Foreword

In deciding what to include in a foreword to this ground-breaking book, I have chosen to focus on seven ‘big ideas’ to put the contributions into a broad context.

BIG IDEA #1

Along with other children with disabilities, we owe a duty of care to those with chronic diseases, as articulated, for example, in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006). This duty arises from the doctrine of human rights, which aims at identifying the fundamental prerequisites for each human being to lead a minimally good life and to enjoy the full rights of citizenship. It rests upon belief in the existence of a truly universal moral community comprising all human beings. A related position on human rights argues that each individual owes a basic and general duty to respect the rights of every other individual because, by doing so, one's individual self-interest is furthered. From this perspective, individuals accept and comply with human rights because this is the best means for protecting one’s interests against actions and omissions that might endanger themselves. When considering human rights, it is useful to distinguish between ‘positive claims rights’ and ‘negative claims rights.’ The former enjoins us to treat individuals in a positive manner by, for example, providing appropriate education and health care, irrespective of an individual’s degree of disability. The guiding principle the latter is that we should do no harm to people who are different.

Another perspective here is the principles of justice put forward by the American philosopher, John Rawls (1971). He argued, firstly, that each person has equal basic rights and liberties. In the case of those with chronic diseases, I would interpret these to include the right to effective medical treatment and to appropriate education. Secondly, Rawls referred to the ‘difference principle’, in which he argued that divergence from strict equality is permitted so long as the inequalities in question would make the least advantaged in society materially better off than they would be under strict equality. Thus, the extra costs in caring for and educating children with chronic diseases are morally acceptable.

BIG IDEA #2

During its history, the broad field of special education has been the site of two quite different paradigms, or models, which posit certain relationships between individuals with special needs and their environments. The first of these is the psycho-medical paradigm, which focuses on the assumption that deficits
are located within individual students. Historically, this paradigm has been the most widespread and has been used in both the diagnosis and educational treatment of children with disabilities. In this model, students receive a medical diagnosis based on their psychological and/or physical impairments across selected domains and both strengths and weaknesses are identified for education and training. Those with similar diagnoses and functional levels are grouped together for instructional purposes. This model is problematic for several reasons. Firstly, it leads to the attribution of student failure to a defect or inadequacy within the individual, thus masking the role that highly constraining educational systems play in creating failure. Secondly, it wrongly suggests homogeneity within various diagnostic categories. Thirdly, studies show that instruction based on categories is generally not effective. The second approach is the socio-political paradigm, which shifts the focus away from the individual to society and focuses on structural inequalities at the macro-social level. In particular, it draws attention to some/many schools’ inability or unwillingness to accommodate to diversity among their student populations. In the case of children with chronic diseases, both paradigms probably have a place: clearly, some disability-specific medical treatments are essential, but so, too, are educational accommodations to enable all children to receive an effective education. As expressed in the UNCRPD, ‘disability is an evolving concept… and results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.’

BIG IDEA #3

In almost every country, inclusive education has emerged as one of the most dominant issues in the education of students with special needs. In the past 40 or so years, the field of special needs education has moved from a segregation paradigm through integration to a point where inclusion is now central to contemporary discourse in most countries. This trend has been given increased impetus by Article 24 of the UNCRPD, which states, in part, that ‘States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels…’ Elsewhere, I have argued that inclusive education is a multi-faceted concept that requires educators at all levels of their systems to attend to vision, placement, adapted curriculum, adapted assessment, adapted teaching, acceptance, access, support, resources, and leadership (Mitchell, 2014). All these conditions are necessary for inclusive education to succeed. All should be taken into account in providing the maximum possible degree of inclusive education for children with chronic diseases.

BIG IDEA #4

Increasingly, around the world, educators are being expected to draw upon research-based evidence in planning, implementing, and evaluating their teaching, as well as in policy formation. This expectation applies no less to those involved in educating children with special needs, including those with chronic
diseases. Elsewhere, I define evidence-based teaching strategies as ‘clearly specified teaching strategies that have been shown in controlled research to be effective in bringing about desired outcomes in a delineated population of learners’ (Mitchell, 2014, p.3). A second aspect of evidence-based teaching is the increasing attention being paid to data-based decision-making, which emphasises careful evaluation of the impact of teaching strategies on student achievement and behavior.

**BIG IDEA #5**

It is almost a truism nowadays to claim that developments in information and communications technology enable anyone to learn anything at any place and at any time. There are two features of such developments that stand out. Firstly, educators are increasingly recognising that access to the Internet is transforming both the content of what children can learn and how they can access it. Children with special needs, including those with chronic diseases, are no less the beneficiaries of these developments, particularly if they are unable to attend their home school for any length of time. Secondly, the past decade or so has seen rapid advances in assistive technology (AT), defined as ‘devices or services aimed at compensating for functional limitations, facilitating independent living, or enabling elderly or disabled people with activity limitations to realise their full potential’ (Estevez, 2009). Such devices are already proven their worth across a broad range of children with special needs and, with the rapid developments that are taking place in technology, are certain to expand their applications and their coverage. A subset of AT is augmentative and alternative communication, directed at children with special needs who have significant difficulties in communicating with others using speech. Her, too, there have been rapid developments in the range of devices and programmes, with a substantial research literature pointing to their effectiveness.2

**BIG IDEA #6**

No other groups of children need more commitment from their families than those with chronic diseases. Their general well-being and their educational success depends in large measure upon engaging their families. This means developing creative and flexible strategies to engage them, making them feel valued, enabling them to give greater support to their child’s education and welfare, and helping them make informed decisions about their children. Some parents will need support, some will need counselling, some will need training, and all will need the best possible quality information about their child’s needs.

**BIG IDEA #7**

*Inter-Agency Collaboration.* Children with chronic diseases frequently have complex needs spanning health, education and, sometimes, social welfare. Thus, it is imperative that these different agencies work together. This means moving away from ‘silo thinking’ and addressing the needs of these children and
their families in an ecologically comprehensive and coordinated manner. It means, developing system-level interventions that aim to wrap existing services around them. At the very least, it means health and education services working together, always asking, ‘what is in the best interests of this child and this family in this place and at this time?’

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REFERENCES


ENDNOTES
