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How parents home educate their children with an autism spectrum disorder with the support of the Schools of Isolated and Distance Education

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Students with an autism spectrum disorder (ASD) often cannot access reliable mainstream inclusive practice that maximises their progress over time. In response to this, some parents have chosen to home educate their children. Limited research indicates that while parents find the experience beneficial for their child, there is a need for considerably more educational, social, financial support and respite. In relation to gaining appropriate support, a small number of families have managed to combine the home education of their children with an ASD with access to the services of the Schools of Isolated and Distance Education (SIDE). Little is known about this experience in the research literature. To address this deficit, the first part of this paper traces the establishment of a distance education provider in the State of Western Australia (WA). It outlines subsequent developments and describes the variety of students now catered for by SIDE inclusive of students at educational risk. The second part of the paper reports on the findings of a recent constructivist grounded theory study conducted in a metropolitan WA context that examined how parents from two families dealt with the home education of their children with an ASD with the support of SIDE.

Keywords: autism spectrum disorder; home education; parent experience; isolated and distance education

Introduction

Even though there has been an increasing development of inclusive 1 practice regarding accommodation of students with an autism spectrum disorder (ASD) over the past two decades (Frederickson, Jones, and Lang 2010; Leach and Duffy 2009), recent research has shown that students with intellectual disabilities, including those with an ASD, often cannot access reliable and consistent mainstream inclusive practice that maximises their progress over time (Ford 2007; Forlin, Keen, and Barrett 2008; Humphrey and Lewis 2008b; MacDermott 2008; McDonald 2010; Shaddock 2005; Shaddock, Smyth King, and Giorcelli 2007; Wing 2007). In response to these difficulties, some parents have chosen to home educate their children with special needs or disabilities (Parsons and Lewis 2010; Reilly 2007). Western Australia

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(WA) is one place where this occurs and it has been shown to be mainly beneficial in the case of families of children with an ASD (Kidd and Kaczmarek 2010). However, while some mothers have felt a sense of empowerment through their role as home educator, others have had feelings of resentment because of the often forced nature of their role and voiced a need for considerably more educational, social, financial support and respite (Kidd and Kaczmarek 2010). In relation to gaining appropriate support for their situation, a small number of families have managed to combine home schooling with access to the services of the Schools of Isolated and Distance Education (SIDE). Little is known about this experience in the research literature. A recent in-depth qualitative study (McDonald 2010) provides some insight into the lived experience of two such families who chose to home school their children with an ASD with the support of SIDE.

The first part of this paper draws on recent research and traces the need for and establishment of a distance education provider in the State of WA (Lopes 2009). Subsequent developments in the provision of distance education in WA are outlined followed by a description of the variety of students now catered for by SIDE with a particular focus on the provision of education for students at educational risk (SAER). The second part of the paper reports on the findings of a recent constructivist grounded theory and autoethnographic study (McDonald 2010) in a metropolitan WA context that examined how parents from two families dealt with the home education of their children with an ASD with the support of SIDE. The paper is concerned with the sub-category of home schooling in the study that identified three main thematic concerns: 'experiencing a crisis point', 'gaining appropriate support' and 'increasing educational fit'. The paper concludes by outlining important implications for parents, educators and policy-makers with regard to providing consistent inclusive education over time, flexible educational pathways and appropriate support for parents who choose to home educate their children with an ASD.

Schools of isolated and distance education

The Swan River Colony (Perth) in WA was settled by Europeans in May 1829 (Colebatch 1929). Within 20 years of the founding of the Swan River Colony, small remote settlements had been established elsewhere in the State (Rankin 1926). For children in these locations, and others even more isolated, there was little chance of accessing a formal education. The State attempted to address the problem of providing an education for geographically isolated children through the use of a number of strategies. These included the use of half-time schools, one-teacher schools and tent schools. Such approaches, however, did not alleviate the problems faced by a significant number of the State's isolated children.

In 1917, the Minister of Education received a letter suggesting the use of correspondence lessons as a way of addressing the educational needs of isolated children (Haynes et al. 1976). Although the Minister felt that the scheme would not work with individuals who could not already read, the Director of Education found that such programmes had already proved successful in Victoria and New South Wales (Eakins 1964). As a result, the Western Australian Correspondence School was established in September 1918. Within eight years, the School boasted a staff of 18 and student enrolments had reached almost 1000 (Rankin 1926). One reason for the rapid increase in enrolment numbers was that the correspondence lessons had applications beyond the original cohort of geographically isolated students and new

groups were soon added to those eligible to enrol with the School. Such students included secondary students, 'handicapped' children, those living overseas and Indigenous children (Eakins 1964).

In 1995, the School was renamed the SIDE to reflect changes in the student body and changing methods of delivering educational materials (Bowden 1993; SIDE 2009). Over the years, a range of strategies, including the use of Itinerant Teachers, the Schools of the Air, Camp Schools and the use of audio tapes, videos, the phone and computers and the Internet have been used to support the increasingly diverse student body (Ashton 1971; Eakins 1964; McAtee and Zani 1975; Rayner 1949).

Although the State's geographically isolated students remain a focus, these students no longer make up the bulk of the School's enrolments. In both the Primary School and the Secondary School, there is a significant and growing group of students who are considered to be at educational risk (SAER). SAER students are those students who are considered to be in danger of 'not achieving the major learning outcomes of schooling to levels which enable them to achieve their potential' (Department of Education 2001, 3). SAER students who are enrolled with SIDE are those who cannot be accommodated in the government education system for a range of reasons.

The teachers at SIDE use a number of strategies to support these students. First, the teachers develop an individualised education plan (IEP) for each student, specifically targeting and supporting their learning needs. Further, the teachers are able to reduce students' workloads and to allow them to work at their own pace. They can be flexible about deadlines for assignments and completion of units of work. SIDE's teachers can adapt the study programme to suit the needs of the individual student, enabling students to enrol in just one or two subjects, to work at their own pace and study at a time that suits their own situation (Lopes, O'Donoghue, and O'Neill 2011). Reilly (2007, 312) has suggested that for some students receiving an education through SIDE is the only humane option. On this, one SIDE teacher suggested that for some students, SIDE is:

a school of last resort (and) for the very first time some of those students are actually having success. So at the end of their enrolment with us we don't say 'That's it'. Part of the programme is to get them into something else so there's a high transference into TAFE (*Technical and Further Education*) or into employment and that's all part of that particular service.

The idea of keeping students engaged in education and perhaps even improving their attitude towards education is further exemplified by one teacher who commented:

A lot of kids that I have are not at a conventional school because they've had a really terrible time at school and their families have a terrible time in relation to that. They find this a really very different learning environment and it is safe. It's just a totally different experience for those kids who've been bullied or have difficulty attending school for whatever reason.

This comment highlights one of the most important aspects of the work of the teachers at SIDE, developing a relationship based on friendship and trust. For many students, the SIDE teacher is a 'significant other, someone who has the time to take an interest in their life' and, for many students and their families, this is, the first positive educational experience they have had. This is borne out in the following discussion of a study that explored the experiences of parents from two WA families who were

compelled to use the services of SIDE as an education of last resort to home school their children with an ASD

Students with an ASD

Prevalence rates for all forms of ASDs worldwide have risen dramatically since the mid-1960s. One recent Australian report indicates that more than 1% of Australian school-age children have a confirmed diagnosis of an autistic disorder or Asperger's disorder (Buckley 2009). As a consequence, there is an ever-increasing need to understand how best to educate such students so that their potential to succeed in life can be maximised.

It is commonly agreed that there is a triad of impairments in students with an ASD involving difficulties in communication, socialisation and behaviour (American Psychiatric Association 2000; AAETC 2008). Beyond the triad of impairments, there are often more cognitive characteristics to consider and these involve deficits in 'theory of mind' skills, difficulties with executive function, weak central coherence, sensory processing and motor functioning problems (AAETC 2008). Such students may also have a number of relative cognitive strengths in the areas of rote memory, visual spatial abilities, compartmentalised learning, preference for routine and rules, intense interests and being logical (AAETC 2008).

There has been an increasing development of inclusive (see note 1) practice regarding accommodation of students with an ASD over the past two decades (Frederickson, Jones, and Lang 2010; Jordan 2005; Leach and Duffy 2009). This 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 (Connor et al. 2008; Fuchs and Fuchs 1994; Oliver 1996). However, recent research has shown that students with intellectual disabilities, including those with an ASD, often cannot access reliable and consistent mainstream inclusive practice that maximises their progress over time (Crosby 1998; Ford 2007; Forlin, Keen, and Barrett 2008; Humphrey and Lewis 2008a, 2008b; Humphrey and Symes 2010; MacDermott 2008; Shaddock 2005; Shaddock, Smyth King, and Giorcelli 2007; Wing 2007).

Concerns have been raised about the lack of appropriate, individualised attention and support available, the high attrition rates and the inordinate degree of bullying experienced by students with an ASD in mainstream settings (Attwood 2007; Heinrichs 2003; Humphrey and Lewis 2008b; Humphrey and Symes 2010; Lynch and Irvine 2009; 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 and Lewis 2008a; Symes and Humphrey 2010; Wing 2007). Among children with disabilities, students with an ASD have been reported to have some of the most challenging behaviour 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 (Benson and Karlof 2009; Tehee, Honan, and Hevey 2009). In response to these difficulties, some parents have chosen or been compelled to home educate their children with an ASD (Attwood 2007, Kidd and Kaczmarek 2010).

Home education of children with intellectual disabilities

Parents have been increasingly turning to home education as an alternative teaching approach to their children in an attempt to increase control over and attend to the individual educational needs of their child (Arora 2006; Parsons and Lewis 2010). This increase has been observed in the USA, the UK and Australia (Arora 2006; Kidd and Kaczmarek 2010; Reilly 2007). Home education is now legally recognised in every state of Australia (Arora 2006; Reilly 2007) and there has been an estimated 20–30% annual growth rate in home education in Australia (McNiece 2001).

Research also indicates that the background of families who choose to home school is varied with respect to their economic status, educational background and their prior professional experience (Arora 2006). It has for some time been known that home-educated students generally academically outperform their regular classroom peers (Medlin 2000; Ray 1997; Thomas 1998) and that there are positive social and emotional benefits in relation to students who are home schooled (Barratt-Peacock 1997; Thomas 1998). These benefits are inclusive of home-educated students with special needs where it has been found that such students experience greater academic success than their peers with similar disabilities who attend public schools (Blok 2004; Duvall et al. 1997).

In relation to other reasons why parents home school their children with intellectual disabilities and special needs, parents do so because they are concerned about the ongoing negative socialisation (including bullying), insufficient academic progress and a failure by schools to understand their child's academic and social profile or the nature of their disability (Arora 2006; Parson and Lewis 2010; Reilly 2007). Parents often reach a 'crisis point' (Reilly 2007, 181) or experience certain negative 'push' factors (Parson and Lewis 2010, 76) during their child's formal schooling at which time they feel compelled to home school their children.

Parents generally undertake home schooling of their children with disabilities with limited funding and the mother often becomes the primary teacher (Ensign 2000; Parsons and Lewis 2010; Reilly 2007). Parents often create support for their homeschooling situation by researching and seeking help from external agencies, especially parent home-schooling networks (Ensign 2000; Parsons and Lewis 2010; Reilly 2007). Further to this, Reilly (2007) indicates that parents who home school their children with intellectual disabilities do so through a process of 'progressive modification'. The three stages involved in this process have been identified as:

- (1) the stage of drawing upon readily-available resources
- (2) the stage of drawing upon support networks in a systematic fashion
- (3) the stage of proceeding with confidence on the basis of having a set of principles for establishing a workable pattern of home schooling individualized for each circumstance. (Reilly 2007)

Parents who home school their children with intellectual disabilities generally work on a one-to-one basis with their child and eventually, through 'trial and error' individualise instruction according to their child's abilities, interests, social needs and pace of learning (Ensign 2000; Reilly 2007). This individualisation and flexible approach often results in improved social and academic progress of the child with special needs and disabilities (Parsons and Lewis 2010; Reilly 2007).

Consistent with other research on home-educating students with disabilities (Duffey 2002; Parsons and Lewis 2010; Reilly 2007), a recent study that investigated the

perspectives of 10 mothers who home schooled their children with an ASD in a metropolitan WA context has similarly found that the children experienced improvements in terms of their academic learning and psychological well-being through use of individualised tuition, modified teaching strategies and flexibility (Kidd and Kaczmarek 2010). Congruent with research on the difficulties associated with educating students with an ASD in mainstream settings (Humphrey and Lewis 2008a, 2008b; Humphrey and Symes 2010; MacDermott 2008; Shaddock 2005; Wing 2007), these mothers reported that the regular school environment was a 'considerable source of anxiety for their child' (Kidd and Kaczmarek 2010, 270). Additionally, these mothers reported that they decided to home school because of difficulties with mainstream school resources (specialised staff and individual instruction), and the school's inability to meet the child's unique educational needs (Kidd and Kaczmarek 2010). Consistent with other research (Spann, Kohler, and Soenksen 2003), the mothers also indicated that the stress experienced by the child in school had a flow-on effect on them and the rest of the family (Kidd and Kaczmarek 2010). By contrast, when these mothers home schooled their children with an ASD, they reported a relative decline in their stress and greater family cohesion (Kidd and Kaczmarek 2010). However, while some mothers in the study felt a sense of empowerment through their role as home educator, others had feelings of resentment because of the forced nature of their role and voiced a need for considerably more educational, social, financial support and respite (Kidd and Kaczmarek 2010). These same needs have been similarly expressed in previous research on parents who home school their children with disabilities (Parsons and Lewis 2010; Reilly 2007).

Even though there has been some development in the body of research literature investigating aspects of home education (Arora 2006), there has been limited recent research investigating the home schooling of students with an intellectual disability (Arora 2006; Parsons and Lewis 2010; Reilly 2007) and in particular, those students with an ASD (Kidd and Kaczmarek 2010). In relation to this, there is little known about the experiences of parents who choose to home school their children with an ASD with the support of SIDE. In response to this deficit, the second part of this paper reports on the findings of a recent interpretive study that examined in part how parents from two families dealt with this situation (McDonald 2010).

The wider study

The wider study that the ensuing discussion is drawn from investigates how parents from six families from diverse backgrounds in a metropolitan WA context dealt with the education of their child with an ASD over time. Different educational pathways were experienced by the six families over the course of the wider study. At the beginning of the study, one family was home schooling their child with an ASD and five families had their children with an ASD in various mainstream educational settings at different points in the educational process. By the end of the study, some five years later, two families had placed their children into segregated school sites; two families were home schooling their children with the support of SIDE; and the remaining two families had their children continuing their education through mainstream educational sites.

Method

In order to generate a theoretical understanding and explanation of how parents deal with the education of their child with an ASD over time, the qualitative research

methods of constructivist grounded theory and autoethnography were used. This was done with the understanding that the constructivist grounded theory method 'explicitly assumes that any theoretical rendering offers an interpretive portrayal of the studied world, not an exact picture of it' (Charmaz 2006, 10). To capture data from the author's own family's experiences of the research area, auto-ethnographic methods were also used. For the purposes of the study, auto-ethnography is understood to be 'an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural' (Ellis and Bochner 2000, 739). The study was produced as a complete member text where the researcher attempted an indepth exploration of the group in which the researcher is a full member and where the researcher became part of the phenomena being studied. To accomplish this task, an 'instrumental' auto-ethnographic case study was undertaken followed by a 'collective' case study (Stake 1995, 2000). The initial, 'instrumental', autoethnographic case study sought to examine a single case in-depth in order 'to provide insight into an issue' (Stake 2000, 437). Following on from this, a 'collective' case study was undertaken in the manner described by Stake (2000) as an 'instrumental study extended to several cases' (437). All participant contributions were imbedded anonymously in the study inclusive of auto-ethnographic data.

Participants

Six mothers and one father of the children with an ASD residing in Perth, WA, participated in the original wider study. The age of the participants' children ranged from 4 to 14 years at the beginning of the study and all of the children with an ASD were male, reflecting the 4.3:1 ratio of male to female ASD diagnosis rate (Fombonne 2003). To strengthen the study, families were purposively selected to reflect diversity in terms of their geographic location, stage/type of schooling, socio-economic status, educational background, family composition, ethnic background, ASD diagnosis and comorbidities (LeCompte and Goetz 1982). Fathers were initially sought to be involved but the need for such sampling diminished as 'theoretical sampling' revealed that the mothers in all cases were the main drivers of the education process for their children with an ASD. Theoretical sampling is understood to be where 'the analyst jointly collects, codes and analyses his data and decides what data to collect next and where to find them in order to develop his theory as it emerges' (Glaser 1992, 101).

Data collection and analysis

The wider study used qualitative methods of data collection and analysis as proposed by constructivist grounded theorists (Charmaz 2006). The basis for data collection was semi-structured interviews, participant observation, informal interviews and documentary data sources consistent with the interpretivist qualitative research tradition. The interview questions were framed around the central research question of 'how do parents deal with the education of their child with an ASD?' and were designed to elicit 'the participant's definitions of terms, situations and events and try to tap his or her assumptions, implicit meanings and tacit rules' (Charmaz 2006, 32). Interviews took place over a five-year period and were conducted in line with grounded theory's recommendation of theoretical sampling.

Data analysis incorporated constructivist grounded theory methods inclusive of open and focused coding that led to generation and testing of propositions of the

theory (Charmaz 2006). To ensure trustworthiness regarding the study findings, there was prolonged and persistent engagement in the field, 'member checking' with participants of the transcribed interviews and their analysis, triangulation with other data sources and numerous 'peer debriefer' sessions with other researchers to ensure confirmation of the emerging theory (Charmaz 2006; Lincoln and Guba 1985).

Findings

In the wider study, the 'seeking of progressive fit' emerged as the overriding basic social process that permeated the lives of parents when dealing with the education of their child with an ASD. This notion of a '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, and Dyson 2006, 304; Laluvein 2010, 42). A key finding of the wider study was that parents often repeatedly struggled to seek, gain, maintain and create educational fit for their child with an ASD so as to maximise their child's educational potential and progress. The four iterative stages involved in this process in the wider study were identified as follows:

- (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) Strategising solutions the stage where parents strategise solutions to remedy the constant difficulties associated with education.
- (4) Framing futures the stage where parents frame futures and begin redressing life imbalance.

The iterative movement between Stages 2 and 3 had the greatest level of interaction where parents continually strategised solutions to remedy the constant difficulties associated with educating their child with an ASD. Parents' direction and speed of movement through the various stages was mediated by the following intervening conditions:

- (a) attitude and background of the parents,
- (b) level of support and accommodation available,
- (c) educational progress of the child over time,
- (d) timing and type of engagement with the educational context and
- (e) advancing age of both the person with an ASD and their parents.

As these parents gradually cycled through the stages, they were imbued with an increasing awareness and confidence regarding how to deal with the individualised education of their child with an ASD. 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.

The four key stages of the theory that emerged from the wider study were experienced by the two families who eventually chose to home school in order to gain, maintain and create 'educational fit' for their child with an ASD. Their decision to home school occurred during Stages 2 (waging war) and 3 (strategising solutions) where they were compelled to withdraw their children with an ASD from mainstream

schooling and home school them with the support of SIDE. An investigation into their experiences generated the sub-category of home schooling in the study that revealed three main thematic concerns: 'experiencing a crisis point', 'gaining appropriate support' and 'increasing educational fit'. These thematic concerns in relation to home schooling with the support of SIDE are discussed in turn below.²

Experiencing a crisis point

Consistent with other research (Arora 2006; Kidd and Kaczmarek 2010; Parsons and Lewis 2010; Reilly 2007), examination of the two families who were compelled to home school their children with an ASD reveals that there was a lack of consistent and reliable accommodation of the child's individual educational needs in their mainstream schooling experience and at a certain time a 'crisis point' was reached.

In the first family, a 'crisis point' was reached during the child's primary school years after the child had unsuccessfully attended three government mainstream, primary school environments. The mother finally intervened at the point where the child with an ASD had expressed suicidal thoughts at the age of 10 as evidenced by her comments below:

And one day I was getting him *(child with an ASD)* ready for school and he said, 'I hate my life I wish I was dead'. And I thought at ten we don't say that. And he shouldn't feel like that at ten. And the warning bells really went off in my head because I have a brother who committed suicide and we did have depression in the family . . . we still do. So I just took his shirt off and I said, 'Right you do not go to school anymore. We will think of something different'.

By contrast, the other family's son with an ASD had previously experienced reasonably successful, inclusive private mainstream schooling over the duration of his primary school years. On this point, the mother made the following illustrative comments:

He (the principal) said that our son (with an ASD) would be most welcome to join one of the grade one classes the following year. He explained how he would organize a team approach to help with our son's inclusion. The grade one teacher assigned to my son would be invited to join a meeting scheduled the first week of school where she would hear about our son's learning differences from the outside professionals who were working with him. We, as parents, would also be invited to attend so that we could coordinate the whole process and keep all parties aware of the bigger picture regarding Kim's (son with an ASD) progress. If needed, the professionals could be consulted by the teacher through us throughout the year if difficulties emerged and alternative strategies were needed to maximize Kim's progress. We could not believe what we were hearing. Finally, a person, better yet a principal, who did not need to be schooled in the ideal and ethos of inclusion of children with special needs.

This experience was followed by continuous difficulties in two mainstream secondary contexts, both private and public, where the student with an ASD experienced both bullying and a lack of reliable inclusive practice until a 'crisis point' was reached. This 'crisis point' occurred when he was physically assaulted on a school bus by a number of his secondary peers during the journey home. The police were subsequently brought into the situation. Under such circumstances, the parents felt that their child with an ASD was no longer safe in a mainstream secondary environment. The parents also indicated that their son with an ASD had suffered too much emotional trauma attending such mainstream secondary environments, so they felt compelled to

home school their son from that point on. The two different experiences of inclusion in primary and secondary mainstream settings indicate strongly that it was not the student's disability that made mainstream inclusion difficult. Rather it was the exclusionary nature of the education contexts that they faced that precipitated the parents' decision to ultimately seek the solution of home schooling to remedy the constant difficulties encountered there.

Gaining appropriate support

Consistent with previous research (Kidd and Kaczmarek 2010; Parsons and Lewis 2010; Reilly 2007), these parents similarly indicated that home schooling reduced the stress and anxiety experienced by their children with an ASD substantially. However, home schooling also put another layer of responsibility onto the parent-incharge of the education programme and added to the sometimes inordinately, difficult nature of their lives (Benson and Karlof 2009; Tehee, Honan, and Hevey 2009) as evidenced by the comments of one of the mothers below:

The only problem with it (home schooling) is that it is a double-edged sword because then you take it all on and then it is your responsibility and you don't have time for the other parts of your life. And I have found by taking on board everything with regard to Kim (son with an ASD) and doing home schooling and all the rest of it I am quite emotionally drained all of the time.

Hence, while home schooling reduced stress in some family members, especially the student with an ASD, it also increased the pressure placed on the parent-in-charge of the home-schooling programme. This is consistent with the findings by Parsons and Lewis (2010), Reilly (2007), and Kidd and Kaczmarek (2010) who found that while some mothers felt a sense of empowerment through their role as home educator, others had feelings of resentment because of the forced nature of their role and voiced a need for considerably more educational, social, financial support and respite. In relation to reducing this extra pressure exacerbated by home schooling, both families in the study enlisted the support of SIDE. This measure lightened the load of the person-in-charge of the home-schooling programme and helped them to sustain their efforts towards the progress of the child with an ASD. However, it should be noted that both sets of parents found the entry requirements to SIDE to be stringent. They were only eligible to gain the services of SIDE because their child had an official diagnosis of an ASD and it could be proved through documentation that mainstream education was no longer a viable option for them.

In terms of their overall experience with SIDE, both families indicated that SIDE was a great support because the programmes offered were very flexible and accommodating towards their children with an ASD. Additionally, both students with an ASD were offered the option of visiting the SIDE main school site a number of times a week, even though this was not the usual arrangement for other students from remote areas accessing the services of SIDE. This arrangement allowed these students to become gradually more independent and practise their social skills in a supported, supervised, mainstream, adult environment. This process was specifically built around the comfort level of the students with an ASD, given their traumatic educational history. The success of this process depended on the open and trusting relationship that was gradually established over time between the staff at SIDE and the students with an

ASD and their parents. Additionally, staff actively encouraged relationship-building among the students who attended the main school site on common days of the week. This served to allow positive youth friendships to emerge under the guidance and supervision of staff members at SIDE.

According to one of the parents, the relationship between SIDE and her family was enhanced particularly by a male 'special needs' teacher who worked closely with her son with an ASD at SIDE on a one-to-one basis. The establishment of such a relationship allowed both the student with an ASD and his parents to gradually gain trust in the teacher. The parent and teacher felt encouraged to communicate openly about the student's difficulties and together were able to organise a specific learning programme around the educational/emotional needs and interests of the student with an ASD and his family. This is evidenced in the comments of the parent below:

(Teacher's name) very quickly worked out what Paul's (son with an ASD) strengths and weaknesses were and also he was cognisant of the fact that Paul's father had recently left home and one of Paul's interests was public transport. He thought it would be good for Paul to increase his independence by coming to SIDE a couple of times a week and to go on the train. And the first time Paul got on the train by himself without me I was standing on the platform at (name of suburb) with a mobile phone in my hand and (teacher's name) was standing at the platform in Leederville with a mobile in his hand. I said, 'He'll be there in eight minutes'. As soon as he got there (teacher's name) rang me and said, 'He's here and we are just walking to SIDE now'. Now he only had to do that twice, wait for Paul at the station and after that Paul said to (teacher's name), 'I'm independent enough to walk up to SIDE on my own, you don't need to come and meet me at the station'.

The visits to SIDE by her son with an ASD also gave this parent much needed respite because at this time, her marriage was failing and she was trying to home school her son and parent two other children mainly on her own. The parent recognised the value of this arrangement as indicated below:

Paul (son with an ASD) caught the train twice a week, walked up to SIDE crossed at the lights and did lessons with (teacher's name), had lunch there and then came home after that. So, that was really good for me because that gave me my break. I was able to have a bit of time to myself and also know that he was in really good hands.

Consistent with recently completed research on SIDE (Lopes, O'Donoghue, and O'Neill 2011) and their accommodation of SAER students, SIDE was able to provide a very flexible and tailored educational alternative for these students with an ASD and provide much needed respite and support for the parents as well.

Increasing educational fit

Congruent with home-schooling research of students with disabilities (Kidd and Kaczmarek 2010; Parsons and Lewis 2010; Reilly 2007), the study revealed that home schooling with the support of SIDE substantially increased the educational 'fit' experienced by the child with an ASD. Both sets of parents indicated that IEPs were organised by SIDE to target their child's specific needs and interests on a one-to-one basis without the need to negotiate a large external mainstream schooling context. This allowed both families to access specific high school courses with support from appropriately trained teachers in these subjects.

The parents found the SIDE programmes to be highly organised, individually paced and mainly visual in nature and according to one of the parents suited her son with an ASD very well:

The SIDE way of learning has also suited Kim (son with an ASD) very well. The SIDE booklets have allowed him to read over sections of his course repeatedly if he needs to do so. He can also ring his teacher on selected days of the week. He knows exactly when all work is due because SIDE prints a yearly timetable indicating due dates for all assignments and tests. He gets on very well with his teachers and does not have to compete with other students for their attention. He also does not have to negotiate difficult adolescent relationships so that he can survive his secondary schooling.

Additionally, this parent indicated that SIDE allowed the student with an ASD access to a wide variety of high school correspondence courses inclusive of structured workplace learning programmes so that his educational potential and preparation for the future could be maximised.

The program is very flexible at SIDE as compared to what is possible at mainstream high school. It suits someone like my son greatly. He has been able to go in to see his teachers on a regular basis because our home is in the next suburb to where SIDE is located. He has also been able to access work experience through the local council library which fulfils the requirements of both the Year 11 and 12 Structured Workplace Learning subjects. So all things considered it has been an excellent educational choice for our son.

Both students achieved reasonably successful educational and social outcomes from their involvement with SIDE. One student with an ASD left SIDE at the age of 16 to successfully complete a retail training course for students with disabilities at a Technical and Further Education (TAFE) college. He has since gained employment at a large supermarket chain. More recently, he has returned to TAFE to complete mainstream childcare studies.

The other student with an ASD left SIDE at the age of 19. He was able to achieve secondary graduation by completing a modified academic and work-based programme at SIDE. This allowed him to secure a school-based traineeship at the local library and complete a TAFE Certificate II in Library Studies. SIDE capitalised on the successful work experience at the local library by nominating the student for a number of awards regarding his involvement with his school-based traineeship. He eventually won a number of awards including a National Australian Vocational Student Prize. This allowed the student to gain entry into a mainstream TAFE Multimedia course the following year after his secondary graduation. It was at this point he was able to successfully return to mainstream education and has since completed a number of qualifications in both Computer Game Design and Engineering.

Conclusion

In line with the growing research on the difficulties associated with educating students with an ASD in mainstream settings (Humphrey and Lewis 2008a, 2008b; Humphrey and Symes 2010; MacDermott 2008; Shaddock 2005; Symes and Humphrey 2010; Wing 2007) and the limited recent studies undertaken regarding home schooling of children with disabilities and those with an ASD (Kidd and Kaczmarek 2010; Parsons and Lewis 2010; Reilly 2007), the wider study reported in this article concludes that there needs to be an ongoing pressure and advocacy to increase the resources,

training, commitment, knowledge and understanding that mainstream education professionals have regarding the appropriate education of such students in their care (Frederickson, Jones, and Lang 2010; Lynch and Irvine 2009; Stamopoulos 2006). Parents in the wider study found educational 'fit' in mainstream environments where they experienced unwavering staff devotion towards the development of the child with an ASD. According to these families, this commitment to their child was exemplified initially in the type of welcome they and their child received at enrolment time and later where they were treated as equal partners in the education process. Parents also nominated as important the self-awareness and reflection shown by the staff regarding their own knowledge and skill level (or lack thereof) when dealing with a child with an ASD. This awareness allowed parents and qualified others the opportunity to provide appropriate, evidence-based information to staff regarding the individual educational requirements of the child with an ASD. Parents also indicated that at least one key staff member, often the principal, was generally responsible for mustering increasing support for 'inclusive' practice within the school. Unfortunately, parents in the wider study were often only able to experience successful inclusion of students with an ASD in mainstream educational settings in an intermittent and unreliable way. Jordan (2005) makes the valuable point that while 'staff need knowledge and skill to understand ASD and the individual child ... above all, they need commitment to doing the best for the child' (111). According to the parents in the wider study, it is this commitment to be fully inclusive of students with an ASD that was often the elusive element missing in mainstream settings that lead to exclusionary practices. To safeguard the mental health and well-being of their family members, some parents in the wider study were compelled, after successive negative experiences in mainstream education, to seek alternative ways, such as home schooling, to educate their child so that their educational potential could be maximized.

Under such circumstances, another important and related implication of the findings, confirmed by Kidd and Kaczmarek (2010), Parsons and Lewis (2010), and Reilly (2007), is the need for greater emotional, social, financial support and respite for parents who undertake home schooling their children with intellectual disabilities, inclusive of those with an ASD. Reilly (2007) makes the suggestion that there should be more guidance available regarding such areas as home-schooling structures, teaching techniques, content and resources. In relation to this, the existence of a government-funded home-schooling consultant with links to local home-schooling organisations, such as SIDE, would be a great support to families (Reilly 2007), especially at the beginning of the process of home schooling when parents have often experienced a traumatic 'crisis point' that precipitated their decision to home school.

The final implication of the findings involves allowing parents of children with an ASD appropriate educational choice by relaxing the entry requirements to all educational options, such as SIDE, because parents cannot presently depend on mainstream schooling to provide appropriate and reliable inclusive education consistently over time. Hence, parents should have the full range of educational options open to them in relation to maximising the educational progress and potential of their child with an ASD and providing support for their family. While all parents in the wider study agreed that inclusivity of their child with an ASD in mainstream education sites was a worthwhile and desired goal, the well-being of their child with an ASD and other family members had to take eventual precedence in their educational decision-making.

As suggested by Kidd and Kaczmarek (2010), more research is required to increase our understanding of the experience of and need for home-schooling students with an

ASD. This is especially so in relation to areas such as SIDE, where families potentially gain appropriate support and students experience positive outcomes. To allow multiple voices to be heard, the perspectives of education professionals at SIDE and students with an ASD who use their services should also be sought regarding their views of the home-schooling experience. As a corollary to this, however, there also needs to be an ongoing investigation into the processes of exclusion and exemplary inclusion presently experienced by families who have children with an ASD in mainstream schooling sites, especially those in secondary contexts. For it is only through such understanding and explanation that there will a greater chance to build more inclusive school communities and reduce the need for alternative pathways of education for students with an ASD. The point must be made that while the present study under discussion revealed educational 'fit' was created very successfully at SIDE, these same educational attributes could have been similarly adopted at any mainstream schooling site to make them more inclusive and successful for the student with an ASD. This is consistent with current thinking about inclusion that places emphasis on mainstream school values and their implementation as being important and central to the process by which schools work to be inclusive (Ainscow, Booth, and Dyson 2006; Booth 2011; Slee 2011).

Notes

1. The definition of 'inclusion' used in this paper concurs with that drawn on by Lynch and Irvine (2009) originally suggested by Ferguson (1995):

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 high-quality education for each student by providing meaningful curriculum, effective teaching, and necessary supports for each student. (286)

2. Pseudonyms are used in the participant quotes presented.

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References

Ainscow, M., T. Booth, and A. Dyson. 2006. Inclusion and the standards agenda: Negotiating policy pressures in England. *International Journal of Inclusive Education* 10, nos. 4–5: 295–308.

American Psychiatric Association. 2000. *Diagnostic and statistical manual of mental disorders*, IV ed., text revision (DSM IV TR). Washington, DC: American Psychiatric Association.

Arora, T. 2006. Elective home education and special education needs. *Journal of Research in Special Education Needs* 6: 55–66.

- Ashton, J. 1971. Out of silence. Adelaide: Investigator Press.
- Attwood, T. 2007. The complete guide to Asperger's syndrome. London: Jessica Kingsley Publishers.
- Australian Autism Education and Training Consortium (AAETC). 2008. *Positive partnerships:* Supporting school-aged students on the autism spectrum. Professional development for teachers and other school staff. Forestville, NSW: Autism Spectrum Australia (Aspect).
- Barratt-Peacock, J. 1997. *The why and how of Australian home education*. Yankalilla, SA: Learning Books.
- Benson, P., and K. Karlof. 2009. Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders* 39: 350–362.
- Blok, H. 2004. Performance in home-schooling: An argument against compulsory schooling in the Netherlands. *International Review of Education* 50: 39–52.
- Booth, T. 2011. Curricula for the common school: What shall we tell our children? *FORUM* 53, no. 1: 31–47.
- Bowden, J. 1993. Schooling through distance education: Perspectives from Western Australia. In *Towards 2000: Schooling through distance education*, ed. D. Riley, 65–71. Toowoomba: SPERA.
- Buckley, B. 2009. Relating autism spectrum prevalence and government policy. Paper presented at the Asia Pacific autism Conference 2009, in Sydney, Australia.
- Charmaz, K. 2006. Constructing grounded theory: A practical guide through qualitative analysis. Thousand Oaks, CA: Sage.
- Colebatch, H. 1929. A story of a hundred years: Western Australia 1829–1929. Perth: Government Printer.
- Connor, D.J., S.L. Gabel, D.J. Gallagher, and M. Morton. 2008. Disability studies and inclusive education Implications for theory, research and practice. *International Journal of Inclusive Education* 12, nos. 5–6: 441–457.
- Crosby, I. 1998. *Models of educational service provision for students with Autism spectrum disorder within government mainstream schooling*. Perth, WA: Department of Education and Training.
- Department of Education. 2001. *Students at educational risk*. Perth: Department of Education. Duffey, J.G. 2002. Home schooling children with special needs: A descriptive study. *Home School Researcher* 15, no. 2: 1–13.
- Duvall, S.F., J.C. Delquadri, D.L. Ward, and C.R. Greenwood. 1997. An exploratory study of home school instructional environments and their effects on the basic skills of students with learning disabilities. *Education and Treatment of Children* 20: 150–172.
- Eakins, C. 1964. A history of the Western Australian correspondence school. Perth: Department of Education.
- Ellis, C., and A.P. Bochner. 2000. Autoethnography, personal narrative, reflexivity: Researcher as subject. In *Handbook of qualitative research*. 2nd ed, ed. N.K. Denzin and Y.S. Lincoln, 733–768. Thousand Oaks, CA: Sage.
- Ensign, J. 2000. Defying the stereotypes of special education: Home school students. *Peabody Journal of Education* 75, nos. 1 and 2: 147–158.
- Ferguson, D.L. 1995. The real challenge of inclusion: Confessions of a 'rabid inclusionist'. *Phi Delta Kappan* 77, no. 1: 281–287.
- Fombonne, E. 2003. Epidemiological surveys of Autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders* 33, no. 4: 365–382.
- Ford, J. 2007. Educational supports for students with disabilities and significant behavioural challenges: Teacher perceptions. *Australasian Journal of Special Education* 31, no. 2: 109–127.
- Forlin, C., M. Keen, and E. Barrett. 2008. The concerns of mainstream teachers: Coping with inclusivity in an Australian context. *International Journal of Disability, Development and Education* 55, no. 3: 251–264.
- Frederickson, N., A.P. Jones, and J. Lang. 2010. Inclusive provision options for pupils on the autistic spectrum. *Journal of Research in Special Educational Needs* 10: 63–73.
- Fuchs, D., and L.S. Fuchs. 1994. Inclusive schools movement and the radicalisation of special education reform. *Exceptional Children* 60, no. 4: 294–309.
- Glaser, B.G. 1992. Basics of grounded theory analysis: Emergence vs forcing. Mill Valley, CA: Sociology Press.

- Haynes, B.T., G.E.B. Barrett, A. Brennan, and L. Brennan. 1976. *Documents on Western Australian education 1830–1973*. Perth: Claremont Teachers College.
- Heinrichs, R. 2003. Perfect targets: Asperger syndrome and bullying: Practical solutions for surviving the social world. Kansas: Autism Asperger Publishing.
- Humphrey, N., and S. Lewis. 2008a. 'Make me normal'. The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism* 12: 23–46.
- Humphrey, N., and S. Lewis. 2008b. What does "inclusion" mean for pupils on the autistic spectrum in mainstream secondary schools? *Journal of Research in Special Education Needs* 8: 132–140.
- Humphrey, N., and W. Symes. 2010. Perceptions of social support and experience of bullying among pupils with autistic spectrum disorders in mainstream secondary schools. *European Journal of Special Needs Education* 25, no. 1: 77–91.
- Jordan, R. 2005. Autistic spectrum disorders. In *Special teaching for special children?*, ed. A. Lewis and B. Norwich, 110–122. Buckingham: Open University Press.
- Kidd, T., and E. Kaczmarek. 2010. The experiences of mothers home educating their children with autism spectrum disorder. *Issues in Educational Research* 20, no. 3: 257–275.
- Laluvein, J. 2010. School inclusion and the 'community of practice'. *International Journal of Inclusive Education* 14, no. 1: 35–48.
- Leach, D., and M.L. Duffy. 2009. Supporting students with autism spectrum disorders in inclusive settings. *Intervention in School and Clinic* 45: 31–37.
- LeCompte, M.D., and J.P. Goetz. 1982. Problems of reliability and validity in ethnographic research. *Review of Educational Research* 52, no. 1: 31–60.
- Lincoln, Y.S., and E.G. Guba. 1985. Naturalistic inquiry. Newbury Park, CA: Sage.
- Lopes, E. 2009. The Western Australian schools of isolated and distance education: Background, functions and issues. Unpublished Doctoral Thesis: The University of Western Australia, Perth.
- Lopes, E., T.A. O'Donoghue, and M.H. O'Neill. 2011. The education of children in geographically remote regions through distance education: Perspectives and lessons from Australia. Charlotte, NC: Information Age Pub.
- Lynch, S.L., and A.N. Irvine. 2009. Inclusive education and best practice for children with autism spectrum disorder: An integrated approach. *International Journal of Inclusive Education* 13, no. 8: 845–859.
- MacDermott, S. 2008. Can you help us to help you? Autism school-age family needs report. Perth: A Joint project by The State Child Development Centre, the Autism Association of Western Australia & Therapy Focus Inc.
- McAtee, W., and T.L. Zani. 1975. *The education of isolated children in Western Australia*. Perth: Research Branch, Education Department of Western Australia.
- McDonald, J. 2010. Seeking Progressive Fit: A constructivist grounded theory and autoethnographic study investigating how parents deal with the education of their child with an autism spectrum disorder (ASD) over time. Unpublished Doctor of Philosophy Thesis: The University of Western Australia, Perth.
- McNiece, B. 2001. Learning in families: The home-education guidebook. Toowoomba: Christian Academy of Life Limited.
- Medlin, R.G. 2000. Homeschooling and the question of socialization. *Peabody Journal of Education* 75, nos. 1–2: 107–123.
- Oliver, M. 1996. Understanding disability. Basingstoke: Macmillan.
- Parsons, S., and A. Lewis. 2010. The home-education of children with special needs or disabilities in the UK: Views of parents from an online survey. *International Journal of Inclusion Education* 14, no. 1: 67–86.
- Rankin, D.H. 1926. The history of the development of education in Western Australia 1829–1923. Perth: Carrolls Ltd.
- Ray, B.D. 1997. Strengths of their own Home schoolers across America: Academic achievement, family characteristics, and longitudinal traits. Salem, OR: National Home Education Research Institute.
- Rayner, S.A. 1949. Correspondence education in Australia and New Zealand. Melbourne: Melbourne University Press.

- Reilly, L. 2007. Progressive modification: How parents deal with home schooling their children with intellectual disabilities. Unpublished Doctor of Philosophy Thesis: The University of Western Australia, Perth.
- Rosendorff, S. 2007. Autism spectrum disorder: The secondary school perspective (Powerpoint Presentation). Perth: Centre for Inclusive Schooling, Department of Education and Training of Western Australia.
- Shaddock, A. 2005. Students with Autism in high schools: A challenge for inclusive practice. In *Disability in education: Context, curriculum and culture* (college year book 2005), ed. C. Newell and T.R. Parmenter, 22–36. Deakin West: Australian College of Educators.
- Shaddock, A., B. Smyth King, and L. Giorcelli. 2007. *Project to improve the learning outcomes of students with disabilities in the early, middle and post compulsory years of schooling*. Barton, ACT: Department of Education, Employment and Workplace Relations.
- SIDE. 2009. SIDE Overview. http://www.side.wa.edu.au/side_overview.html (accessed August 23, 2009).
- Slee, R. 2011. The irregular school: Exclusion, schooling and inclusive education. London: Routledge.
- Spann, S., F. Kohler, and D. Soenksen. 2003. Examining parent's involvement in and perceptions of special education services: An interview with families in a parent support group. *Focus on Autism and Other Developmental Disabilities* 18, no. 4: 228–238.
- Stake, R.E. 1995. The art of case study research. Thousand Oaks, CA: Sage.
- Stake, R.E. 2000. Case studies. In *Handbook of qualitative research*, ed. N.K. Denzin and Y.S. Lincoln, 435–454. Thousand Oaks, CA: Sage.
- Stamopoulos, E. 2006. Empowering preservice teachers to embrace diversity. *Australian Journal of Early Childhood* 31, no. 4: 30–39.
- Symes, W., and N. Humphrey. 2010. Peer-group indicators of social inclusion among pupils with autistic spectrum disorders (ASD) in mainstream secondary schools: A comparative study. *School Psychology International* 31, no. 5: 478–494.
- Tehee, E., R. Honan, and D. Hevey. 2009. Factors contributing to stress in parents of individuals with Autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities* 22: 34–42.
- Thomas, A. 1998. Educating children at home. London: Cassell.
- Wing, L. 2007. Children with autistic spectrum disorders. In *Included or excluded? The challenge of mainstream for some SEN children*, ed. R. Cigman, 23–33. London: Routledge.