

SYMPOSIUM PROPOSAL – MAY 15TH 2009

AARE

**November 29- December 3rd 2009, Canberra
Inspiring Innovative Research in Education**

Symposium title:

**Adolescents living and learning with chronic illness:
Resilience, goals and life trajectories**

**Proposed Discussant: Chris Halse, University of
Western Sydney**

Participants:

Peter Ferguson, University of Melbourne

Sarah Drew, University of Melbourne, Royal Children's Hospital

Julianne Moss, University of Melbourne

Ria Hanewald, University of Melbourne

Pam St Leger, University of Melbourne

Mary Dixon, Deakin University

Symposium Abstract

This symposium consists of papers drawing from an ARC project tracking thirty students managing chronic health conditions. The project uses qualitative and visual methods and its focus is on the young people's own sense of themselves, their experiences with education and health institutions, and the trajectory they develop in relation to education, social and family connections and their post school lives. The initial short title of the project 'Keeping connected' reflected interests of our partner in this Linkage project (the Royal Children's Hospital Education Institute) and their concerns about ways schools and hospitals might contribute to disconnection through the approaches they adopted. However in the project many of the interviews with the young people as well as with professional groups and retrospective groups have suggested a different perspective, that the young people, who are the focus of the project, are highly 'resilient'. Their stories and self-depictions often portray very positive (and non-deficit) accounts of how they manage their lives, exhibit resilient characteristics and utilise strategies to project their lives positively into an uncertain future. Even though their personal histories describe an often problematic and disjointed relationship with schooling, education plays a key role in the future trajectories many describe. In this session we bring together papers that focus on different elements of our project to this point (now in its final year). We consider the relevance of the concept of 'resilience' as a way of focusing on young people and their

experiences with and beyond education, a term often drawn from a social work and psychological rather than educational and sociological perspective, and its value and limitations as a way of understanding the identities and trajectories of the young people we are studying. We also consider findings from the project, and in particular differences among young people in our study, and the relevance of issues such as age of onset of the condition, age in relation to schooling, family demographic factors, and family relationships within the patterns we see and the stories we hear. A third paper uses the 'resilience' issue to consider the role that institutions involved in our project play and face in supporting this group. Overall the focus of the session is to convey the stories and experiences we encounter in this longitudinal qualitative study, and to use that material to reflect on the ways in an education context we conceptualise characteristics and needs of young people and their differences.

Paper 1:

Chronic illness and resilience: Personal strengths, material resources and social supports that help young people remain engaged with education and social life

**Peter Ferguson, Sarah Drew, Hannah Walker
University of Melbourne**

Abstract

Adolescence is a time of rapid social, psychological and biological change, with most young people experiencing some degree of 'adjustment' in their lives even if they are in good health. For many it is a time of working out who they are and who they might want to be. Emerging identities are shaped by young peoples' own ways of seeing and coping with the world around them, as well as by a variety of broader social and cultural influences as well. Adolescence is often accompanied by some degree of stress and uncertainty combined with opportunity and planning for the future. As individuals begin to make sense of themselves and their place in the world, they are often more vulnerable to engaging in risky behaviour. Research has identified underlying resilience as a critical trait enabling adolescents to deal with this phase of their lives effectively (Masten et al 1990), although it is a much debated concept, particularly in the adolescent health literature (Olsson et al 2003).

The aim of this paper is threefold. First, to investigate the vulnerabilities and risks experienced by young people with chronic illness. Second, to discuss how resilience underpins their ability to manage the pressures of adolescence combined with a chronic health condition. And third, to consider the personal, material and social resources that help promote that state of resilience. We examine the strategies used by these adolescents to manage not only their illnesses but other stressful events in their lives and how we believe this has made them 'resilient' in the face of significant adversity.

The participants in this study have all had major, and often ongoing, disruption to social and educational aspects of their lives, spending varying amounts of time in hospital care, with prolonged absences and

dislocation from 'normal' social groups and from institutions such as school. The data reported come from a larger study, longitudinal and qualitative in design, which followed a group of these students through three of their adolescent years.

Most of the adolescents exhibited considerable resilience holding on to broader life goals when confronted with a high degree of unpredictability in their day to day lives. They employed a range of strategies and called on external supports to allow them to keep as much 'normality' in their lives as possible. This paper will report on some of these specific strategies and relationships.

While much of the literature considers chronic illness as a significant risk factor for young people, participants in our study appear to be successfully 'managing' their illnesses, and indeed their lives, in a number of ways.

Paper 2:
Growing up with a long-term chronic illness: A story of a girl
Julianne Moss
University of Melbourne

Abstract

This paper, arguably a single case study is produced as part of a three-year project by a Melbourne based multi-disciplinary team who are investigating trauma-affected and chronically ill adolescents and their wellbeing. The research focuses on their developing self-image, their relationships with others and engagement within changing contexts, and their altered opportunities in the world.

The paper develops a case study portrait of a girl. Janita was 14 years old when the project commenced. She attends a local secondary government school and lives with her mother and two younger brothers an hours drive outside of Melbourne. Janita has a mitral heart valve prolapse; a heart problem in which the valve that separates the left upper and lower chambers of the heart does not close properly. As a result, her upper body is bent and her overall physique appears very frail and skinny. Some of the symptoms associated with this condition are palpitations (sensation of feeling the heart beat), chest pain, difficulties in breathing (especially after activity), fatigue, coughing and shortness of breath. Due to her health issues, Janita has been home most of the current year and subsequent years of school that I am in touch with her. When at school, she receives support namely, three weekly one-hour tutoring blocks.

Clothes and body image feature strongly in Janita's life although she finds it extremely difficulty to purchase clothing that she likes and fit because of her body shape. She describes how she wears lots of leggings. Janita does not have anorexia nervosa, but to the untrained eye, one could make that assumption. Stories of public humiliation tumble out as her mother reported a supermarket cashier to her supervisor for making comments about Janita's physique. Janita has a love of animals and wants to be a zoologist, particularly working with monkeys. Alternatively, she would like own a café where she does front of house, overseeing the running of the place. Janita is heavily engaged in the Hospital's support and

entertainment programs. After participating in a number of their events, she has compiled a scrapbook to capture the memories. Like all the other participants in the longitudinal case studies, Janita expressed a desire to feel 'normal' and to lead a 'normal' life, wellness rather than illness is dominant.

Staged over time, the image production part of the study, underpinned by visual methods and interviews, enables Janita to tell a story. Is this a story of a girl, and her personhood struggling against the dominant discourses of education and health services? The case has relevance for educators and health care workers, opening spaces to challenge deeply held views on the traditions of the helping professions.

Paper 3:

Health and Education Professionals Perspectives of Young People who have Chronic Health Conditions

Ria Hanewald, University of Melbourne

Pam St Leger, University of Melbourne

Mary Dixon, Deakin University

Abstract

Throughout the Keeping Connected Project, many stories have emerged about how young people negotiate relationships with their teachers and the health professionals who work with them in hospital. This paper focuses on how these professionals view young people's experiences and their relationships to school and other forms of social connectivity. It also examines the priorities that professionals set in their respective roles and successful and unsuccessful practices that have emerged in both the hospital and school settings.

Data were collected from focus groups, individual face-to-face and phone interviews with metropolitan and rurally based professionals in the third year of the project. From the health professionals' perspective, shifts in their practice have occurred as medical knowledge and technology has extended life expectancy and enabled many young people with chronic illnesses to look forward to social and educational activities in which their peers are engaged. Where the health professionals once saw the health condition first and the young person second, they now see them as resilient young people with capacity to self-manage their lives of which the chronic condition is only a part.

While some education professionals spoke of these young people as students whose needs they tried to meet like any other student, thus taking an inclusive stance, they were, nevertheless concerned about school connection and specific issues coming out of the young person's health condition. These included areas such as funding for integration aides and modifying the school environment; challenges of finding time to modify the curriculum, organize homework and home visits; communicating with health agencies; and ethical considerations such as how much information to disclose to school staff and students about a young person's health condition.

The findings suggest that, for health and education professionals collectively, there is a need for better communication within and across

sectors about how to best support individual young people in achieving their broader life and educational goals. There are also implications for policy and practice in both sectors such as how this knowledge might be diffused into broader professional communities.