

6. DIFFERENT MEANS ME

I Just Learn Differently

This chapter draws on interviews with our sons, as well as observation and reflection that we are able to contribute as mothers of students with a disability. Each of our families has a boy of school age who experiences sensory and physical challenges, and each of our families has experienced difficulties obtaining a diagnosis, encountered disbelief and rejection of their experiences by professionals and extended family regarding the diagnoses of dyspraxia in one case, and Asperger syndrome and Attention Deficit Hyperactivity Disorder (ADHD) in the second case. Our children have faced exclusion, negativity and misunderstanding, and the need for parental advocacy has been important. These elements connect to a common theme of stoicism on the part of both our sons and ourselves, and a constant questioning of what “normal” means for us.

The experiences are authentic and we allow much of the student voice to speak without interruption. The narratives are both powerful and yet are also the ordinary, lived experiences representing many families from New Zealand, Australia, and the wider world. If the stories are hard to hear it is because they share experiences that are in conflict with the espoused commitments to inclusion expressed in national policy, curriculum and school policy. They also challenge ideas about normativity.

LITERATURE

The purpose of the literature briefly reviewed in this section is to note the espoused commitment to child and disability rights, and to inclusive practice. This provides a framework for comparison to the narratives of disability shared later in the chapter.

Rights and Discourse

The United Nations *Plan of Action* sets out three necessary outcomes: the best possible start in life for children, access to a quality basic education, including free and compulsory primary education, and ample opportunity for children and adolescents to develop their individual capacities (United Nations General Assembly, 2002). Rights-based research that connects to the *United Nations Convention on the Rights of the Child* (United Nations, 1989) includes a focus on human dignity, profound moral respect, rightful entitlements, and empowerment (Lundy & McEvoy, 2012).

Inclusion is a matter of social justice (Higgins, MacArthur, & Kelly, 2009; Purdue, 2006). Research can also support the opportunity for children to express a view and facilitate how they are able to express their views (Lewis, 2010; Lundy, 2007).

The purpose of the New Zealand *Disability Strategy* (Office for Disability Issues, 2016) and the Australian *National Disability Insurance Scheme* (Commonwealth of Australia, 2013) is to change society from disabling to inclusive and enabling. These policy initiatives also document a commitment to the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006). The policies also reinforce a social model of disability and reject normative or pathological views. “Disability is a process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people may have” (Minister for Disability Issues, 2011, p. 1). This definition and philosophical commitment leads to the responsibility for society to ensure that barriers to participation and respect are mediated, rejection of negative terms such as “abnormal”, “deficit” and “deviant”; and challenge to the normative basis of terms such as “average”, “age-appropriate” and “normal” (Forlin, Chambers, Loreman, Deppler, & Sharma, 2013; Macartney, 2008; Nirje, 1994; Purdue, 2006).

Inclusive Practice

Curriculum in Australia and New Zealand articulate a commitment to effective pedagogy for all learners, and a view of student competence and capability (ACARA, 2015; DEEWR, 2009; Ministry of Education, 1996; Ministry of Education, 2007); with strong connection to family-centred and strength-based practice (McLachlan, Edwards, Margrain, & McLean, 2013). However, just because a curriculum espouses this commitment does not mean it translates into practice for all learners. Macartney (2012) notes that that educational settings are not “neutral”, but instead “operate in ways that reproduce and/or resist inequality and exclusion” (p. 172). It is important that critical reflection on student experience occurs as “The power that adults have to influence what is happening in an educational environment ... has significant consequences for a child’s identity, learning and participation” (Macartney, 2009, p. 25).

Many publications include examples of effective inclusion experiences (Cologon, 2014F). Participant stories can, however, illustrate that the lived experiences of individuals are not always positive. Of particular impact to the authors has been the publication of research by Macartney (2007, 2008, 2009, 2012), detailing persistent misunderstanding and marginalising discourse. This chapter adds to the literature by documenting the challenges that families have faced with diagnosis, and rejection.

METHODOLOGY

This section reports the design, participants, methods of data collection and associated ethical considerations.