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Changing Climates: Education for Sustainable Futures

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

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Symposium Abstract
This symposium 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 multidisciplinary 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. In this symposium, papers from different researchers involved in the project will discuss the design of the project and its interest in using visual, narrative and longitudinal case-study methods to provide new kinds of perspectives from the young people and on the professional and institutional contexts in which they are located. The papers raise methodological and ethical challenges faced by the researchers in developing the project, and some of the insights that are emerging at this mid point in the research.

Paper 1
Research design and the *Keeping Connected* Project
Lyn Yates, University of Melbourne
Abstract

The initiative to develop a new approach to researching young people involved with the Education Institute of the Royal Children's Hospital in Melbourne came both from the Director of the Institute and from a number of the researchers who are now involved in the project. Those involved shared an interest in the perspectives of the young people themselves, and an interest in understanding how the different professional agendas and practices that they were subject to affected (or failed to affect or support) those young people. The 'industry partner' and the researchers were agreed on the need for a project that took continued connection to school and community rather than the health issue as its research focus. This paper discusses some issues of design and methodology relating to the project. One set of these are what might be considered pragmatic framing effects from external or contingent sources: how the shape of the project we designed is affected by politics of funding, institutional ethics processes, and strategic agendas of researchers working in different institutional contexts. A second discussion elaborates some of the methodological questions we face and debate in the process of the longitudinal qualitative case-study work: issues related to the appropriateness of different steps or techniques to the intent of the project and the possibility of producing good insights and evidence from it. Here the different research histories, interests and theoretical commitments of the large team of researchers, together with our experience of the first wave of the longitudinal case-study work itself, has produced an ongoing dialogue between us about the specific setting up of interviews and the use and limitations of different kinds of visual technologies and other narrative methods for the purpose of this project.

Paper 2:
Negotiating partnership to build strategy for supporting young people with chronic illness in schooling

Tony Potas, Royal Children's Hospital Education Institute
Julie Green, Royal Children's Hospital Education Institute
Pam St Leger, University of Melbourne
Margaret Robertson, Royal Children's Hospital Education Institute
Abstract

The Keeping Connected project emerged out of a developing partnership between the Royal Children's Hospital Education Institute (RCHEI), the Melbourne Graduate School of Education and the Centre for Adolescent Health. It took two years before the partnership relationship was sufficiently robust to reach a point of writing a proposal for an Australian Research Council Linkage Grant. In this paper we discuss the genesis of the project, the issues that had to be negotiated between the partners, the characteristics that we have found necessary to sustain a partnership of this kind, and implications for professionals. For the RCHEI, the industry partner, the key drivers were to: (a) develop an evidence base to further their understanding of how young people see themselves within the changing conditions of their health and the effects of this on their

learning and educational outcomes; and (b) establish a research culture to underpin its service provision. This has significant implications for the RCHEI and the style of service it provides at the health-education interface and associated professional practice in assisting young people to either maintain relationships with their peers and teachers or make a successful transition back to school. Because of its growing standing as a bridging entity and strong networks within the education and health sectors, the RCHEI is well-placed to translate the Keeping Connected research findings into broader policy and practice in both the education and health sectors. From the University's perspective, this kind of partnership presents ongoing opportunities for further research into social inclusion in schools. The ongoing relationship is also a conduit for the University's imperative to disseminate research knowledge into the wider professional community.

Paper 3   Voicing Identity

Peter Ferguson, University of Melbourne
Julie White, Latrobe University
Trevor Hay, University of Melbourne

Abstract

Our complex study has at its core a clear focus on the voice and identity of young people with chronic illness or trauma associated with the Royal Children's Hospital Education Institute. Within the research design the second research question emphasizes this importance of voice and identity: 'What do young people who have experienced TCI articulate about themselves and their experiences in relation to education connectedness, identity, social relationships, experiences with professionals?' We are attempting to explore this question through a combination of ethnography and case study and offer the young people video cameras and digital cameras to support the telling of their story. The project recruited thirty clients of the RCH Education Institute between the ages of 10 and 18 years of age. Young people were allocated to the researchers primarily on the basis of geography and a mixture of rural, regional and metropolitan locations. Initially the young people were identified to the researcher from a data base that was essentially clinical in nature and defined them in terms of location, contact details, age, gender and medical condition. The project was designed for data collection to take place in four waves over a two-year period. In order that the research wasn't driven by researcher presumptions about the identity of the participants, the first data-gathering wave was very open-ended. We wanted to ensure that the power in the research interviews was shared with the young people and that they could describe and portray themselves how they chose. The second wave was designed to introduce the focus of the study, which is connections, relationships and education. The study is now approaching the end of this second wave of data collection. We describe the importance of the developing relationship between the researchers and young people and how this has evolved throughout the project. We highlight issues of voice and reflexivity, not only in the case of participants, but in the relationships between participants and researchers and the relationships between narrative and interview explored in various approaches to recording participant's

experience. Between the three of us, we have fifty per cent of the participants in this element of the study and we have been surprised by the extraordinary diversity and individuality we encountered. This was exhibited through both the stories they told and the methods and artifacts they chose to support their portrayal of themselves. We have learned much about connection - to family, friends, schooling, professionals and other organizations (e.g. Guides, clubs).

Paper 4: Schooling, identity and social connectivity

Julianne Moss, University of Melbourne, Australia

Abstract

This research is ambitious at many levels. It is ambitious not only in the conception of the project and our assertion that we are going to provide a differently focused empirical contribution to the study of chronic illness. Practically we are working between a major hospital and linked education and health institutes and a large university graduate school in Melbourne, Victoria. The team of 9 researchers and two project officers one year ago were all within a single geographic location. Now our workplaces are dispersed across Melbourne, Singapore, and reaching as far as Scotland. 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. 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, 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). 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. 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, but by adding generative tools and concepts drawn from social capital theory and socio material practices, the networks of things, people, artefacts, places, machines, technologies and spaces, we may well move beyond preconceived categorizations and understandings of when you are chronically ill.

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