How Parents Deal with the Education of Their Child on the Autism Spectrum

The Stories and Research They Don’t and Won’t Tell You

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Powerful moral, social justice and political arguments have convinced parents that it is their democratic right to place their children on the autism spectrum into mainstream educational environments so that their children may eventually take up their rightful place in a mainstream adult life. But what is really happening for some of these parents when they try to gain and maintain an appropriate education for their child in these mainstream contexts and beyond? What is the educational experience like for these families who are in the midst of this generational change from historical exclusion to inclusion? Current research indicates that while islands of excellent mainstream inclusive practice do exist the educational experience for many students on the autism spectrum can often be one of hostility, inconsistency and unreliability. Without appropriate understanding of best practice educational methods, these students can present an inordinate educational challenge to both parents and educators alike. How do parents deal with such complex educational profiles? How do they continue to maximize their children’s development over time? What are the barriers that hinder their quest? What are the facilitators that help their quest? To answer these questions, this book provides an in-depth, recent examination of the real life journeys of families who attempted to gain an appropriate education for their children on the autism spectrum including the areas of diagnosis, early intervention, mainstream schooling, home education, segregated schooling and transition to work and further study.

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How Parents Deal with the Education of Their Child on the Autism Spectrum
STUDIES IN INCLUSIVE EDUCATION
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Scope
This series addresses the many different forms of exclusion that occur in schooling across a range of international contexts and considers strategies for increasing the inclusion and success of all students. In many school jurisdictions the most reliable predictors of educational failure include poverty, Aboriginality and disability. Traditionally schools have not been pressed to deal with exclusion and failure. Failing students were blamed for their lack of attainment and were either placed in segregated educational settings or encouraged to leave and enter the unskilled labour market. The crisis in the labor market and the call by parents for the inclusion of their children in their neighborhood school has made visible the failure of schools to include all children.

Drawing from a range of researchers and educators from around the world, Studies in Inclusive Education will demonstrate the ways in which schools contribute to the failure of different student identities on the basis of gender, race, language, sexuality, disability, socio-economic status and geographic isolation. This series differs from existing work in inclusive education by expanding the focus from a narrow consideration of what has been traditionally referred to as special educational needs to understand school failure and exclusion in all its forms. Moreover, the series will consider exclusion and inclusion across all sectors of education: early years, elementary and secondary schooling, and higher education.
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NIHIL DE NOBIS, SINE NOBIS

(Nothing About Us, Without Us)*

*A slogan used to communicate the idea that no policy should be decided by any representative without the full and direct participation of members of the group(s) affected by that policy.
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FOREWORD

As Jasmine McDonald declares in the opening of this book, *How Parents Deal with the Education of their Child on the Autism Spectrum*, the dramatic increase in the incidence of children with Autism Spectrum Disorders has not been matched by growth and improvement of support for these families. Given the volume and intensity of official declarations on the education rights of people with disabilities from governments, peak international organisations such as the United Nations and the OECD, and education jurisdictions globally, we ought to be able to expect more.

The Disability Standards for Education were foreshadowed in the Disability Discrimination Act (1992) and were enacted in August 2005. The recent *Report on the Review of the Disability Standards for Education 2005* (DEEWR, 2012) published in June 2012 by the Department for Education, Employment and Workplace Relations highlights serious shortcomings in their implementation across state and territory jurisdictions. That same year the Victorian Equal Opportunity and Human Rights Commission (2012) released *Held Back*, a report based on extensive research it had commissioned to investigate the experiences of children with disabilities in Victorian schools. On the basis of a survey completed and returned by 883 educators, 617 parents and carers and 60 students the researchers reported that the educational experiences of children with disabilities are not consistent, that discrimination exists and that not all children with disabilities are eligible for support to enable them to access the curriculum as is required by the Disability Discrimination Act (1992).

Notwithstanding this evidence of exclusion as an established feature of our education landscape there remains little public acknowledgement of this fact. *The Sydney Morning Herald* (May 15th, 2013) reported on then Prime Minister Julia Gillard choking back tears as she spoke to the final reading of the Bill before parliament to enact the National Disability Insurance Scheme. According to Prime Minister Gillard, “... there will be no more ‘in principle’ and no more ‘when circumstances permit’. There will be launches not trials, permanent care not temporary help ... there will be no turning back.” Education policies on inclusive education, taking their lead from disability discrimination legislation, do apply caveats of conditionality. Education for children with disabilities in this country, as is certainly the case elsewhere, remains contingent. Parents and carers are at the mercy of systems that have a highly variable track record when it comes to including students with disabilities.

This book draws on empirical research in Western Australia to demonstrate the reluctance of an education jurisdiction to include the voice of parents of children on the autistic spectrum in decisions about their children’s education. This is not an isolated occurrence. We have accepted as an article of faith in education that we are in a partnership with parents to educate their children. Too frequently there is a variance of contract for parents of children with disabilities. *How Parents Deal
FOREWORD

with the Education of their Child on the Autism Spectrum poignantly chronicles the experiences of parents as they struggle to secure the right of their children to be included.

Securing rights is often tortuous and far too often parents have to create alternative pathways for their children. The material and emotional costs are high. In The Irregular School (Slee, 2010) I related the experience of hearing a father of a disabled boy tell an audience of educators how every morning he would send his son off to school with his satchel full of hopes and dreams. Everyday his son would return from school; his bag having been emptied in the dust. Expectations have been built through the inclusive discourse of educational policies and human rights legislation that are not matched by institutional practices and cultures in education. This is not acceptable.

For this reader, the strength of How Parents Deal with the Education of Their Child on the Autism Spectrum is drawn from its origins. Jasmine McDonald writes from the heart as a parent and advocate who has walked this path. She has experienced the struggle and has taken on advocacy beyond her own family to build better educational experiences for all. I am reminded of my encounter with a parent many years ago who told me of how her daughter; a child with Down syndrome, was held at the side of the stage during a school performance. All of her classmates performed on the stage at the Christmas concert. When the distraught parents approached the teacher and their distressed daughter to find out what had happened, the teacher declared that she didn’t want the child to feel upset about looking different from the other children. Every time I tell this story others will match it with their own horror stories. We have to change the script. I believe that you will find that Dr. McDonald is doing precisely that in this important text. Jasmine McDonald moves beyond the analysis of these experiences to build an alternative way forward.

REFERENCES


Roger Slee
Melbourne, 2014
DEDICATION & ACKNOWLEDGEMENTS

I dedicate this to fellow parents who have desperately struggled over the years to help their children on the autism spectrum realise their educational and life potential.

I am especially grateful to the parent participants of my PhD. study who so willingly and generously shared many painful memories about their inordinately, difficult and complex journeys when trying to educate their children on the autism spectrum. Their stories revealed a very determined, resourceful and courageous group of parents who fought, often unrelentingly, for their child’s right to be educated in ways that maximized their potential.

I would also like to thank Professor Roger Slee, a leading light in the field of inclusive education, for encouraging me to produce this publication and for contributing an insightful foreword. I must also thank fellow parent, Heidi Brandis, for allowing me to reproduce some of the education information found in her Autism Parent Handbook.

Finally, to my family I must give my greatest thanks. They have underpinned and supported my ongoing investigations into this very difficult area of research. In particular, I wish to single out my eldest son. His unyielding courage to keep going forward, often in the face of discrimination and persecution, is an eternal inspiration to me.
CHAPTER 1

WHO HAS THE RIGHT TO SPEAK?

INTRODUCTION

There has been a worldwide explosion of children being diagnosed on the autism spectrum over the past twenty years (Fombonne, 2009). Recent figures in Australia indicate that at least 1 in a 100 individuals has a confirmed diagnosis of an autism spectrum disorder (ASD) with rates acknowledged to be on the rise (Aspect, 2012; Australian Advisory Board on Autism Spectrum Disorders, 2011; Buckley, 2009, 2012). However, these figures belie the fact that many Australian parents find it difficult to gain an accurate and timely diagnosis for their child that will allow them to gain much needed, funded intervention at the earliest opportunity (McDonald, 2010; Valentine, Rajkovic, Dinning, & Thompson, 2010).

Powerful moral, social justice and political arguments have convinced parents that it is their democratic right to place their children into mainstream educational environments so that their children may eventually take up their rightful place in a mainstream adult life (Oliver, 1990, 1996; Oliver & Barnes, 2010; Slee, 2011). But what is really happening for some of these parents when they try to gain and maintain an appropriate education for their child on the autism spectrum in these mainstream contexts and beyond? What is the educational experience like for these families who are in the midst of this generational change from historical exclusion to inclusion?

Current research indicates that while islands of excellent mainstream inclusive practice do exist (Cologon, 2013; McDonald, 2010; Morewood, Humphrey & Symes, 2011) the educational experience for many students on the autism spectrum can often be one of hostility, inconsistency and unreliability (Harrington, Foster, Rodger & Ashburner, 2013; Cologon, 2013; Humphrey & Lewis, 2008a, 2008b; Humphrey & Symes, 2010; MacDermott, 2008; McDonald, 2010; Roberts, 2013). Without appropriate training in best practice educational methods, these students can present an inordinate educational challenge to both parents and educators alike. To begin with, each student on the autism spectrum has their own unique, idiosyncratic profile with distinctive difficulties found in the common areas of communication, socialization, restricted and repetitive behaviour and sensory processing (American Psychiatric Association, 2013b; Australian Autism Education and Training Consortium (AAETC), 2008a, 2008b). Additionally, these students frequently have problems with theory of mind skills and executive function. They also often experience weak central coherence and motor functioning problems (AAETC, 2008a, 2008b). Such students may also have a number of relative cognitive strengths
in the areas of rote memory, visual spatial abilities, compartmentalized learning, preference for routine and rules, intense interests and being logical (AAETC, 2008a, 2008b).

How do parents and educators deal with such complex educational profiles? How do they continue to maximize these students’ development over time? What are the barriers that hinder their quest? What are the facilitators that help their quest? To answer these questions, this book provides an in-depth, recent examination of the real life journeys of six families who attempted to gain an appropriate education for their children on the autism spectrum over a five year period in a West Australian metropolitan setting. It provides a ‘grass-roots’, parental view of the issues involved with their child’s diagnosis, early intervention, mainstream schooling, home education and segregated schooling. It also describes the processes and strategies that parents used to overcome some of the difficulties they encountered trying to maximize their children’s educational potential in both mainstream and other educational contexts.

Many publications regarding education of students on the autism spectrum are written from the perspective of the educational professional and researcher. Research often concentrates on what is needed to promote the practice of inclusivity in mainstream contexts (Frederickson, Jones and Lang, 2010; Jordan, 2005; Leach and Duffy, 2009; Morewood et al., 2011; Parsons, Guldborg, MacLeod, Jones, Prunty & Balfe, 2011; Ravet, 2011; Roberts, 2013). While these publications are imperative and highly useful, there is relatively little published about the actual experience of education from the perspective of parents of children on the autism spectrum and how such parents deal with this process over time. This publication seeks to address this gap. The book reveals how parents initially broaden their view of ‘education’ in relation to their unusual children and how such meanings drive their decision making regarding the best ways to maximize their children’s ultimate and unique life potential. It also shows how such parents often continually strategize solutions to gain, maintain and create educational fit to maximize their children’s educational potential.

The parent voice is featured throughout this publication to explain the often complex processes undertaken by them. This publication has been written in the hope that it will potentially benefit parents who may be struggling to gain and maintain an appropriate education for their child on the autism spectrum in mainstream and other educational contexts. It provides an understanding of the processes undertaken by these parents from pre-diagnosis to the final years of their child’s formal schooling and immediately beyond. Parents will be better placed to make informed decisions about the realities of the different educational contexts that potentially exist for their children inclusive of home education and segregated schooling sites (education support schools). The book also shows ways that families have strengthened their overall well-being over the course of the educational journey by gaining appropriate early intervention and timely support for all family members not just the child on the autism spectrum.
Additionally, this publication is potentially of benefit to researchers, policy makers, educators and health professionals who may regularly deal with families who have a child on the autism spectrum. It provides an understanding and explanation of the cumulative effect of the ongoing difficulties such families often face trying to access an appropriate education for their child on the autism spectrum over time. The book will provide professionals with a deeper and more realistic understanding of the collective pressures these families often endure over many years. It also explains why it is important that appropriate and timely support be gained for not only the child on the autism spectrum but other family members at the earliest opportunity to ensure the overall well-being and stability of the family across time.

While the stories captured are taken from a recent Western Australian (WA) context, current research indicates these issues have broad relevance for parents and professionals in most developed Western nations who regularly deal with the education of children on the autism spectrum (Eldar, Talmor & Wolf-Zukerman, 2010; Humphrey & Lewis, 2008a, 2008b; Humphrey & Symes, 2010; Lynch & Irvine, 2009; MacDermott, 2008; McDonald, 2010; McDonald & Lopes, 2012; Parsons et al., 2011; Ravet, 2011).

WHO HAS THE RIGHT TO SPEAK?

Common sense would dictate that parents of children on the autism spectrum should have the fundamental right to speak and be heard about their own child’s educational welfare but research informs us that their views are often discounted. Many parents have historically been seen as peripheral to their child’s education and in some cases they have been viewed as obstacles or even adversaries (Hardman, Drew, & Egan, 1995; Turnbull & Turnbull, 2001). It has been found that less than optimal levels of cooperation can often emerge between parents and the education system and this can affect the overall efficacy of service delivery and eventual well-being of those being served (Lake & Billingsley, 2000). Much of the research conducted has examined parent-professional interaction from the perspective of the education community with limited studies being undertaken from the parent perspective (Stoner, Bock, Thompson, Angell, Heyl, & Crowley, 2005). Limited research from a parental perspective has identified such issues as: difficulty obtaining services, inadequate service delivery, and lack of collaboration as key parental concerns (Dunlap, Robbins, & Darrow, 1994; Kohler, 1999, MacDermott, 2008; McDonald, 2010).

Research has also found that the process of educators engaging with parents of children on the autism spectrum is an integral component towards the achievement of teacher-parent efficacy in the ‘inclusive’ classroom (Ferraro, 2008). An Australian review of early intervention ASD research has further shown the importance of parents by stating that parents “play a critical role in supporting their children’s learning” (Roberts & Prior, 2006, p. 74). Research also indicates that parents can often drive the decision making process and regularly take a primary role in delivering intervention (Feinberg & Vacca, 2000; Lord & McGee, 2001; Roberts
& Prior, 2006). This allows all key stakeholders to be part of the decision-making process and often leads to improved learning outcomes for the child on the autism spectrum (Roberts & Prior, 2006). Interaction with parents also helps the education team to more easily transition a child from one education environment to another; identify the child’s strengths and interests; to develop student-centred plans and provides joint problem solving opportunities when difficulties arise (AAETC, 2008a, 2008b; Stoner, Angell, House & Bock, 2007).

For these reasons and over many years, regular schools in Australia have been encouraged to engage parents in active communications, however, such interactions do not typically occur as state policy directives require (Stanley, Beamish, & Bryer, 2005, MacDermott, 2008; McDonald, 2010). Given that many parents of children on the autism spectrum spend many years researching their child’s circumstances (MacDermott, 2008; McDonald, 2010; Stoner et al., 2005), they often feel justified in their expectation that they will be included in discussions and decision-making regarding their child’s specific educational situation. The importance of this element is further confirmed in Western Australian research by MacDermott (2008) who investigated the views of 92 local families who had school-aged children with a suspected or confirmed ASD. MacDermott (2008) found:

One of the ‘loudest’ points to come out of this study’s findings was the need by families to be heard and for their experiences, expertise and opinions to be accepted as important and equal in the care and development of their children … It is essential that the professionals and service providers working with families listen, hear what is being said, and engage with parents in a respectful and collaborative process to not only maximize the day-to-day functioning of these families and their children but also to enable them to thrive and weave their unique voices into the fabric of their surrounding communities (pp. 7-8).

Unfortunately, Australia does not presently have an equivalent to the U.S. 1997 amendment to the Individuals with Disabilities Education Act (IDEA), which mandates that parents of children with disabilities have the legal right to be involved in all aspects of their children’s education. On this point, MacDermott (2008) states that:

families / carers need to be recognized as having unique and specific information regarding their child’s strengths, challenges and learning styles and provided with opportunities to be ongoing collaborative partners in designing and implementing intervention / educational programs (p. 9).

The positive value of parental involvement in the educative process cannot be understated or underestimated and is supported throughout the research literature but engagement with parents is often lacking throughout schooling communities (Ferraro, 2008; MacDermott, 2008; McDonald, 2010; Stoner & Angell, 2006; Stoner et al., 2005). This is the case even though parents are a constant in the lives of their children on the autism spectrum and as such have the ability to provide a
WHO HAS THE RIGHT TO SPEAK?

rich, on-going account of what works best for their offspring when engaging with education professionals (Ferraro, 2008; O’Brien & Daggett, 2006). Not surprisingly, it has been found that parental involvement, parent-efficacy and satisfaction with the education process of children on the autism spectrum is closely related to the cognitive, behavioural and social development of their children (Ferraro, 2008). However, this parental involvement needs to be part of a collaborative process with school-wide commitment among parents, educators, students, community, and policy makers towards long-term outcomes (Ferraro, 2008).

However this collaborative process is often not easy to establish or maintain. Research by Stoner et al. (2005) revealed that over time parents’ trust in recognized experts often diminishes while parents’ trust in their own instincts is reinforced. Stoner et al. (2005) explain how:

The struggle for a diagnosis initiated a pattern of persistent behaviour, and a sense of distrust (in the parents) with medical professionals, which continued and influenced parent interactions with education professionals (pp. 41- 42).

Parents of children on the autism spectrum often need to take on a variety of roles when interacting with their child’s school and such interactions are mediated by trust. Stoner and Angell (2006) indicate that:

Parent participants, especially mothers, consistently engaged in four roles: (a) negotiator, (b) monitor, (c) supporter, and (d) advocate. In addition, the degree of perceived parental trust in education professionals affected the extent of their engagement in the roles of negotiator, monitor and supporter. The data also indicated that parents’ education monitoring was mediated by the trust the parents placed in the education professionals (p. 177).

Research shows that most mothers adopt an enhanced advocacy role for their child on the autism spectrum and in some cases demonstrate an activist role and extend their efforts towards campaigning for change outside of their own families (Ryan & Cole, 2009). It is within this space that this book is written. As a fellow parent of an adult son on the autism spectrum, I have felt for some time that the voices of parents and other family members have not been heard loudly or considered seriously enough by the external world especially in the area of education. This began my journey into further study and research which has now culminated in the publication of this book.

WHY WRITE THIS BOOK?

When considering the reasons for undertaking the present publication, I recalled one tragic Australian case which illustrates the sometimes, extreme pressures associated with parenting a child on the autism spectrum. In 2003, a desperate Australian mother suffocated her ten-year old son who was diagnosed with severe autism and then attempted suicide. After her son’s death, a news article commented that she had despaired about her son’s future and that her existence had grown unbearable...
(Lamont, 2004, June 1). At the same time as caring for her child 24 hours a day, she was losing countless battles trying to gain better services and more specialist support for her son. Her marriage was ending and her father had died only a few weeks before. In her misery and confusion, she believed her son could not cope without her. The New South Wales Deputy State Coroner cited depression and lack of appropriate services as the main reasons for her despair. He cautioned that unless services improved for families with disabled children, especially those children on the autism spectrum, there was a strong possibility that this tragedy could happen again (Cummings, 2006, October 14).

I remember relating closely to this tragic case because of my own family’s situation. Discrimination, lack of understanding and support had permeated my own family’s life since the birth of my son on the spectrum and I knew how excruciatingly difficult life could be at different points in time. At the beginning of my journey with my son I would have appreciated greatly an understanding of the ways other parents negotiated the lengthy, often inordinately difficult, education process of their child on the autism spectrum. However, such information was not readily available some twenty years ago. For some time, there has been a call for disability research to give more consideration to the ‘authentic voices’ of those in the field inclusive of parents, disabled students and their advocates (Simpson, 2005; Slee, 1996). This call is embedded in the understanding that:

discourses are about what can be said and thought, but also about who can speak, when, where and with what authority (Ball, 1994, p. 21).

With a teaching background in secondary, tertiary and home education and experience educating my own son on the autism spectrum over two decades, I felt well-placed to ‘speak’ and do research investigating how parents deal with the education of their child on the autism spectrum over time. I also knew that there were an ever-increasing number of families who had a family member diagnosed on the autism spectrum who may need such parental insight regarding the educational journey. I was cognizant that all of these families would eventually need to navigate an acceptable educational pathway for their children in order to maximize their child’s progress.

Surprisingly, my background as an educator had not greatly prepared me for the significant difficulties that lay ahead when parenting and teaching my son. In response, I embarked on a search for appropriate ways to maximize his progress in order to help not only him, but the rest of my family as well. I reasoned that if he gained skill and became more independent it would make things much easier for us all. This eventually led me down a pathway to further study.

In my studies I came across research that confirmed that the impact on families who have a child on the autism spectrum could be extremely high where parents were more likely to experience serious psychological distress than parents of children with other developmental disabilities (Benson & Karlof, 2009; Bromley, Hare, Davidson, & Emerson, 2004; Sanders & Morgan, 1997; Sivberg, 2002). Early
research had also indicated that this stress could be potentially reduced over time in inverse proportion to the success of the education of the child on the autism spectrum (Robbins, Dunlap, & Plienis, 1991). This had been borne out in my own family’s experiences. We found that as our son gradually gained skill in negotiating the world and became more independent our own stress levels reduced slowly but significantly over time. It became obvious that an appropriate and effective education for our son was a key factor in the survival of all members of our family.

I had also witnessed similar, gradual improvements in the lives of other families in the autism community who had access to appropriate and timely educational intervention for their child on the autism spectrum. I had noted that the eventual progress of such children was not only determined by the amount and quality of evidence-based intervention that parents were able to gain for their child, but factors such as support, family resources, severity and complexity of impairment also seemed to be important. Sadly, I had also seen how some parents were unable to put in the time, energy and targeted intervention necessary to maximize their child’s progress because of lack of appropriate support and services and the complexity of their family’s circumstances. These children often became more difficult to deal with as they grew in physical maturity. Without appropriate intervention, the stress experienced by such families often increased over time with sometimes devastating results for all family members.

The complexity inherent in writing a book about how parents deal with the education of their child on the autism spectrum over time was daunting. For a start, the nature of the disorder is highly idiosyncratic and each child manifests their autism differently. This makes educating individuals on the autism spectrum a very difficult task for both parents and professionals alike. I had experienced and witnessed how we, as parents, often struggled to ensure that our child’s needs were being reliably met over the course of their educational journey. For some time research has indicated that there was no single best-suited and universally effective educational method for all children on the autism spectrum over time (National Research Council, 2001; Parsons et al., 2011). The best programs are those that incorporate a variety of objectively verified practices and are designed to address and support the needs of individual students, the professionals and families with whom they are linked (National Research Council, 2001; Olley, 1999; Parsons et al. 2011; Simpson, 2005, 2007; Simpson & LaCava, 2007).

This placed us all, parents and professionals alike, in very demanding circumstances regarding adoption of appropriate and effective educational practices for individual children on the autism spectrum. Consequently, there has been a longstanding tradition by some parents of children on the autism spectrum of accepting educational and supplementary strategies that sometimes lack efficacy and proven utility (Francis, 2005; Gresham, Beebe-Frankenberger, & MacMillan, 1999; Heflin & Simpson, 1998). As parents, we have not had access to educational research of specific profiles of students on the autism spectrum which meets rigorous peer review and has a history of yielding positive results (Simpson, 2004) especially
in the latter years of schooling (Parsons et al., 2011). The difficulty is that there are only limited samples of students on the autism spectrum with similar characteristics because of the highly idiosyncratic nature and progress of the disorder (Parsons et al., 2011; Simpson, 2005).

Additionally, there appears to be no apparent correlation among the severity of difficulty experienced by individuals on the spectrum in one area of their profile to that experienced in another area. This variability and lack of apparent correlation among areas of difficulty is only now being investigated and understood through recent research (Happe, 2009).

I have also witnessed how some children on the autism spectrum have a superior skill or hyper-focus in one or more areas that can be used to improve their educational, recreational and career prospects (Grandin & Duffy, 2004; Howlin, 2009; Sonne, 2009a, 2009b). Research is only now beginning to provide understandings of the many different ways autism can present itself in an individual with superior splinter skills sometimes being part of the profile (Grandin & Duffy, 2004; Sonne, 2009a). In line with this, there has been a call by some in the autism community to change our understanding of Autism Spectrum Disorders (ASDs) to include the notion of “diff-ability”, focusing on difference rather than impairment (Lawson, 2009). Some parents and individuals on the spectrum have also called for autism to be viewed as a ‘condition’ rather than a deficit, disorder or disability (Lawson, 2009).

Recent research confirms that adults on the autism spectrum are significantly disadvantaged regarding employment, social relationships, physical and mental health and quality of life (Aspect, 2012; Howlin & Moss, 2012). There is an urgent call for more to be done to understand the trajectories of development over the lifespan of an individual on the autism spectrum, from childhood through to the adult years, to determine what factors influence prognosis to ensure a better future (Howlin & Moss, 2012). In a preliminary way this publication seeks to answer such a call.

THE VOICES OF PARENTS

I have therefore done research and subsequently written this book highlighting the parent voice in response to these calls to help unravel some of the complexity associated with the education process of children on the spectrum over time. For it is my belief that if we are all more knowledgeable about the education process from the outset we can make better, informed decisions and thereby give our children on the spectrum and the rest of the family the best chance to maximize their emotional well-being and life potential.

To capture the voices of parents currently in the field I investigated the educational experiences of six diverse families who all had children diagnosed on the autism spectrum over a five year period from 2005 to 2010 in a metropolitan West Australian context (McDonald, 2010). As is recommended in such qualitative, grounded theory studies, diversity of family profile was built into the mix of
families chosen to be included in the study. Constant comparative (Charmaz, 2000) and autoethnographic (Ellis, 2009) research methodologies were chosen and used to compare different parents’ views, situations, actions, accounts, experiences and documentation. This allowed a number of diverse parent voices to be heard and their situations to be investigated over an extended period of time. The seven children in the six families had various diagnoses on the autism spectrum resulting in assorted, idiosyncratic profiles. All were male reflecting the disproportionate numbers of males diagnosed on the autism spectrum as compared to their female counterparts (University of California, 2009). The basis for data collection was semi-structured interviews, participant observation, informal interviews and documentary data sources consistent with the interpretivist qualitative research tradition. Data analysis occurred concurrently with data collection and incorporated open coding, focused coding and member checking that led to generation and confirmation of propositions of a constructivist grounded theory (Charmaz, 2006).

I was interested in capturing the similarities and differences of each family’s individual educational trajectories and what processes they undertook to deal with their diverse situations. The ages of the children involved in the study ranged from 4 to 16 years of age at the beginning of the study. By the end of the study the youngest child was 9 and the eldest was 21 years of age. This incorporated investigating and following these families and their children through diagnosis, early intervention, primary, secondary and tertiary education incorporating mainstream (public and private), segregated (public), home education and work contexts.

The background of the families involved in the study included Italian, Greek, Indian, Australian and Irish heritages. All families in the study nominated the mother as the driving force behind the education process and as such she became the main source of information gained for the study. The geographic location of the families was varied across the Perth metropolitan area.

Perth is the capital and largest city of the Australian state of Western Australia. It is the fourth most populous city in Australia, with an estimated population of 1.9 million. The families in the study came from low to upper middle class socio-economic backgrounds, with parents’ educational background ranging from secondary schooling to post-graduate education. Two of the families were single parent families. The families chosen all had other children apart from their child or children on the autism spectrum. As research attests, many of these other children also had complex educational issues of their own which further complicated the task for these parents (Bailey, Palferman, Heavey & Le Couteur, 1998). Pseudonyms have been used throughout this book and information used has been de-identified to protect the identity of these families.

CURRENT RESEARCH ON INCLUSION

There has been an increasing development of inclusive practice regarding accommodation of students on the autism spectrum over the past two decades
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(Frederickson et al., 2010; Jordan, 2005; Laluvein, J., 2010; Leach and Duffy, 2009; Lynch & Irvine, 2009; Morewood et al., 2011; Ravet, 2011). For the purposes of this publication, the elusive notion of ‘inclusion’ refers to:

A unified system of public education that incorporates all children and youths as active, fully participating members of the school community; that views diversity as the norm; and that ensures a high-quality education for each student by providing meaningful curriculum, effective teaching, and necessary supports for each student (Lynch & Irvine, 2009, p.286).

This increase in the development of inclusive practice has been in response to powerful moral, social justice and political arguments that have for some time asserted that positive attitudes towards individuals with disabilities are developed when children with disabilities and their typically developing peers interact at school and these attitudes are sustained in adult life (Cologon, 2013; Oliver, 1996; Fuchs and Fuchs, 1994). Further to this, there is an increasing imperative that schools be an agent of change, provide an education in democracy and be a model for social improvement (Slee, 2011).

However, research has also shown that students with intellectual disabilities, including those on the autism spectrum, often cannot access reliable and consistent mainstream inclusive practice that maximizes their progress over time (Cologon, 2013; Crosby, 1998; Ford, 2007; Forlin, Keen & Barrett, 2008; Humphrey & Lewis, 2008a, 2008b; Humphrey & Symes, 2010; MacDermott, 2008; McDonald, 2010; Shaddock, 2005; Shaddock, Smyth King and Giorcelli, 2007; Wing, 2007). Concerns have been raised about the lack of appropriate, individualized attention and support available, the high attrition rates and the inordinate degree of bullying experienced by students on the autism spectrum in mainstream settings (Attwood, 2007; Harrington et al., 2013; Heinrichs, 2003; Humphrey & Lewis, 2008b; Humphrey & Symes, 2010; Lynch & Irvine, 2009; MacDermott, 2008; McDonald, 2010; Roberts, 2013; Rosendorff, 2007). Additionally, such students often experience social isolation, anxiety and sensory difficulties in mainstream settings where their need for routine and predictability is often at odds with the chaotic, noisy happenings of mainstream school life, especially at the high school level (Humphrey & Lewis, 2008a; Symes and Humphrey, 2010; Wing, 2007).

Among children with disabilities, students on the autism spectrum have been reported to have some of the most complex profiles to deal with in mainstream settings (Leach and Duffy, 2009). Research has also found that those who parent such children, especially mothers, are potentially at greater risk for mental health problems than any other parent group who have a child with a disability (Allen, Bowles, & Weber, 2013; Benson and Karloff, 2009; Tehee, Honan and Hevey, 2009). In response to these difficulties, some parents have been compelled to seek other educational pathways, such as segregated schooling sites and home schooling for their children on the autism spectrum (Attwood, 2007; Kidd and Kaczmarek, 2010; McDonald, 2010; McDonald & Lopes, 2012).
AN INTEGRATED SYNTHESIS OF SIX FAMILIES’ JOURNEYS

To help the reader understand the essence of the central process adopted by the six families investigated and reported in this publication, I adopt Strauss & Corbin’s (1998) suggestion of writing an integrated storyline that explicates both the central idea, and the other concepts and categories that relate to it. Following this, a diagrammatic representation of the full theory is included showing the four stages of the grounded theory (McDonald, 2010). Full development of the theory and its associated diagrammatic representation is provided in later chapters to follow:

Before their child is born, parents imagine a wonderful future and ideal scenarios often abound in their minds. When their child finally arrives and is significantly different from their dream vision, parents struggle to match their internal, idealized scenario with the reality of parenting such a child. After experiencing often, inordinate difficulties with their child’s behaviour, parents feel increasingly worried about their child. The atypical behaviour of the child continually sets off alarm bells in their minds. Parents recognize early in their children’s lives that the external world will not necessarily welcome, accommodate or be supportive of such different children. In response to this, parents set about gaining an appropriate education for their unusual child to help maximize their progress and increase their independence and skill levels in all areas.

Within the family, the child frequently becomes the centre of attention because of the inordinate difficulties associated with their behaviour. The lives of others in the family often become subsumed under the demanding needs of this unusual child. Sometimes, parents are able to register almost from the beginning that there is something very different about the development of their child in relation to other children. In contrast to this, some parents do not notice any significant differences until sometime later when their child loses previously held skills and regresses into their own world. Still other parents notice worrying differences but interpret them as a positive sign of the child being of superior intellect, and are encouraged by others to believe that they are raising a little genius. Parents often feel driven to share their fears about their child with trusted and qualified others. Unfortunately, they are often told their worries are unjustified and mainly based on their own parental inexperience.

As difficulties persist, most parents feel compelled to research their situation through various informal and formal sources. Through researching, parents gradually gain more awareness and trust in their own estimation of the unfolding situation; however, this is often juxtaposed against variable negative feelings regarding the difficulties of everyday life and the possible future consequences of a diagnosis of an autism spectrum disorder. After researching their situation for some time, parents often seek an accurate diagnosis in earnest for their child. Parents initially expect that a diagnosis will lead them to appropriate early intervention and, eventually, suitable schooling in order to improve the difficult situation experienced by both the child and their family. However, some parents question whether such a
diagnosis will be advantageous to their child’s overall life chances because it has
the potential to be a double-edged sword. Some parents fear that while there may be
successful intervention with a diagnosis there could also be the prospect of lifelong
stigmatization.

When parents continue with the process of seeking a diagnosis, they are often
met with a punishing diagnostic process. The diagnostic process is a very difficult
time to endure where family emotions run extremely high and misdiagnoses are
common. Many parents experience a long-winded pathway toward an eventual
diagnosis of an autism spectrum disorder. Some parents feel relief with a diagnosis
because they finally understand what they are dealing with. With diagnosis, parents
realize they are only just beginning to battle a situation that could be potentially life-
long. Parents receive little formal emotional support during this time even though
it is one of the most stressful and lonely times in these parents’ lives. Parents assess
the value and accuracy of a diagnosis against their own experience with their child,
their research into the area and the potential intervention benefits gained by such
a diagnosis. Parents experience different time trajectories when seeking a formal
diagnosis depending upon the conditions operating in their lives and the complexity
of their child’s profile. The length of time that it takes for parents to believe that
there is something atypical about their child’s development and to then gain an
accurate diagnosis has a direct bearing on when effective, early intervention can be
undertaken.

From their perspective, parents define ‘early intervention’ as including many
different types of therapies, educational or otherwise, delivered as early as possible
and assessed by them to be useful in their quest to help their child learn and improve
in all areas of development. For most parents, intervention does not just occur during
the distinct time phase before formal schooling starts but often continues in the form
of supplementary programs alongside the child’s regular schooling over many years.

Parents often feel like they are waging the war of their lives trying to gain
appropriate and effective services to maximize the potential of their children on
the autism spectrum. Some parents store hope in the belief that with the right type
and intensity of intervention they will be able to cure their child of their autism.
As time goes on, parents gradually realize they will have to become increasingly
self-reliant and continually strategize solutions to secure the most appropriate
educational interventions for their individual child. The resources of the family, both
financial and otherwise, often determine the type and intensity of early intervention
eventually available to their child on the autism spectrum.

Parents in the most vulnerable of circumstances have to settle for early
intervention services only available through the government system. This lack of
family resources also affects the length of time taken to gain an accurate diagnosis.
These vulnerable parents can only use the most accessible, least intensive of the
government-funded services because their reduced circumstances do not allow other
options to be investigated or funded.
By contrast, a second set of less vulnerable parents feel compelled to improvise their own early intervention programs based on their own research because there is little appropriate, specific ASD intervention on offer to their child at the time. They employ maverick intervention strategies and implement individualized, home-based programs based on their child’s profile so that intervention can occur at the earliest possible opportunity.

Yet, a third set of parents find themselves able to choose from early intervention programs based on best practice ASD intervention both through the private and public system. However these parents experience particular difficulties in terms of prohibitive cost, availability of staff and the on-going quality and intensity of these programs. These parents discover that home-based early intervention is heavily reliant upon family and financial circumstances supporting the high demands of the program and this often places increased pressure on the families involved with them. By contrast, parents involved in government-funded best practice school-based early intervention programs find that it delivers a high standard of intervention with consistency and quality built into the program. It reduces the financial strain and also provides some much needed respite for their family. However, parents find that places in such programs are often limited and parents often compete with one another to secure a place for their child.

All three early intervention pathways experienced by parents result in particular difficulties that are combated by the creation of various parent-devised strategies. Some of the difficulties experienced by parents are time-period specific and give rise to use of a particular strategy. However, once learned, parents often use a particular strategy repeatedly in order to combat difficulties at other times in the educational journey of their child on the autism spectrum.

During the time of early intervention parents learn that an appropriate education that targets both the strengths and difficulties of their child on the autism spectrum is the best way to help their child progress during their formal schooling years. Through research and discussion with other families, parents develop a starting belief that placing their child into a mainstream formal schooling environment will give their child the best chance to take their rightful place in preparation for a mainstream adult life. Therefore, parents initially try to gain a place for their child in a mainstream schooling situation. Parents broaden their understanding of education for their child on the autism spectrum to include both mainstream curriculum requirements and supplementary programs to address the idiosyncratic nature of their child’s profile. This process is undertaken with the hope of maximizing the development and future independence of their child.

Parents gradually realize that the education of their child on the autism spectrum will be much more expensive, time-intensive and arduous than what is required for their neurotypical peers. Some parents also have the accompanying belief that a successful education for their child on the autism spectrum will eventually decrease the pressure on the rest of the family over the course of their child’s life.
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After early intervention, parents often desperately chase a mainstream schooling placement where their child will be welcomed for enrolment and where appropriate educational expertise and commitment to their child will be found. Parents are very reluctant to place their child into a school where they and their child feel unwelcome because they fear the on-going negative treatment their child may receive in such an environment. At enrolment, parents feel that their children are often perceived by schools to be burdensome and to place more pressure on staff and other students. Additionally, they feel their children are often seen by schools as students who need extra resources and are therefore much less desirable when such support is not readily available. Parents find that some schools reject their child outright or demand specific diagnoses and external financial support in the form of aide time before they will accept their child for enrolment even though such actions are potentially against the spirit and letter of Australian disability discrimination laws. Parents combat this discrimination by use of many creative strategies but such strategies place even more pressure on the fragile lives of such families.

When parents eventually gain a place for their child on the autism spectrum at a mainstream school, they experience a process of variable involvement with the school depending upon the school’s notion of ‘inclusive’ practice. Parents find that mainstream schools have many different understandings of ‘inclusion’ and this affects the type and intensity of inclusive teaching practice undertaken by staff over time. Parents are often forced to continually negotiate and advocate an acceptable educational pathway for their child on the autism spectrum. Parents’ involvement with the school is variable according to the success or otherwise of the inclusive culture and practice operating at the school. Parents progressively recognize the fragile and fluid nature of inclusive practice operating in their child’s schooling context that can increase or decrease educational fit at any time for their child on the autism spectrum.

Some parents describe situations where a final crisis point is reached for their child on the autism spectrum in some mainstream schooling contexts. This occurs after numerous traumatic incidents have occurred where the child either refuses to attend school or is excluded, suspended or expelled from school. Parents indicate that without a firm commitment by staff, especially the administration, to appropriate inclusive practice, allocation of resources and specific evidence-based staff training to deal with students on the autism spectrum, the situation often rapidly deteriorates into one where the student is blamed for any difficulties that arise. Most parents believe that the difficulties that occur with their child are directly precipitated by a lack of appropriate inclusive practice operating in the schooling context over time.

By contrast, some parents reveal how they can sometimes find exemplary inclusive mainstream school contexts that provide appropriate educational fit for their child on the autism spectrum. Parents indicate that the key element found in these mainstream schooling environments is the unwavering devotion of the staff, including the principal, toward the emotional, social and academic welfare of the child on the autism spectrum and their family. Parents also nominate as important
the welcome they receive at enrolment and the self-awareness shown by the staff regarding their own skill level (or lack thereof) when dealing with a child on the autism spectrum. Parents claim that this awareness allows parents and qualified others the opportunity to be part of a team (a community of practice) and provide appropriate, evidence-based support to staff regarding inclusivity and the individual educational requirements of the student on the autism spectrum. Parents find that when key educators behind the inclusive culture leave the school, the situation can rapidly deteriorate for their child on the autism spectrum.

Through experience, parents gradually learn that mainstream school environments can have very different cultures and commitments to inclusive practice that directly affects their ability to continually and reliably provide an appropriate education for their child on the autism spectrum over time. In response to this fragility of educational experience, parents often choose to supplement their child’s formal schooling with a multitude of interventions to ensure that they maximize the educational progress and emotional well-being of their child irrespective of their mainstream experience. The quality and quantity of supplementing, however, is directly affected by the individual circumstances of each family.

At its best, the school is able to work with the family to incorporate and utilize these supplementary programs within the child’s educational program at school to maximize their development. When a family’s resources are limited, supplementing is reduced to what is provided through the government-subsidized system. Parents find such services are often lacking in appropriate individualization, intensity and quality of service provision. Parents also find that when they supplement their child’s education they undertake yet another responsibility associated with maximizing the educational progress of their child and this adds to the already burdensome nature of their lives.

When parents continually struggle to maintain an appropriate inclusive mainstream schooling context they often reach a crisis point with their child’s schooling. At this time some parents feel compelled to remove their child altogether from mainstream schooling to preserve the mental health of their child and the rest of the family. Some parents choose to home educate their child on the autism spectrum. Parents find that home education dramatically increases the educational fit for their child and generally reduces stress on the whole family. Parents indicate they are able to create individualized education plans organized to target their child’s specific profile without the need to negotiate an external schooling context. Parents specify on-going negative socialization (bullying), insufficient academic progress and the failure of schools to understand their child’s academic and social profile or the nature of their disability as reasons for their decision to home educate their child. Parents make use of both informal and formal external home education services and often adopt maverick strategies to improvise their own educational programs depending upon the parent’s background, experience, confidence, the age of their child, finances and the nature of the educational programs that their child may need. Parents receive little financial support for the home education of their child which translates to yet another financial burden that is borne by such families.
Alternatively, when some parents experience a continual lack of educational fit or a crisis point for their child on the autism spectrum in a formal mainstream schooling context they opt to place their child into a segregated education support school contextually designed for children with disabilities. Parents find that such schools in WA are generally only available to children on the autism spectrum who have an accompanying intellectual disability (IQ of approximately 70 or below). Some parents are frustrated to find that other states in Australia have education support schools for children on the autism spectrum on offer irrespective of a child’s IQ status.

Parents inculcated in the notion of ‘inclusion’ sometimes find it hard to reconcile their decision to segregate their child to an education support school with their quest to help their child eventually take up their rightful place in the external mainstream world. However, parents gradually accept that they must place their child in an educational environment where their child can experience the most reliable educational fit and maintain their mental health in order to realize their greatest educational and emotional progress. Parents note that some of the best aspects of inclusive practice experienced in mainstream schools are utilized in some of these segregated school sites.

In the final years of the formal schooling process, parents’ thoughts turn to seeking appropriate future educational, employment and recreational pathways for their child. This influences their educational decisions sending parents’ minds down many future planning tracks. Previous experiences warn parents that seeking, finding, creating and maintaining an appropriate fit for their child on the autism spectrum in the adult mainstream world will be an on-going and potentially difficult quest. While parents have gradually learned multiple coping strategies over time that help them seek, gain, maintain and create an appropriate educational fit for their child on the autism spectrum, they have also become acutely aware of the discrimination and difficulties their older child potentially faces in the external world. Parents find that they can not just rely on external services to support their child’s transition process into the adult world. Parents have to, once again, advocate on behalf of their child and often become the driving force behind any successful transitions to the adult world that need to occur.

As the schooling process progresses, some parents begin to shift their thinking from mainly focusing upon maximizing the educational potential of their child on the autism spectrum to one that incorporates the quality of life and mental health experienced by all members of the family. Some parents realize earlier than others, that unless the family can survive intact over time the chances of maintaining the best quality of life for their child on the autism spectrum over their entire lifetime will be diminished. Some parents redress this imbalance of attention afforded their child on the autism spectrum by gradually reducing their own involvement and importing more external support and respite. Other parents redress the imbalance by reaping the benefits of their child’s increased competence and independence gained during their formal schooling years. By contrast, still others are limited in their ability to redress the constant imbalance in their lives because of their reduced circumstances.
and the lack of progress achieved by their child on the autism spectrum. In all circumstances, improved funding and autism specific, support services implemented early are nominated as imperative to help families survive and maintain a healthy life balance for all family members throughout the life journey of the child on the autism spectrum.

DIAGRAM OF THE PROCESS

For ease of understanding, the following diagram provides a generalized representation of the process undertaken by the families involved in the study. It is inclusive of four stages and shows the types of movement possible throughout these four stages. The strands of ‘increasing awareness and confidence’ and ‘variable negative feelings’ are presented as distinct; however, in the application of this model these entities are typically integrated. The battle metaphors (Beginning Battle, Waging War) used to name two of the stages were taken directly from the parents’ own words when they described the difficulties they encountered when dealing with their child’s educational journeys. The constructivist grounded theory method (Charmaz, 2006) used to conduct the study (McDonald, 2010) delineated in this publication encourages use of such ‘in vivo’ codes where these codes “serve as symbolic markers of participants’ speech and meanings” (Charmaz, 2006, p. 55).

In the study (McDonald, 2010), seeking progressive fit emerged as the overriding basic social process that permeated the lives of these parents when dealing with the education of their child on the autism spectrum. This notion of ‘lack of fit’ between a school’s established mainstream practices and some of its students, disabled or otherwise, has been raised previously in discourse on inclusive practice (Ainscow, Booth & Dyson, 2006, p.304; Laluvein, 2010, p.42).

A key finding of the study (McDonald, 2010) was that parents struggled to seek, gain, maintain and create educational fit for their child on the autism spectrum in order to maximize their child’s educational potential and progress. The four iterative stages involved in the process were identified as:
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1. Beginning Battle – the stage where parents struggle to find an appropriate diagnosis.
2. Waging War – the stage where parents fight to seek, gain, maintain and create educational fit.
3. Strategizing Solutions – the stage where parents strategize solutions to remedy the constant difficulties associated with education.
4. Framing Futures – the stage where parents frame futures and begin redressing life imbalance.

It should be noted that the iterative movement between Stages 2 and 3 has the greatest level of interaction where parents continually strategized solutions to remedy the constant difficulties associated with educating their child on the autism spectrum.

The study also found that parents’ direction and speed of movement through the various stages was mediated by the following intervening conditions:

a. the attitude and background of the parents,
b. the level of support and accommodation available,
c. the educational progress of the child over time,
d. the timing and type of engagement with the educational context,
e. the advancing age of the person on the autism spectrum and their parents.

As these parents gradually cycled through the stages they were imbued with an increasing awareness and confidence regarding how to deal more effectively with the individualised education of their child on the autism spectrum. However, the educational journey also created variable negative feelings in the parents as they progressively realised the enormity of the difficulties they often faced throughout the educational journey of their child on the autism spectrum.

CONCLUSION

This chapter has given a brief introduction to the reasoning behind this publication. Chapter 2 provides a contextual understanding of the study and Chapter 3 offers a brief literature review of the research area. Chapters 4, 5, 6, 7 and 8 provide a deep, synthesized understanding of the various educational pathways undertaken by the parents in the six families involved in the study (McDonald, 2010) over a five year period. It gives precedence to the parent voice and explicates the parent experience from pre-diagnosis to the final years of formal schooling and the years immediately beyond. It examines the parent experience inclusive of such areas as diagnosis, early intervention, mainstream schooling, home schooling, supplementing, segregated schooling sites and transitioning to the adult world of tertiary study and work. While the experiences of these parents cannot be generalized to all families who may educate their children on the spectrum, it is hoped that their stories will resonate and be instructive for other parents and help to inform and fortify them during their own difficult educational decision making. The final chapter of the book gives an overview of the parent experience with suggestions for future research and recommendations for policy and practice.
CHAPTER 2

CONTEXTUAL UNDERSTANDINGS

This chapter is broken into three major sections and gives a brief contextual background to this publication locating it appropriately in both time and place. Section one, The International Context, gives a brief history of the international trends regarding the education of students with disabilities. Section two, The Australian Context, gives a short outline of how the Australian educational context has responded to such trends. Finally, in section three, The West Australian (WA) Context, there is a more concentrated examination of the WA context in relation to Diagnosis, Prevalence, Early Intervention, General Disability Educational Provision and specific ASD Educational Provision.

THE INTERNATIONAL CONTEXT

Historically, the international movement toward inclusive educational practices for disabled students has been a gradual one. For some time, the notion of ‘inclusion’ has been seen as a problematic term because of its overuse and its lack of understanding in everyday discourse (Skidmore, 2004, p. ix). The term ‘inclusion’ is primarily used to describe situations where a disabled child’s education is “embedded within the normative educative pathways within the classroom and the school” (Uditsky, 1993, p. 88). More recently the term ‘inclusion’ has incorporated the notion that schools should view ‘diversity as the norm’ as evidenced by the definition of ‘inclusion’ included in the introduction to this publication (Lynch and Irvine, 2009, p.286). Research over time informs us that because we live in a time of generational educational change for students with disabilities there can often be a divide experienced between the rhetoric and reality of inclusive practice (Cologon, 2013; Kavale & Forness, 2000, Oliver & Barnes, 2010).

There has been an interaction of differing factors spanning several decades, in various Western countries that has influenced the range of educational options now on offer to students with disabilities within Australia. Significant international influences on Australia’s movement toward ‘inclusive’ practice can be found in binding and non-binding international conventions, disability legislation of both the United States of America (USA) and the United Kingdom (UK) and the deconstruction of traditional notions of ‘disability’ by leading voices in the disability movement over time (Oliver, 1990, 1996; Oliver & Barnes, 2010, Slee, 2011).

One significant international influence on Australia’s movement toward inclusive practice has been the binding and non-binding international conventions by the United Nations. Through a rights-based approach, UNESCO has promoted
inclusive education policies, programmes and practices to ensure equal education opportunities for persons with disabilities. Various conventions have confirmed the rights of disabled students to be educated in mainstream schools. The United Nations (UN) Convention on the Rights of the Child (1989) decreed that all children with disabilities should have the right to an education that would allow their fullest possible social integration and individual development. The UN Standard Rules on the Equalisation of Opportunities (1993) reaffirmed that the education of students with special needs should be an integral part of education systems (Shaddock et al., 2007). The influential Salamanca Statement (United Nations Scientific & Cultural Organisation (UNESCO, 1994) further proclaimed that schools should accommodate all children including those with a disability (Shaddock et al., 2007). The Dakar Framework for Action (2000) (UNESCO, 2000) restated an international commitment to education for all children in ‘inclusive’, educational environments. This has since been strengthened by the UNESCO (2004) Changing teaching practices: Using curriculum differentiation to respond to students’ diversity (UNESCO, 2004) agreement and Article 24 of the UN Convention on the Rights of Persons with Disabilities (2006). Since the Salamanca Statement (UNESCO, 1994) Australia has adopted a similar approach to the international movement towards greater inclusion (Forlin et al., 2008). However, the majority of jurisdictions in Australia retain a continuum of placement options for students with disabilities (Forlin et al., 2008; Pearce & Forlin, 2005).

Another significant influence upon Australian inclusivity has been the movement toward inclusive education in the USA. This influence had its roots in the American civil rights movements of the 50s and 60s. This movement focused attention on race-related educational segregation, gained impetus and started to exert international influence during this time (Shaddock et al., 2007). This led educators, parents of disabled children and the disabled themselves to question the legitimacy, ethics and cost effectiveness of segregated educational placements of students with disabilities (Barnes, 1996; Forlin, 2004; Shaddock et al., 2007). Specific legislation in the USA in the form of the Education for All Handicapped Children Act in 1975 mandated that there should be free and appropriate public education (FAPE) for all disabled children between the ages of 3 and 21. In 1990, this Act was amended and re-authorised under the Individuals with Disabilities Education Act (IDEA) (Shaddock et al., 2007). Further re-authorizations in 1997 and 2004 (Disabilities Education Improvement Act of 2004) required school staff to continually monitor and evaluate the student’s progress by developing an Individualised Education Plan (IEP) at least once a year (Shore & Rastelli, 2006). Parents were also given the legal right to be involved in all aspects of their child’s education (Stoner & Angell, 2006). Parents were also entitled to an Individualised Family Service Plan (IFSP) for pre-schoolers at risk, which took into account the strengths and needs of parents (Shore & Rastelli, 2006).

Disabled students were also afforded the right to be educated with their peers in the least restrictive environment possible (Myles, Swanson, Holverstott, & Duncan,
Students with behavioural difficulties were also entitled under the Act to a functional behavioural assessment to determine the most appropriate intervention to change such behaviour (Myles et al., 2007). Parents were able to request an extended school year for their child if the child needed help in the summer break to maintain his or her progress (Shore & Rastelli, 2006). Prior to the implementation of IDEA individuals with disabilities often did not attend school or were placed in segregated special education settings without access to the general education curriculum or their non-disabled peers (Myles et al., 2007). Over the past 25 years, IDEA has ensured significant progress has been made in the development and implementation of special education programs and services for students with disabilities in the USA (Shaddock et al., 2007). However, on-going concerns have been expressed regarding the dissonance between the rhetoric and reality of ‘inclusive’ practice as it operates in different educational contexts irrespective of legislation (Kavale & Forness, 2000). This has led to an increase in litigation by some US parents who wish to ensure that an appropriate, supported mainstream education is available to their child on the autism spectrum (Yell, Katsiyannis, Drasgow, & Herbst, 2003).

The UK experienced the emergence of a similar climate of social reform that resulted in a comprehensive national review of educational provision for individuals with disabilities. This culminated in the Warnock Report (1978) which outlined recommendations and was subsequently used as a basis for legislation. As a consequence of the report, the Education Reform Act (1988) legislated that every child, disabled or otherwise, should have access to the national curriculum (Shaddock et al., 2007). Subsequent to this was the implementation of the 1995 British Disabilities Discrimination Act (DDA) which legislated that all schools should allow admission of disabled students and provide facilities to allow these students to access an appropriate education (Shaddock et al., 2007). This was followed by the Special Education Needs and Disability Act of 2001 which legislated that children with special needs should be educated in mainstream schools (Shaddock et al., 2007). More recently, there has been the implementation of the UK Autism Act 2009. This Act makes specific provision about the needs of adults who have autism. It is the first ever disability-specific legislation to be passed in the United Kingdom (National Autistic Society, 2014).

One UK initiative, the Index for Inclusion (Booth, Ainscow, Black-Hawkins, Vaughan, & Shaw, 2000), initially devised and implemented in the UK, has been trialled in Australian schools (Deppeler & Harvey, 2004; Forlin, 2004; Jenkins, 2005). This instrument allows schools to identify and address issues surrounding inclusivity (Forlin, 2004; Jenkins, 2005) and has been used in both government and private West Australian rural and metropolitan schools in both primary and secondary sectors.

Underpinning the evolving nature of the international conventions and legislation in both the UK and USA has been a deconstruction of traditional notions of ‘disability’ by international disability scholars. Skidmore (2004) asserts that there are three major paradigms which currently permeate modern discourse on disability.
CHAPTER 2

These incorporate the psycho-medical, sociological and organizational models of disability. The psycho-medical paradigm traditionally focuses on assessment and treatment of deficits in the individual and operates at the micro level. This theoretical model conceptualizes “special needs as arising from deficits in the neurological or psychological make-up of the child, analogous to an illness or medical condition” (Skidmore, 1996, p. 34). ‘Disability’ is seen as an individualized paradigm where a disabled child’s ‘misfit’ with mainstream education is due, in the main, to the disabled child’s deficits and provides the rationale for ‘special education’.

By contrast, the sociological model, asserts that there are “structural inequalities in education at the macro level” (Shaddock et al., 2007, p. 13). There is a clear distinction in this model between ‘impairment’ and ‘disability’. Whereas ‘impairment’ refers to a mental or physical deficit, the term ‘disabled’ is used to describe the environmental, social and political relations of disability (Ainscow, 1993, 1995; Fulcher, 1993; Oliver, 1990, 1996; Slee, 1996). While some students are deemed to have ‘special needs’ the onus seems to fall upon the student to ‘fit’ the system and not the reverse. This “individualistic gaze” is explained by Ainscow (1993) as “an approach to naming and framing the problems experienced by pupils and teachers which takes little or no notice of the wider environmental, social and political contexts in which they occur” (p. 206). It is the contention by a number of leading voices that it is the system itself which ‘disables’ because it fails to ‘enable’ many children with different educational needs to be successful in mainstream education (Ainscow, 1993; Fulcher, 1993; Oliver, 1990, 1996; Slee, 2011).

Related to the social model is the construct of the organizational model which occurs at the meso or institutional level which argues that “learning difficulties arise from deficiencies in the way schools are currently organized” (Skidmore, 2004, p. 10). In recent times this organizational paradigm has come to “assume a position of dominance in the field” (Skidmore, 2004, p. 7). The solution to such organizational deficiencies is to restructure schools where a:

… properly implemented policy of school restructuring will produce a system of schooling which is better adapted to meeting the educational needs of all pupils, and which will therefore eliminate or reduce to a minimum the problem of students who fail to fulfil their learning potential in the formal education system (Skidmore, 2004, p. 7).

The ‘inclusive’ school would therefore, adapt and respond to the diversity found in the student population and no group would require a so-called ‘special’ form of educational provision (Skidmore, 2004).

Each model draws on a distinctive theoretical framework, operates with its own implied epistemology and level of focus, posits a different model of causation and proposes a correspondingly different form of intervention (Skidmore, 2004). There are limitations inherent in each paradigm. Skidmore (2004) asserts that trying to reduce ‘disability’ into any one of the three paradigms is potentially reductionist and does not account for the complexity inherent in the nature of disability.
Skidmore (2004) explains reductionism as “the tendency to explain an intrinsically complex phenomenon in terms of a single, unidirectional model of causation, and (concomitantly) to propose a single form of intervention as a complete and adequate solution to the problem” (p. 11). It may be as Skidmore (2004) suggests that “learning difficulties are conceptualized as the product of factors located within the individual, or society at large, or the school, but the possibility or interaction between factors operating at different levels of analysis” should not be “overlooked” (p. 11).

Disability is increasingly being reconstructed as natural to the human condition with the understanding that most people will experience some form of disability (indirectly or directly) at some stage in their lives (Shaddock et al., 2007). According to Shaddock et al. (2007), the practical implication of this is that “if disability comes to be seen as unexceptional then all mainstream services, including education will ‘naturally’ be required to take responsibility for a more diverse clientele” (p. 15). This sentiment has been echoed in the research literature on ‘inclusive’ education and best practice for children with an ASD where there has been a similar call to use a more unified model of education where all children will receive the educational support they require (Lynch & Irvine, 2009) as a matter of basic human rights (Nussbaum, 2009). Shaddock et al. (2007) further suggests that the way forward may be “to pay more attention to the everyday effects on a person’s life of disability and impairment” (p. 16). This framework “draws attention to what is happening, and what can be done, at the level of the body, the person and the society and emphasizes the person’s access, or lack of it, to activity and participation” (Shaddock et al., 2007, p. 16).

More recently, in specific relation to students on the autism spectrum, there has been a questioning of dominant and seemingly contradictory perspectives – the rights-based and needs-based perspectives – where an integrative inclusionist position is tentatively explored as a bridge between such polarising perspectives and where the needs of the individual student more rightly drive educational decision making (Ravet, 2011).

THE AUSTRALIAN CONTEXT

Australia is presently involved in the process of creating and disseminating a national curriculum (ACARA, 2013) and until it is fully implemented its six states and two territories are individually responsible for the provision of primary and secondary school education. The major responsibility for ‘special education’ was devolved to the states and territories with the Commonwealth retaining limited power (Forlin & Forlin, 1998). Historically, there were limited educational opportunities for children with disabilities in Australia prior to the Second World War. Following this time, federal, state and territory governments enacted legislation to ensure that all students of differing ages and abilities received an education. To illustrate, the Western Australian Education Act (1928) was amended in 1952 to make education of children with disabilities compulsory (Chalmers, 1998). Responsibility for
educating these children was originally given to the health departments of different states and territories. However, by the 1970s this responsibility shifted to the education departments of those states and territories (Jenkinson, 2001). During this time, segregated ‘special education’ institutions were established and were seen as the most cost-effective method of delivering intensive educational programs to children with disabilities (Jenkinson, 2001).

In line with the international disability movement, segregation of disabled students was eventually challenged in Australia by parents, educators and researchers who voiced concerns about excluding students with disabilities from their non-disabled peers (Ashman & Elkins, 2005). In response to this, the Schools Commission in Australia in 1975 recommended a system of ‘integration’ and by the 1980s this was endorsed by education systems throughout Australia (Ashman & Elkins, 2005). Despite this, there was little ‘integration’ evident and most students with disabilities still received their education in locations that excluded them from regular classrooms (Dempsey, Foreman, & Jenkinson, 2002).

Like its international partners, Australia has supported a strong philosophical movement over the last two decades toward greater inclusion of students with special needs into regular school communities (Forlin, 2004). Inclusion has been supported at a federal level within Australia by the enactment of both the Disability Discrimination Act (DDA) (Commonwealth of Australia, 1992) and the Disability Standards for Education (Commonwealth of Australia, 2005). The DDA has been revised several times and requires that educational institutions in Australia be free from discrimination on the grounds of disability in terms of admission, access or harassment (Commonwealth of Australia, 2006). The DDA has been seen as mainly providing direction for individuals who have experienced discrimination and does not have the far reaching human rights protection of the USA Bill of Rights (Lindsay, 2004). The DDA does not prevent discrimination from taking place but rather deals with it after the discrimination has occurred. The alleged victim of discrimination must therefore take his or her case to the Human Rights Equal Opportunity Commission (HREOC). The HREOC does not have the power to enforce decisions resulting from its hearings and when conciliation has not been successful, the complainant has the right to take their case to the Federal Court (Jones & Basser Marks, 1999). The DDA has several exemptions for institutions with the most contentious being the exemption of ‘unjustifiable hardship’. This potentially allows any educational institution to avoid a finding of unlawful discrimination if it can prove an ‘unjustifiable hardship’ would be imposed on their institution if it complied with the DDA (Commonwealth of Australia, 2006; Waldeck & Guthrie, 2004).

Following on from the DDA (Commonwealth of Australia, 1992) has been the formulation of the Disability Standards for Education (Commonwealth of Australia, 2005) which explains sections of the DDA that pertain to education (O’Reilly & Smith, 2008). These Standards have the same legal status as the DDA and encompass the following five areas where disabled students are entitled to support and accommodations: enrolment; participation; curriculum development, accreditation
and delivery; student support services; harassment and victimization. According to the Standards (Commonwealth of Australia, 2005), disabled students have the same right to services and facilities as anyone else and education providers have an obligation to make ‘reasonable adjustments’ (O’Reilly & Smith, 2008). The term ‘reasonable adjustments’ is understood to mean “an adjustment is a measure or action taken to assist a student with disability to participate in education and training on the same basis as other students” (O’Reilly & Smith, 2008, p. 146). Accommodations and support are subject to an educational institution receiving formal documentation regarding a students’ disability and their resultant requirements. An institution is only required to provide what is considered to be ‘reasonable’ under the circumstances and decisions do not necessitate consultation with all stakeholders. In line with the DDA (Commonwealth of Australia, 1992) the Disability Standards for Education (Commonwealth of Australia, 2005) also has exemptions inclusive of the difficulties associated with the ‘unjustifiable hardship’ exemption. A recent review on the Standards, Report on the Review of the Disability Standards for Education 2005 (DEEWR, 2012) has found serious shortcomings in its implementation across both state and territory jurisdictions.

Despite their limitations, both the DDA (Commonwealth of Australia, 1992) and the Disability Standards for Education (Commonwealth of Australia, 2005) have been credited with exerting a major influence on education providers in Australia (Shaddock et al., 2007). Modification of education policies to comply with the DDA and Disability Standards for Education has occurred in state and territory education departments throughout Australia and substantial funding has occurred to support these changes. However, while individual policies exist the responsibility to implement these policies still rests with each individual education provider. Most states and territories continue to provide an array of education options including segregated special schools, education support centres and special education classes within regular schools, however, there are an increasing number of students with special needs being catered for in regular classrooms (Ashman & Elkins, 2005; Forlin, 2004).

More recent Australian research indicates that despite the legislation and resultant state and territory policies, Australian teachers in regular classrooms indicate that they tend to incorporate “accommodations that can be made for the whole class, that are efficient of teacher time and effort and that do not involve major changes to class organization or substantial individualization” (Shaddock et al., 2007, p. xiv). This aligns with comprehensive international research which shows that “many teachers worldwide say they do not have the time or resources to make adaptations for students with significant individual needs and these concerns have been expressed for many years” (Shaddock et al., 2007, p. xiii). Hence, while students with disabilities may have increased rights regarding access and enrolment in regular schools and classrooms, issues have now arisen regarding the quality and outcomes of the education they receive in such environments (Cologon, 2013; Kavale & Forness, 2000; MacDermott, 2008; McDonald, 2010; Ravet, 2011; Shaddock et al., 2007; Ypinazar & Pagliano, 2004,).
This is borne out in recent extensive research (Victorian Equal Opportunity and Human Rights Commission, 2012) conducted in Victorian schools which surveyed 883 educators, 617 parents and carers and 60 students and found that the educational experiences of children with disabilities was not consistent, that discrimination still exists and that not all children with disabilities are eligible for support to enable them to access the curriculum as is required by the Disability Discrimination Act (1992). Further to this, preliminary results from a Queensland study investigating how nine students on the autism spectrum and their parents experience participation in mainstream school over time has found that seven of the nine students experienced frequent, disrupted mainstream participation for most of their schooling years (Harrington et al., 2013). The study recommended more support for transitions; finding a student champion at school; greater collaboration among school staff, students on the spectrum and their parents; and, provision of a continuum of education options being made available to families (Harrington et al., 2013).

In response to the education difficulties experienced by families who have a child on the autism spectrum, specific government support has been undertaken. From 2008 the Australian Government committed funds to provide a Helping Children with Autism (HCWA) support package (The Hon Bill Shorten MP, personal communication, 7 May, 2008). The package seeks to provide earlier and more accurate diagnosis of children with an ASD, increased access to early intervention programmes, and further support services for educators and parents/carers of children with an ASD (O’Reilly & Smith, 2008).

Further to this in 2014, under the Australian Education Act, 2013, the federal government has begun a funding loading formula for school students with disability which applies to eligible students with disabilities whether they attend a government or non-government school (The Hon Christopher Pyne MP, personal communication, 2014). The loading is set at 186 per cent of the base per-student Schooling Resource Standard (SRS) amount which is $9271 for primary students and $12,193 for secondary school students. Students with disabilities in segregated school sites are eligible for an extra loading of 223 percent in recognition of the more complex needs of these students (The Hon Christopher Pyne MP, personal communication, 2014). Additionally, under their More Support for Students with Disabilities (MSSD) initiative, the government is providing $300 million over the 2012–2014 school years to build capacity of Australian schools and teachers in educating students with disability, contributing to improved student learning experiences, educational outcomes and transitions to further education or work under their MSSD initiative (The Hon Christopher Pyne MP, personal communication, 2014). Unfortunately, the latest 2014 federal Budget indicates that these school funding commitments may be scrapped from 2017–18 (Gonski et al., 2011; Australian Government, 2014).

It is important to note that home educators in Australia are presently not eligible to access the same funding provided to schools for their children with disabilities even though it could be argued that they are often compelled to provide an appropriate
education for their children with disabilities when there has been a repeated failure by formal schooling contexts to do so.

**THE WEST AUSTRALIAN (WA) CONTEXT**

*Diagnosis*

Education of individuals with disabilities in WA has followed the same linear pattern set by other states in Australia and countries in the Western world (O’Donoghue, 1998). The pattern has been initially exclusion (1830s to 1920s), through to segregation and integration (1930s to 1960s) and finally to limited inclusion (1970s to the present) (O’Donoghue, 1998). For students with a suspected ASD to gain funded services in WA they must seek a diagnosis. All states in Australia have different assessment and diagnostic practices for a diagnosis to be made. To receive government funding in WA for early intervention and educational support, parents must firstly seek a diagnosis of an ASD. Prior to 2013, the Diagnostic and Statistical Manual-IV-TR (DSM-IV-TR), was used in Western Australia to identify a set of Pervasive Developmental Disorders (PDDs) that were considered “autism spectrum disorders” (ASDs). These included: Autistic Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

According to the DSM-IV-TR, PDDs were “characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behaviour, interests, and activities” (American Psychiatric Association, 2000, p. 69). The DSM-IV has been under revision for 14 years and a new edition, the DSM 5, has recently been released in 2013. Significant changes to the criteria and categories of ASDs have occurred in the new edition.

One of the most significant changes is that the separate diagnostic labels of Autistic Disorder, Asperger’s Disorder, and PDD-NOS have been replaced by one umbrella term “Autism Spectrum Disorder” (DEEWR, 2013). Diagnosis has also been reduced from considering three to two domains. The domains of social interaction and communication have been collapsed into one domain with the accompanying domain of restricted interests/repetitive behaviour being preserved as the other domain (DEEWR, 2013). Under the domain of restricted interests/repetitive behaviour there is now recognition of the sensory difficulties experienced by many on the autism spectrum. Further distinctions have also been made according to three severity levels, from level 1 (requiring support) to Level 3 (requiring very substantial support) (DEEWR, 2013).

Concerns have been raised regarding how these changes might impact individuals on the spectrum. One of the biggest concerns is that some individuals who are higher functioning will no longer meet the stricter diagnostic criteria and will therefore have difficulties accessing relevant support services, even though these individuals may have the greatest chance of making a substantial contribution to the community if
appropriately intervention and support is provided. Questions have been raised about what will happen to people currently diagnosed with Asperger’s Disorder or PDD-NOS. Furthermore, there is uncertainty regarding how state educational services and insurance companies will adopt these changes (Matson, Hattier, & Williams, 2012; Gibbs, Aldridge, Chandler, Witzlsperger, & Smith, 2012; McPartland, Reichow, & Volkmar, 2012).

In response to these concerns, a recently released statement by the American Psychiatric Association (APA) titled, *DSM-5 Autism Spectrum Disorder Fact Sheet*, indicated that:

The DSM-5 criteria were tested in real-life clinical settings as part of DSM-5 field trials, and analysis from that testing indicated that there will be no significant changes in the prevalence of the disorder. More recently, the largest and most up-to-date study, published by Huerta, et al, in the October 2012 issue of American Journal of Psychiatry, provided the most comprehensive assessment of the DSM-5 criteria for ASD based on symptom extraction from previously collected data. The study found that DSM-5 criteria identified 91 percent of children with clinical DSM-IV PDD diagnoses, suggesting that most children with DSM-IV PDD diagnoses will retain their diagnosis of ASD using the new criteria. Several other studies, using various methodologies, have been inconsistent in their findings. (American Psychiatric Association, 2013a)

However, such assurances will need to be borne out in further studies undertaken over the next few years.

Presently, the West Australian Disability Services Commission (DSC) applies internationally recognized standards for diagnosis (Lewis, 2009). Primary government diagnostic and assessment agencies (State Child Development Centre, DSC Individual and Family Support Autism Team) and private practitioners/organizations are currently able to make ASD diagnoses (Lewis, 2009). The *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition, text revision (DSM-IV-TR) (American Psychiatric Association, 2000) has been the most commonly used basis for diagnosis of children with a PDD (Lewis, 2009). However, this will change with the recent release of the DSM 5 (American Psychiatric Association, 2013b).

To gain a diagnosis, parents or carers generally seek a referral from medical and allied health practitioners, school psychologists and/or other educators in both government and private sectors (MacDermott et al., 2007). The Disability Services Commission (DSC), Health Department and private practitioners are then able to receive the referral and organize an assessment (MacDermott et al., 2007). Diagnosis of children currently usually involves a multi-disciplinary team made up of a paediatrician, psychologist and speech pathologist conducted either privately or through the health or disability sectors (Palm Consulting Group, 2005). However, when needed, a psychiatrist, social worker and occupational therapist may also be involved (MacDermott et al., 2007). The multi-disciplinary team responsible for the diagnosis then makes intervention referrals and recommendations. The client
is then referred to DSC for eligibility for level and type of services determination (MacDermott et al., 2007).

Diagnosis through the government system and private practitioners has often been a protracted experience in WA. WA has however, a relatively high standard of practice regarding the difficult task of diagnosis. There is a WA Autism Diagnosticians’ Forum (http://www.waadf.org.au/) that meets quarterly to discuss international standards, processes, and clinical issues in assessment and diagnosis of ASDs. This forum includes clinicians across the disciplines of speech pathology, paediatrics, psychiatry, social work, psychology and research who are working in the government and non-government sectors. From 2008 the federal Helping Children With Autism (HCWA) package has provided some extra funding for diagnosis and development of a treatment plan for children under the age of 13 years.

Prevalence

WA presently has an established ASD diagnostic register, the WA Register for Autism Spectrum Disorders (Glasson et al., 2006). The register is prospective and has been collecting information since 1999 on: the number and ages of people diagnosed; the severity of disability; shared biological, psychiatric and developmental features; and group changes over time (Glasson et al., 2006). It serves as a primary resource to researchers, clinicians and service providers to assist with their knowledge of ASDs in WA (Glasson et al., 2006). WA is an ideal location to manage a register because of its geographic isolation and centrally distributed population (Glasson et al., 2006). The register has application in both research and planning for services. Over the past two decades the number of new diagnoses per year has increased nearly 20 fold (Glasson et al., 2006). This increase in identified children with an ASD has been similarly observed internationally (MacDermott et al., 2007). Some reports indicate that approximately 300 WA children are diagnosed with an ASD each year (Painter, 2009). A recent study comparing prevalence statistics for Denmark and Western Australia found that ASD prevalence rates were higher in Denmark (68.5 per 10,000 children) compared with Western Australia (51.0 per 10,000 children), while the diagnosis of childhood autism was more prevalent in Western Australia (39.3 per 10,000 children) compared with Denmark (21.8 per 10,000 children) (Parner, Thorsen, Dixon, deKlerk, Leonard, Nassar, Bourke, Bower & Glasson, 2011).

Early Intervention

After diagnosis, the Disability Services Commission (DSC) eligibility determination team provides the family with a letter informing them of what government-funded early intervention (EI) services their child is eligible. The family then chooses which EI provider they wish to receive services from and wait lists vary at each centre (Lewis, 2009; Painter, 2009; Therapy Focus, 2012). Parents who want to use government funding for EI may choose from accredited Autism early intervention
providers who offer a choice of ASD early intervention models (Lewis, 2009). They may also choose to use other organizations that have contracts with DSC to provide EI services for children with disabilities (Lewis, 2009). Parents may also choose private organizations/professionals where families may purchase services.

Unfortunately, some government-funded EI services that are on offer do not necessarily provide the type or intensity of intervention recommended in best practice programs (Roberts & Prior, 2006) at the earliest possible time and wait lists are common (Painter, 2009). Funding for one of the most efficacious interventions based on long term research (Roberts & Prior, 2006) is presently still under-funded, although some extra money has become available through the federal Helping Children with Autism (HCWA) package. The package provides all children aged six and under who are diagnosed with an ASD and are not yet school-age to gain funding of up to $12,000 (up to $6,000 per financial year) to assist with the financial cost of accessing EI services. This funding is not dependent upon whether the child with an ASD has an accompanying intellectual disability. Parents access this funding through an Autism Advisor located at the Autism Association of WA.

This figure unfortunately falls far short of providing appropriate funding for the intensity of EI recommended by a government review (Roberts & Prior, 2006) which investigated current research regarding the most effective models of EI for children with an ASD. The recommended model of intervention is based on Applied Behaviour Analysis / Discrete Trial Training (ABA/DTT) methods and recommends that EI “be extensive and intensive” and be conducted “a minimum of 20 hours a week over two or more years” as early as possible in order for young children to make major gains (Prior & Roberts, 2006, p. 3). Government funding for this model is still inadequate and does not cover the hours per week of recommended intervention needed in best practice models.

WA also presently has EI transition to school programs conducted by the West Australian Department of Education (DoE) to teach essential skills to children with an ASD or Global Developmental Delay/Special Needs for eventual transition into mainstream (Lewis, 2009). These programs are conducted over the kindergarten and pre-primary years and are generally based on the principles of ABA incorporating DTT (Lewis, 2009). The programs were initially set up in response to research and parent input outlined in the report commissioned by Department of Education and Training, Models of Educational Service Provision for Students with Autism Spectrum Disorder within Government Mainstream Schooling (Crosby, 1998). The report indicated that parents wanted a government funded, best practice EI program specifically using ABA/DTT that would allow their children to gain skills to cope more successfully with eventual mainstream schooling (Crosby, 1998).

General Disability Educational Provision

Each Australian state or territory is required to ensure that federal legislation regarding schooling for children with special needs is appropriately embedded within their
individual Acts and policies (Forlin, 2004). Various educational reports (Andrews, Elkins, Berry, & Burge, 1979; Beazley, 1984; Shean, 1993) undertaken in WA have increasingly supported the principle of integration. These reports and subsequent legislation and policy documents have led to improvements in service provision towards placement of students with disabilities in regular schools, whenever possible (Education Department of Western Australia, 1993, 1998, 1999; Forlin, 2004).

WA school-age children are currently educated in a variety of settings ranging from one-teacher schools in remote rural locations to large senior high schools (both public and private) in metropolitan locations with student populations of 2,000 or more. The system is similar to those operating in other Western nations in that WA has generally well trained teachers, modern school facilities and educational resources, and highly developed curricula. Students with general disabilities constitute 3-4% of the total student population in WA government schools with the majority attending local schools with differing provision of resources, services and supports (Department of Education and Training, 2004; Forlin, 2004). A continuum of placement options still exists in WA and range from segregated Education Support Schools, Education Support Centres (separate schools on shared sites with regular schools), Education Support Units (classes within regular schools), to full inclusion in regular schools. Presently, students with disabilities in WA may experience a range of segregated, integrated, inclusive or home education settings (Forlin et al., 2008; O’Donoghue, 1998; O’Donoghue & Chalmers, 2000; Kidd & Kaczmarek, 2010; McDonald, 2010; McDonald & Lopes, 2012; Reilly, 2007; Wills & Jackson, 2000).

With regard to the majority of students with an intellectual disability in WA, these students are most often enrolled in an Education Support Unit, Education Support Centre or Education Support School (Forlin, 2005; Forlin et al., 2008). Initiatives by the WA Department of Education regarding providing ‘inclusive’ practice in mainstream schools have included a comprehensive review of educational services for students with disabilities in the form of the 2004 Pathways to the Future (Department of Education and Training, 2004). The report outlines the seven principles of ‘inclusive’ education adopted in the review: (1) all students have the right to enrol, access and participate in schooling which meets their individual needs; (2) all levels of the system value diversity and operate within an ‘inclusive’ framework; (3) a range of effective and appropriate adjustments is provided to ensure access, participation and achievement; (4) adjustments are provided on a needs basis and are equitably resourced; (5) the system supports the development of pedagogy to meet individual student needs; (6) the range of coordinated programs and services provided are flexible and delivered according to student needs; and (7) services are provided and supported by collaborative models and partnerships (Department of Education and Training, 2004). More recently, the Australian Curriculum, Assessment and Reporting Authority (ACARA) has provided guidance to WA schools on how to appropriately accommodate student diversity in the Australian Curriculum (inclusive of students with a disability, gifted and talented students and students for whom English is an additional language or dialect) (ACARA, 2013).
Additionally in 2014, a change to WA school funding is to occur (Bickers, 2014, July 20). A new stream-lined funding model is to be introduced where early intervention and student-centred funding is to be given precedence. The funding changes are based on the results on a 2012 review of WA school funding which recommended that schools be funded on student numbers with additional money to help children with special needs/disabilities. Presently, WA has a current budget of $4.6billion in 2014-15 of which 83.7% comes from the State Government. How such funding decisions will impact on the inclusivity of WA schools in relation to students on the autism spectrum is yet to be determined.

The Australasian Curriculum Assessment and Certification Authorities (ACACA) has also developed Guidelines for Assessment Quality and Equity (1995) and confirmed the right of students of ‘difference’ to alternative assessments and accommodations (Toner, 2009). All Australian states and territories education departments have now given students with disabilities the right to request accommodations during assessments. Potential accommodations include: separate settings, extra time, alternative presentation and response modes (Toner, 2009). Disabled students need to justify their reasons for requiring accommodations substantiated by expert opinion to prove that they are not seeking an unfair advantage (Cumming, 2006).

International research of students with general disabilities has shown a gradual increase in the number of students with disabilities entering universities, with the biggest increase being students with ‘invisible disabilities’ (Wolf, 2001). In Australia, this increase has been due to the overall improvement of educational provision of the disabled and the Federal government’s formal recognition of people with disabilities as a designated equity group entitled to accommodations in tertiary study (Cooper, 2003). University policies introduced in response to the 1992 Disability Discrimination Act (Commonwealth of Australia, 1992) affirmed the responsibility of the tertiary sector to provide necessary accommodation for disabled students to realize their potential in higher education (Toner, 2009). The number of disabled students attending Australian universities doubled between 1996 and 2006 (Carrick Institute for Learning and Teaching in Higher Education, 2006). In 2006, an original policy Guidelines Relating to Students with a Disability (Australian Vice-Chancellors’ Committee, 1996) was upgraded and revised to comply with the Disability Standards for Education (2005) (Commonwealth of Australia, 2005). It covered three key areas: Policy and Administration; Teaching and Learning; and Campus Life. The Guidelines also obliged all universities to have a Disability Action Plan, which is lodged with Universities Australia. A website (www.cats.edu.au), Creating Accessible Teaching and Support (CATS) is available to university staff to assist them in meeting the requirements of the Guidelines and their institution’s individual policies (Toner, 2009).

Most tertiary institutions in WA have mandatory policies to support students with disabilities. There has been a significant increase in students with ‘invisible disabilities’ seeking accommodations in the WA tertiary sector (Toner, 2009),
although the real number of disabled students needing accommodation is probably under-reported (James, Baldwin, Coates, Krause, & McInnis, 2004). Research has indicated that some students with ‘invisible’ disabilities at tertiary level fear perceived reactions to their disability and therefore do not declare their disabled status (Patwell & Herzog, 2000; Smith, English, & Vasek, 2002; Wade, 2003). When tertiary students do register their disability to receive accommodation they must furnish documentation to prove their disabled status and an agreed ‘management plan’ is then discussed, approved and distributed to those concerned. Disability officers in WA tertiary institutions have no control over lecturers’ teaching methods and can only make recommendations regarding appropriate accommodation regarding individual students’ needs (Toner, 2009). At this stage, the WA tertiary sector provides support when it is requested by individual disabled students. Flexible methods of course delivery are sometimes on offer to benefit all students who potentially have learning differences. There is a growing need by the tertiary sector to proactively promote universal teaching design in all teaching staff to cater for individual student differences (Garguilo & Metcalf, 2013; Toner, 2009).

**Educational Provision for Students on the Autism Spectrum**

Presently, WA students on the autism spectrum can be found in mainstream schools, schools with Education Support Units, Education Support Schools/Centres and in home schooling environments. They may be enrolled in a WA Department of Education (DoE) school, a Catholic Education Office of Western Australia (CEOWA) school or an Association of Independent Schools of Western Australia (AISWA) school. All of these schools have varying autism educational provision. DoE provides services for students with disabilities, including those on the autism spectrum, through their Socio-Psycho Education Resources (SPER), Schools Plus (SP) and School of Special Educational Needs: Disability (SSEND) programs. CEOWA provides a Special Learning Needs Team who help schools respond to the special needs and talents of students who experience significant difficulties with learning; support the inclusion of students with disabilities in appropriate educational settings; and promote exemplary pedagogical practices for students with special learning needs (MacDermott et al., 2007). AISWA employs a small number of Inclusive Education Consultants who are available to give advice aimed at supporting their students with a range of learning difficulties and disabilities. The consultants provide a range of collaborative services for parents and teachers within and across member schools (MacDermott et al., 2007; Therapy Focus; 2012).

From the commencement of school-age, the major educational service provision for children on the autism spectrum rests with the DoE. A 1998 report, *Models of Educational Service Provision for students with an ASD within Government Mainstream Schooling* (Crosby, 1998), sought information about existing practices so that policy and a range of educational options could be developed to cater for the varying needs of students on the autism spectrum in WA government schools.
Results indicated that in order to meet the needs of a wide range of students on the autism spectrum in a variety of mainstream schools a flexible approach to the delivery of educational services was essential. A range of issues were identified that impact on the ability of the Department of Education to develop and implement effective models of service delivery for students on the autism spectrum. No single approach completely addressed all the issues as many of the solutions had a degree of incompatibility with solutions to other issues (Crosby, 1998).

In relation to specific educational service provision for students with an ASD in WA, the WA government has indicated commitment to providing evidence based, flexible and responsive support to students on the autism spectrum in public schools (Banks, 2005). Their nominated aim is to provide a quality lifelong learning environment in which everyone will have the opportunity to reach their learning and skills potential and contribute to society (MacDermott et al., 2007). In relation to this, Schools Plus (SP) (Department of Education and Training, 2006) was developed by DoE as a model of informed practice to match the educational needs of students to supplementary resourcing for schools. SP allows schools to plan, implement and review appropriate educational programs on the basis of educational need and provides supplementary resources to schools that have eligible students. A diagnosis on the autism spectrum qualifies as one of the 8 groups identified by SP as an eligible condition. This is determined on a case-by-case basis and the student must require significant levels of on-going adjustments that are beyond the school’s current level of resourcing to access SP support (MacDermott et al., 2007).

The DoE School of Special Educational Needs: Disability (SSEND) also provides support to government school students on the autism spectrum. SSEND provides state-wide support for students with disabilities and learning difficulties via dedicated teams inclusive of the Autism Education Service Team (Therapy Focus, 2012). The team is comprised of a Team Coordinator and Visiting Teachers for students on the autism spectrum (MacDermott et al., 2007). The team allocates members according to particular districts’ needs and the team meets on a regular basis to discuss student, school and district based issues and needs (MacDermott et al., 2007).

DoE was the only state education department to be one of the four members of the national Australian Autism Education & Training Consortium (AAETC) responsible for the formulation and implementation of the Helping Children with Autism (HCWA) package being undertaken across Australia (AAETC, 2008a; 2008b). This innovative package provided nationwide professional development for teachers and other school staff in both metropolitan and country areas to support school students with an ASD. Workshops and information (including an ASD website) for both parents and carers of preschool and school-aged children on the autism spectrum in both city and rural areas are also being provided through the HCWA initiative. An interim evaluation (AAETC, 2009) of the positive partnerships component of the HCWA support package indicated that participants in the professional development program “reported statistically significant increases in five areas: attitudes, knowledge, skills, inclusive teaching and collaboration and partnerships” (AAETC,
2009, p. 1). It is also reported that “participant evaluation data from the parent/carer workshops and information sessions indicates statistically significant increases in knowledge of educational environments, knowledge of parenting and partnerships” (AAETC, 2009, p. 2). Based on its success, the program has been extended past its 2012 end date and is presently still operating across Australia.

Unlike some states in Australia, WA does not have any purpose-built primary or high schools for students on the autism spectrum or appropriate support for home educators of these students. There has been a strong call by parent groups over many years in WA for a specific school for students on the autism spectrum to be established and more appropriate home education support and funding to be provided so that all education options may be available to families when mainstream education options are no longer viable (See Parliamentary Submission in Appendix A).

Presently, in response to on-going difficulties experienced by adolescent students on the autism spectrum, there have been a small number of specific DoE Secondary Autism Extension Units set up at the mainstream high school level. These units have been specifically designed for students with an ASD in Years 8, 9 and 10 with the intention of being responsive and flexible to the individual needs of such students. Each unit presently caters for a small number of students with increased staffing. The Units provide a different model of service delivery to high school students on the autism spectrum who are experiencing significant difficulties in a high school setting and are at risk of disengagement and alienation. They have limited intake numbers and as such entry can be competitive between students/families (McDonald, 2010).

The students in the Units have access to both a mainstream and a home-room environment within the school. Staff involved in the Units have specialist training and are given support by the DoE Autism Intervention Team. The educational program undertaken is flexible and is determined by the students’ individual needs. The learning program uses such evidence-based practices as transitional programming, structured environments, specific teaching strategies, computer technologies, visual tools and documented education plans. The program also offers students with an ASD the opportunity to explore their special interests. The Units have not yet been independently evaluated (McDonald, 2010). However, the WA Department of Education is presently conducting a review of public high school options in the Fremantle area where the South Fremantle Autism Extension Unit is located. It remains to be seen what the results will be from such a review and if these results will be released to the community.

At the university level, courses available to teachers in WA are presently ad-hoc in their content regarding ‘inclusivity’ and may or may not have much specific instruction on supporting or accommodating students on the autism spectrum. To combat this, the DoE Autism Education Service has been offering a semester-long accredited unit of instruction on supporting students with ASDs in the mainstream classroom. Not all faculties in the WA tertiary sector have the inclination, time or the requisite funding to include such courses in their pre-service teaching programs even though such instruction has widespread application for the increasingly diverse
population regular mainstream teachers must now accommodate and support in their ‘inclusive’ classroom (McDonald, 2010).

In terms of specific investigation of the current state of students on the autism spectrum at the tertiary level, only a small amount of research has been done. Recent Australian research indicates that while many on the autism spectrum may not have an intellectual disability they may still have significant learning support needs in tertiary settings. A recent Australian study of 300 adults with a diagnosis of high functioning autism or Asperger’s syndrome from every Australian state and territory found that more than 80% had commenced or completed a tertiary qualification (Aspect, 2012). However, adults in the study reported that they had experienced significant struggles to reach their full potential in education. Almost half the respondents reported they received no or insufficient additional support for their learning needs and many felt their teachers failed to understand their needs and treated them unfairly as a result. Approximately one quarter of adults on the spectrum reported having commenced a course of study only to abandon it before completion (Aspect, 2012).

A small number of tertiary education disability officers who were also interviewed for the study identified:

... difficulties in verbal comprehension, planning and organisation, social awareness, and group work as key challenges for adult students with ASD.

They perceived a lack of awareness and understanding of ASD among tertiary educators (Aspect, 2012, p.13).

More recently a pilot peer-to-peer specialist mentoring program has been set up at Curtin University in WA specifically providing support for students on the autism spectrum. This Curtin Specialist Mentoring Program (CSMP) has recently gained Cooperative Research Centre (CRC) funding to have the program replicated and evaluated at the University of WA. The results will eventually be available to other tertiary institutions on the CRC website (www.autismcrc.com.au).

CONCLUSION

This chapter has provided a brief description of pertinent aspects of the context of the study. It identified the differing factors that have influenced, over several decades in various Western countries, the range of educational options now on offer to students with disabilities within Australia and WA. The chapter also provided a more specific investigation of the WA context inclusive of the following areas: ASD prevalence, diagnosis, early intervention, general disability educational provision and educational provision for students on the autism spectrum. The following chapter will provide a brief review of the research literature and is approached with the intention of providing a general overview of relevant areas of research that informed the study (McDonald, 2010) explained in this publication.