

Introduction

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From the outset we would like to emphasise that this book is uniquely different from other books on autism spectrum disorders (ASD) in that it is not a compilation of academic research findings. Rather, the book highlights the practices of Aotearoa New Zealand teachers and educational professionals who have adapted and implemented interventions that are evidence-based and align with the recommendations of the *New Zealand Autism Spectrum Disorder Guideline (NZASD)* (Ministries of Health and Education, 2008). It is intended to inform and inspire other educational professionals working with children and young people with ASD who may currently be hesitant to undertake new practices.

As a phenomenon, autism needs no introduction given the regularity with which it features in the media. Media spotlight aside, what we know is that around one in 100 children are diagnosed with ASD in Aotearoa New Zealand,¹ and the ratio gets alarmingly higher internationally. As a result there is a huge impetus, both here and internationally, to identify effective strategies to support individuals with ASD across their life span. The body of knowledge relating to understanding the causes, effects, assessments, treatments and interventions for this condition is growing exponentially.

The growing prevalence of this condition inevitably means there will be a steady increase in the number of children and young people

with ASD in our educational system. This calls for teachers and other professionals to be confident and competent to include children and young people with ASD alongside their peers, rather than perceiving them to be what I call an *and* syndrome: “I have 26 children *and* an autistic child in my classroom/centre.” We hope this book can contribute to dispelling teachers’ angst about having children and young people with ASD in their classrooms and early childhood settings, and support them to ‘give it a go’.

The realm of ASD

So why have we chosen to present case practices related to ASD? Why does the condition attract such a high profile in comparison to other forms of disability, and why is it often a major barrier to children and young people accessing and participating meaningfully in their educational contexts? The answer lies in the complexity of the condition. It is now well established that ASD is a neurological (mis)configuration that results in reciprocal communication difficulties and behavioural challenges across the life span. The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (American Psychiatric Association, 2013) stipulates the presence of two core factors as the basis for a diagnosis of ASD: “communication and social deficits, and fixed or repetitive behaviours”. However, these difficulties exist in various permutations and combinations among individuals with ASD, making it a particularly idiosyncratic condition. The common saying that goes with this phenomenon is that “If you know one child with autism, you know one child with autism”. This highly individualistic nature is an ongoing challenge for educators who may perceive themselves to be pedagogically less equipped to provide meaningful learning opportunities for those with ASD.

Since there is no known cure for ASD, the condition is best managed by having an early diagnosis and appropriate interventions, which can lead to better outcomes for the individual. Given that the condition is life-long, there is a wide range of interventions across multiple settings during various stages and ages. Currently these include therapies such as sensory therapies, speech and language therapy, diet therapy, music therapy, and behavioural and developmental interventions, with the latter two being the most prevalent and subscribed interventions for

improving social, behavioural and adaptive skills (Ospina et al., 2008). The nature and intensity of interventions vary vastly depending on the severity of the condition. It is a fundamental tenet that whatever the nature or duration of the interventions, they follow the ethical principles of doing no harm and are undertaken in the best interests of the individual with ASD.

Within a plethora of interventions, some aim at teaching specific skills in discrete settings, while others take the approach of using natural contexts including classrooms and early childhood settings. The key to the success of any intervention is that it is flexible and adapted to an individual's needs—one size does not fit all. There are currently many interventions that are trialled repeatedly and evaluated internationally to establish their rigour and face validity, thus building a strong collection of evidence of what works for individuals with ASD.

What is evidence-based practice?

Evidence-based practice (EBP) has its origins in the medical field, but slowly and surely it is permeating education to systematically improve the quality of outcomes for all children and young people, particularly those with disabilities (Cook, Tankersley, & Harjusola-Webb, 2008). However, in both health and education what constitutes a rigorous evidence base continues to be debated among researchers, practitioners, families and those with disabilities.

Recognising the importance of family values, culture and beliefs, as well as the expertise of professionals and the findings of research, Bourke, Holden and Curzon (2005) have proposed a three-ringed model of EBP. They propose that EBP lies at the intersection of the three bases of knowledge: research evidence; knowledge held by families, children and young people; and the expertise and experience of practitioners and professionals.

Bourke et al. (2005) strongly argue that evidence from each of the individual areas of knowledge (the circles in Figure Intro.1), though critical and valuable, is unlikely to produce as effective an outcome as when all three aspects are involved. They situate EBP at the intersection of the three bases of knowledge. In most instances this framework underpins the approach already taken by many teachers and other professionals working in educational settings. Macfarlane (2012)

Evidence-Based Practice

What constitutes evidence?

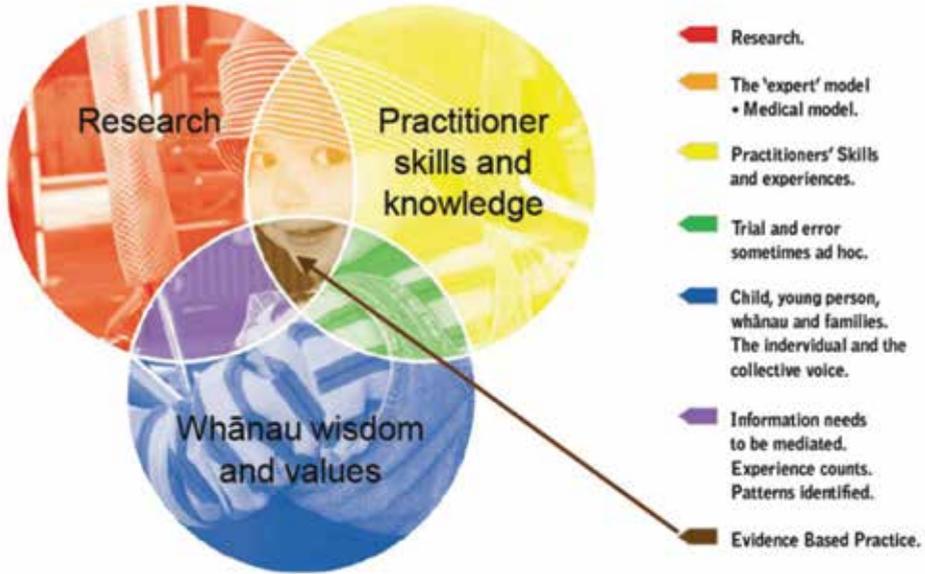


Figure Intro.1 The three components of evidence-based practice
Source: Bourke, Holden and Curzon (2005)

Culturally responsive EBP He ritenga whaimōhio

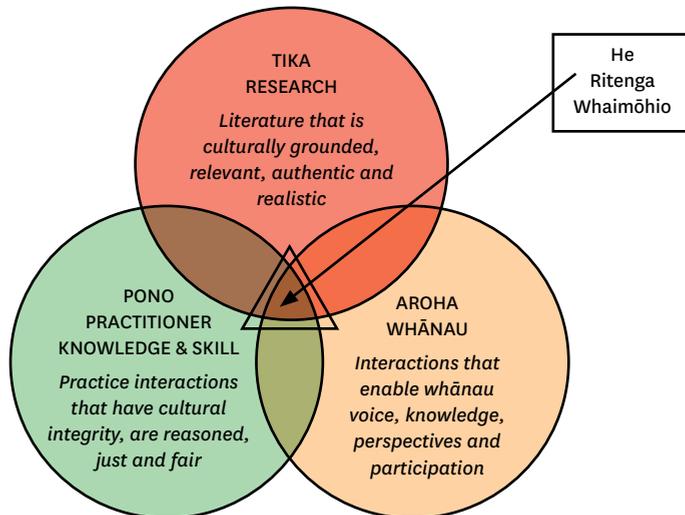


Figure Intro.2: Components of culturally responsive evidence-based practice
Source: Macfarlane (2012)

has integrated the concept into a Māori cultural framework of tika (research), pono (practitioner expertise) and aroha (embracing family expertise).

Mazzotti, Rowe and Test (2013) summarised EBP as making decisions that draw upon the available best research evidence, tempered by professional judgement and the needs and values of students. Schlosser and Sigafos (2009) view the three circles of evidence as *cornerstones* for practice, while stressing the importance of the *social validity* of EBP.

Internationally there are large ongoing projects to identify and build a strong evidence base of effective strategies that have been repeatedly proven to be successful—from diagnoses through to intervention and assessment for ASD. One of these projects is led by the National Autism Center in the USA, which has a programme dedicated to evaluating and identifying evidence of interventions that are trustworthy and have statistical and social validity. Their National Standards Project² report of the Phase 2 ASD evaluations has identified 14 interventions that have been “thoroughly researched and have sufficient evidence for their effectiveness” (National Autism Center, 2015, p. 41). Similar programmes to identify effective ASD interventions are being conducted by the National Professional Development Centre (NPDC)³ and Research Autism.⁴

The Aotearoa New Zealand context

Over the past decade and a half Aotearoa New Zealand has paid considerable attention to improving the learning and social outcomes for children with ASD. One initiative—a world first—is the compilation of the *NZASD Guideline* (Ministries of Health and Education, 2008)⁵ Although not mandatory, the *Guideline* has been well received by educational professionals, who see this as a valuable resource for their practice. This exhaustive best practice compendium is a cross-government sector initiative funded by the Ministries of Health and Education.

The scoping of the project began in 2002. The Paediatric Society of New Zealand led the development of the assessment and diagnosis section of the *Guideline*; the Special Education arm of the Ministry of Education led the education work stream; and the Disability Directorate was charged with developing the support and transition

section. After an extensive consultation period with a range of stakeholders, the *Guideline* was released in 2008. It has eight segments:

- diagnosis and initial assessment of ASD
- support for individuals, families and carers
- education for learners with ASD
- treatment and management of ASD
- living in the community
- professional learning and development
- Māori perspectives
- Pacific peoples' perspectives.

Apart from being a world-first robust guideline in the field of autism to support practitioners working across the life span with individuals with ASD, the *Guideline* also has a unique feature. Rather than being a static, one-off guideline, it came with the proviso that “the guideline will be considered for review as new evidence becomes available, using a ‘living guideline’ approach” (Ministries of Health and Education, 2008, p. 16). Since then, the Living Guideline Group, a small group of experts, has continued to keep the *Guideline* alive by examining newly emerging evidence in the various fields of autism, and updating existing information and recommendations as warranted. More information on this group’s work can be found on the Ministry of Health website: <http://www.moh.org.nz>.

There are various ASD-specific training programmes offered in New Zealand, among which EarlyBird and TIPS for Autism⁶ are two ongoing initiatives to support children and their families. The EarlyBird programme is run by Autism NZ,⁷ which also runs a range of educational and other support programmes for children, young people and their families. Whereas EarlyBird is a home-based programme for children with ASD and their parents, TIPS for Autism is a Ministry of Education-funded programme which involves teachers, families and a range of professionals who work with children with ASD. Altogether Autism⁸ and Cloud 9⁹ are other organisations that provides support, advocacy and programmes for individuals with ASD and their families.

A unique parent initiative to raise awareness of ASD also saw every school and early childhood setting in New Zealand provided

with a DVD called *In My Shoes: An Everyday Look at Autism Spectrum Disorder*. The resource, produced by a parent-led Māori organisation, PAI 4 ASD TRUST,¹⁰ contains four scenarios—primary school, secondary school, community, and Māori—which consider ASD from the perspective of the child with ASD and their family/whānau.

Genesis of the book

The beginnings of this book were rather serendipitous, but first some contextual background to explain its genesis and uniqueness. Children and young people with ASD in Aotearoa New Zealand are present in both special and regular education. Increasingly, parents of children with ASD and other disabilities are keen for their children to attend their local schools and early childhood facilities and be part of the community they live in. As a result, teachers across all educational settings encounter children with ASD on a regular basis.

Given that those with ASD can have varying degrees of social, communicative and behavioural difficulties, they are supported in a number of ways in schools and early childhood settings. These range from working with paraprofessionals, to the use of specific technology to support and address the communication and learning difficulties of children. While additional assistance can be available, it is critical that the teachers and other professionals who have the primary responsibility for supporting children and young people acquire a deep understanding and knowledge of ASD and related interventions. They need certain basic strategies to address the cognitive and affective challenges faced by these children and young people.

As one way to build teacher capability, from 2011 the Ministry of Education has funded a postgraduate qualification in Specialist Teaching, the PGDip (ST) endorsed in ASD, and has provided study awards for teachers and other professionals who work with children and young people with ASD.

Implementing interventions in everyday settings

When setting out to support the complex needs of those with ASD, it is important that education professionals be given opportunities and support to trial interventions in their classrooms, centres and other natural learning contexts, which have been proven to be effective for those with

ASD. This can be quite daunting, for even the most experienced teachers and other educational professionals need some support to take those initial steps in planning and supporting the learning needs of children with ASD. With this in mind, the practicum assignment in the PGDip (ST) programme was designed to enable students to implement an evidence-based intervention in their own learning context. As part of their practicum requirement they had to undertake and evaluate aspects of an evidence-based intervention with two children with ASD: one with classical autism (severity level 1 in DSM-5), and another with Asperger's syndrome or high-functioning autism (severity level 3 in DSM-5). As Cook et al. (2008) observe, implementing educational practices that have an effective research base relies on the capabilities and wisdom of teachers, while giving interventions a sense of *social validity*. It is also in line with teachers increasingly being required to demonstrate research-informed and evidence-based practice (Taber, 2007).

In preparation for the assignment, the course content for PGDip (ST) provided the students with a deeper understanding of a range of interventions they could implement. They examined practices recommended in the *NZASD Guideline* and evidence-based interventions identified by the National Autism Centre, the National Professional Development Centre and Research Autism. The interventions they trialled were in response to the needs of children and young persons which were carefully ascertained through information gathered and assessments undertaken in partnership with families and whānau, staff in the educational setting, and other professionals involved. Students also had to be mindful of the cultural appropriateness of their chosen interventions and to consider adaptations that might be needed to make the intervention effective in the Aotearoa New Zealand context.

On completion of their practicum intervention, the students were required to write a scholarly assignment that included some immediate outcomes they had noticed as a result of their intervention. It is important to bear in mind that students had very finite time limits to undertake their intervention to fit in with the academic calendar and course requirements. On average, the students, who were all experienced teachers and practitioners, spent between 30 and 40 hours on the intervention over a 20-week period. The calibre of their assignments

and the reported positive outcomes for the children and young people they worked with were the catalyst for this book. Despite the strict time constraints they were under and the wide range of challenges they faced—such as lack of resources, incomplete pre- or post-intervention data, children’s absences during the intervention, and some “unconvinced” professionals or parents—the students experienced positive outcomes. We felt that sharing these experiences would motivate and bring about an ‘I can do it too’ attitude among other teachers and educational professionals.

We realised that capturing practitioners’ voice and real-life experiences is critical in terms of authenticity. The interventions reported in these chapters were not conducted in clinical settings or in circumstances where resources, time and support were guaranteed. Instead, they were introduced in settings and under circumstances that are the grass-roots reality of educational professionals in Aotearoa New Zealand. They are evidence of what is possible when implementing research-endorsed interventions amidst everyday practice in home-grown contexts.

As mentioned previously, this book is not a collection of ‘gold standard’ research and evaluation as undertaken by academics. Rather, the chapters are based on interventions and issues related to supporting children and young people with ASD in their learning in early childhood settings, schools and beyond, undertaken by Aotearoa New Zealand teachers and other educational professionals. It is a bold move by these chapter authors to share their successes in having positive outcomes for young people with ASD, which we hope will inspire others in the educational field. In a small way, these authors are contributing to building a research-to-practice repository.

In 2012 the United Nations General Assembly unanimously adopted resolution 67/82. In this resolution the UN member States recognised:

that the full enjoyment by persons with autism spectrum disorders [...] of their human rights and their full participation will result in significant advances in the social and economic development of societies and communities.¹¹

What better place than educational institutions to take the first steps to ensure full participation of those with ASD?

Book structure

The book is divided into two distinct parts. Part One is about specific interventions, and Part Two is about wider issues involved in the successful education of children and young people with ASD. The chapter authors include teachers in tertiary institutions, primary and secondary schools, special needs coordinators (SENCO), speech-language therapists, resource teachers and a psychologist. Some of them have chosen to write in the first person while others have preferred the more formal third person. It was the editors' decision to respect the authors' preferences, rather than seeking uniformity in the book.

It should be noted that, in the interests of confidentiality and anonymity, pseudonyms have been used for children in the chapters throughout the book.

Part One: Interventions

A wide range of interventions ranging from early childhood education to school-aged students with ASD is covered within the chapters in this section. It begins with the use of a comprehensive intervention framework—SCERTS—in which Anna Christie, a speech-language therapist, explains how an adapted version of the SCERTS framework was used to improve a 4-year-old boy's social communication, interactions and participation in routines at his early childhood centre. Following on from this people-intensive framework, the focus of the second chapter is the use of technology. The use of iPads has opened up a whole new world of communication and interactions for children and young people with ASD. In her chapter Tracy Watkin uses peer- and self-video modelling in combination with iPad use to successfully prepare a young child to transition to school.

Chapters 3 and 4 focus on increasing the communication and social interactions of children. In Chapter 3, Heather Polson describes the development of a Makaton resource in the Samoan language, and outlines how it was used with two young children who have speech and language challenges. In the following chapter, Tangi Johnson-Ross uses a Social Script supported by visuals of a young boy's special interest—SpongeBob Squarepants—to help him participate appropriately in social situations he finds difficult.

In Chapter 5, Dervla Hayes explains *colourful semantics*, an

intervention that uses colour coding to show sentence structures. She also provides an example of how colourful semantics was used with an 8-year-old girl with ASD to foster her literacy and communication skills.

Behavioural approaches to ASD have a large evidence base. Chapters 6 to 9 describe different behavioural interventions targeting specific goals to support children and young persons in early childhood facilities to high school settings. In Chapter 6, Sharon Ketter describes the ways she used the structured teaching component of the TEACCH intervention to include two Māori students in the regular classroom in a semi-rural primary school. In Chapter 7, Fran Dowson focuses on the use of functional behaviour assessment, musically and electronically adapted Social Stories and video modelling to teach a student how to 'keep his hands to himself'. June Chiaroni explains the pivotal response training (PRT) intervention in Chapter 8 and presents its use with a young child and a student at high school. Finally in this section, Jenny Tippett explains the successful use of the Ziggurat Model with two primary school-aged boys with varying levels of severity of autism.

Part Two: Issues

The issues covered in this section are centred around diagnosis, assessment, interventions and transition.

The section begins with the important, but often less discussed issue, of the role culture plays in the lives of children with ASD and their families and whānau. In Chapter 10, Jill Bevan-Brown and Alexandrina Moldovanu focus on ethnic minority culture and the impact it has on how ASD is experienced and managed. Various cultural differences and issues relating to ASD are discussed, and the implications for professional practice are shared. In Chapter 11, Natalie Paltridge questions the validity of standardised assessment for young persons with ASD and provides a strong argument for the use of narrative assessments to capture the learning of children with ASD across their whole education. In the following chapter, Sharyn Gousmett discusses the complications and implications of having a dual diagnosis of deafness and ASD. She illustrates the challenges faced through the story of a 7-year-old girl with bilateral hearing loss and ASD.

In Chapter 13, Julianne Swanepoel turns the spotlight on sensory difficulties experienced by those with ASD, and provides information

on the much debated and controversial topic of sensory interventions. She outlines a small selection of promising sensory approaches and their implications for practice.

This issues section aptly concludes with the topic of transitioning young persons with ASD from secondary school into meaningful after-school opportunities. In this final chapter, Alison Browning describes the significant issues that can arise for students with ASD in this transition process and outlines a few successful strategies.

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Endnotes

- 1 See <http://www.autismnz.org.nz>
- 2 National Standards Project: <http://www.nationalautismcenter.org/national-standards-project/>
- 3 NPDC: <http://autismpdc.fpg.unc.edu/>
- 4 Research Autism: <http://www.researchautism.net/>
- 5 *NZASD Guideline*: <http://www.health.govt.nz/publication/new-zealand-autism-spectrum-disorder-guideline>
- 6 Details of these initiatives funded by the Ministry of Education can be seen on its website: <http://www.minedu.govt.nz/NZEducation/EducationPolicies/SpecialEducation/OurWorkProgramme/SupportingChildrenWithASD/CurrentMinistryFundedASDProjects.aspx>
- 7 Autism NZ: <http://www.autismnz.org.nz>
- 8 Altogether Autism: <http://www.altogetherautism.org.nz>. It is a service funded by the Ministry of Health and is provided in joint partnership by Parent to Parent and LIFE Unlimited.
- 9 Provides support for those with Asperger's.
- 10 A website to support this DVD is <http://www.inmyshoes.co.nz>
- 11 Source: <http://www.autisticminority.org.nz>