schools and independent schools, meeting attendance requirements. Others however are frequently marked absent.

What supports these young people's connections to schooling? The first layer of case study data generated from digital still images reveals that very few young people have taken their camera into schools. They have concentrated on a life outside of school. Friends, families, naming photography as a hobby, the way things are for me now, not when I am

unwell well, but when I am well. Emerging initially as snap shots these digitised images if we look to recent work in visuality and the range of theoretical position that support this field in the production of social science and education research (Author, 2008; Thompson, 2008) these student produced images can be understood as opportunities for the young people to reflexively *perform* an identity through their self generated images.

Rather than understanding the images as lifeless and static objects and a springboard to get to the source of the real data "the interview" produced as photo voice after the assemblage of the images alongside the researcher, what we are needing to have at hand theoretically, as indicated by Shiu (2002, 2004) will demand multiple theoretical perspectives. Social capital theory, poststructuralist theory and socio-material practices are potentially enabling of an analysis that can pursue relationally, beyond the functional and privileged signifiers of the field of being ill and being chronically ill at school. As these young people stand both in front and behind of their digital cameras they have offered us a gallery of "imagery"[i] constructed from socio technical connections with and alongside chronic illness.

The research team are ready to move on from the first phase of data production. At one level we all will need to do this as it is a requirement of the project to collect other imaged based data sources that include video data in the second wave of the project. Potentially all of the phase 1 data generation in the first instance could be read as an integrated visual data set and subject to a socio-material analysis after Latour (2005) and Haraway (2004) through the human and the non-human, producing an analysis that "looks more like a trellis, an esplanade than a tree. You cannot tell up from

down, and everything seems to go sidewise" (Haraway, 2004, p.298). Placing the medical and the social in a differing relationship, this form of analysis focuses how the young people's "(e)ntities and phenomena come into being in relation to each other through actor-network assemblages of things, people, artefacts, places, machines, mobilephones, and so on. (Al-Mahmood, 2008, p.148). As Al-Mahmood continues, "(t)he power of the relational tool of ANT is that it surfaces the breadth of materialities, so, for example, we can glimpse how the embodied practices of learners, their spaces, and their learning are interconnected through human and non-human entanglements…"

Entanglement with social capital theory and some of the concepts may also be useful, but with due regard to an analysis which seeks to undo concepts of social capital that mitigate social inclusion. A common problem with defining social capital is uncertainty over whether social capital is a value held, such as trust, or a network that facilitates action, such as a voluntary association. Most definitions now appear to incorporate both aspects. The Organisation for Economic Co-operation and Development (OECD), for example understands that:

> Social capital has been defined variously by different researchers, but is here taken to include the networks, norms, values and understandings that facilitate co-operation within or among groups. It is to be distinguished from the more formal political, institutional and legal arrangements which have a complementary role in this process (OECD, 2001).

A further dimension possibly is that social capital may be comprised of participatory actions or practices in themselves. Putnam (2000) included various measurements of social capital involving not just cultural norms such as trust and associational networks, for example membership but measurements of actions such as volunteering. Doing this through a first

stage visual analysis may seem impossible. But Bourdieu has made a contribution to the understanding of cultural practices through the social uses of photography (Bourdieu, 1965, 1990).

Producing knowledge about chronic illness
In this project we have invited the young people to tell their stories initially through digitised relationships with their social contexts. They have volunteered their lives openly with an enthusiasm which has surprised what some members of the qualitative team may have expected in a phase 1 data production. These young people have on the whole told little of their contact and experiences with schooling. Some schools have banned the cameras, other students have not felt comfortable taking the camera to school. Some students who are not attending school due to their illness are unable to recall through imagery the socially embedded institutional character of schooling but call in associated networks through their memory work. School connectedness and retention is an established key to both immediate and long-term health, academic and life outcomes. The focus on social capital building provides a new and potentially rich theoretical space for understanding the needs of young people with chronic illness. However I do not wish to loose sight of how I got to this thinking, that is the socio-technical networks highlighted by the young people in the first round of data generation. This research has another two years to run and will generate more qualitative and quantitative data. Taking an approach that foregrounds education relationships (rather than an approach that foregrounds chronic illness experience), even though we are at the very early stages of the data production and analysis we have heard little of social capital suggested by Mc Gonigal et al. that might be operating in schools:

- 'Club capital', operating at physical (sport), intellectual (chess or debating) and emotional/social (charity or community service) levels.

- 'Envisioned capital', operating through the imaginary tasks and contexts that are frequently used as learning strategies in classrooms, ranging from role play and simulations to talent competitions and school shows.

- 'Virtual capital' which will use websites and sanctioned Internet

contacts, as well as local media, to link with the wider world. This will also involve the use of mobile phones, even where the use of these in schools is not officially sanctioned.

- 'Working capital' which will operate formally through work experience placements, and informally through part-time and weekend jobs.

- Alternative or 'black economy' capital of subcultures, evidenced in gangs, sets of pals or in-groups, style norms and petty crime (McGonigal et al., 2007, p. 90).

Bourdieu (1965;1990) defines "Photography as a middle brow art'. His reference to the relationship between individuals and photographic process as "a mediate relationship, because it always includes references to the relationship that the members of other social classes have to photography and hence to the whole structure of relationships" (Bourdieu, 1990, p.9) and "the photograph itself is usually nothing but the group's image of its own integration" (p.26) linked to claim by McGonigal et al., that "social capital in theory ought to be observable" (McGonigal et al., p. 91) sets out competing

theoretical disjunctures that may have the potential to reframe understandings of chronic illness. As researchers we could be prepared to understand chronic illness through representations of visual texts and some words that these young people currently are happily generating, that is through mimetic approaches, "reflecting the true meaning as it already exists in the world" (Hall, 1997, p.24). The education of young people with chronic illness, accident and trauma is constructed by specific discourses within schools and in the community that regulate sets of practices that probably are not sustainable. Whether it is the initial service provision, with the education institute, our partner or between the young person and the site of their education, or the connection to the public discourses, these young people have in the first phase of data production put strong **social** stories that rely on community level concepts, bonding rather than bridging capital.

This research has the potential to produce knowledge that better reads and understands the discursive formations of when you are chronically ill and how your connections to education are formed and severed over time. By adding generative tools and concepts drawn from social capital theory and socio material practices, the representations and networks of things, people, artefacts, places, machines, technologies and spaces that these young people have already drawn our attention to, we may well move beyond preconceived categorizations and understandings of when you are chronically ill. The assemblage of a "semiotic square" (Haraway, 2004, p.77) may be a useful analytical machine from which differing conceptions of being connected to schooling can be made and remade. Even in this very early stage of data analysis it is apparent that the quadrants of the semiotic square may include:

A

presenting your self as being well—
also a sign of deep
structures of domination;

B

differential/oppositional images and
practice in a life outside of school
might promise something else
inside of school

C

virtual space and the regeneration
of the politics of hope for ongoing and
sustained podagogies and connections

D

differing biomedical body, a
concept as yet untangled
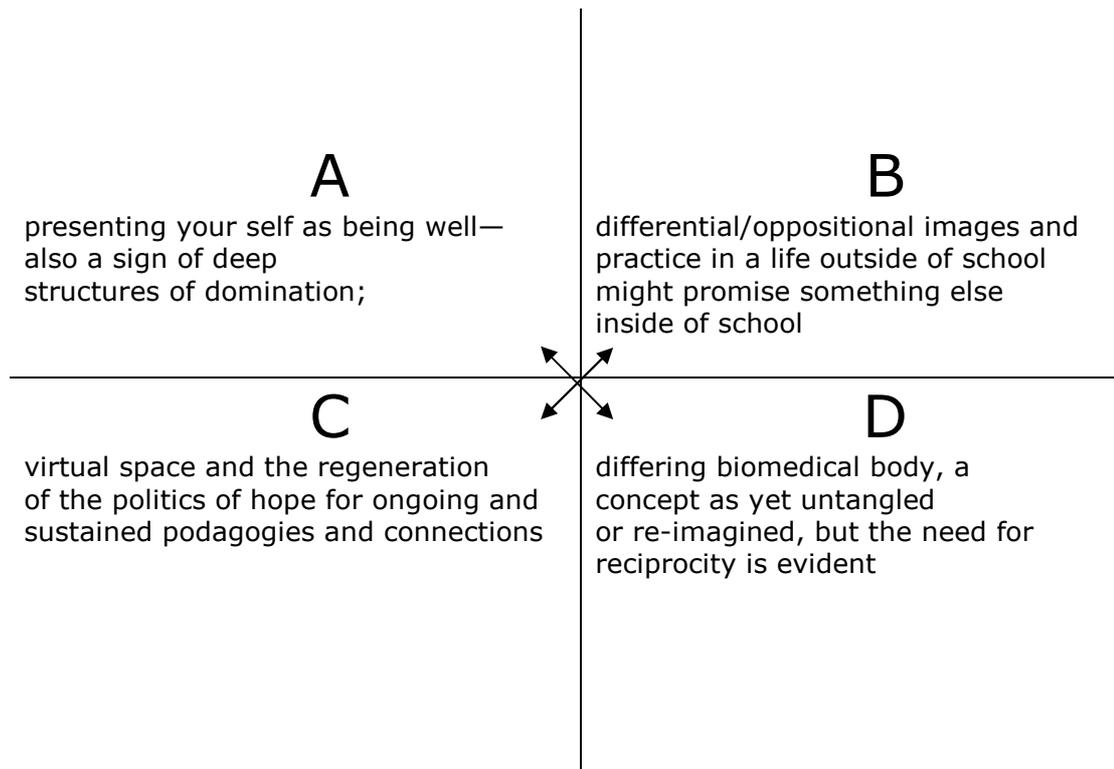or re-imagined, but the need for
reciprocity is evident

Figure 1: A small semiotic sign system quadrant analysis of schooling, identity and social connectivity.

The aim of this paper is to open out the theoretical and analytical possibilities for doing mixed method qualitative research within a larger mixed method design. Representing the emerging standpoints for our potential qualitative analysis the contribution intends to shape a deliberative platform that produces the record of research in progress, records that are often lost or perceived to be ephemeral. In 2009 the data sets from the overall mixed method design and the remaining qualitative elements will be completed. The small semiotic sign system quadrant through the later phases of research will evolve or dissolve. Between these spaces are the issues of identity for young people with chronic illness. The research located within the state of Victoria, Australia, home to more than 1.2 million children and young people, and representing just under 25 per cent of the national child population, will go some way towards understanding the 'ill-self', the 'preferred'

narratives of young people taking into account changing community and cultural

contexts.

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[i] In this paper there is not sufficient space to discuss the arguments that differentiate pictures and images. See Mitchell, 2005, pp. 76-110.