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O'Hagan, S, Bond, C and Hebron, J (2021) What do we know about home education and autism? A thematic synthesis review. Research in Autism Spectrum Disorders, 80. 101711. p. 101711. ISSN 1750-9467

https://doi.org/10.1016/j.rasd.2020.101711

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What do we know about home education and autism? A thematic synthesis review

Keywords: Autism spectrum disorder; Asperger's; home education; home schooling; flexi-schooling; exclusion

ABSTRACT

Background: Mainstream education can be difficult for autistic children given the social communication difficulties, highly focused interests and sensory sensitives associated with autism. Educators can still find providing a safe, inclusive and supportive environment for autistic students challenging. Subsequently some parents decide to remove their children from school and home educate. The purpose of this thematic review is to synthesise reported findings on home educating autistic children.

Method: PRISMA guidelines informed the review process. Articles included were published in the last 10 years and specific to autistic children being educated at home. Of the 22 articles meeting eligibility for full text review, 10 matched the final inclusion criteria.

Results: Findings related to four main themes emerging from the synthesis: the motivations and reasons that led parents to home educate their autistic children; parents' experiences of home educating; practices and pedagogical approaches used by parents; and the impact of home education on the outcomes for autistic students. Findings revealed that home education can be a positive experience for families with good academic and social outcomes for autistic children and young people. Limitations of the evidence base are considered.

Conclusion: Although not all parents may be in a position to home educate their children, this review indicates that parents with appropriate educational, financial and social supports have found home educating their autistic child empowering. They report being able to provide flexible, balanced and individualised education leading to positive outcomes.

1. Introduction

Autism is a diverse neurodevelopmental condition which encompasses a continuum of ability ranging from mild to severe difficulties with social communication and interaction, and restricted, repetitive

patterns of behaviour, interests or activities (DSM-5; American Psychological Association, 2013).¹ Sensory sensitivity is included in the latter domain. In regards to prevalence, it is estimated that in the United Kingdom (UK) autism affects 1 in 100 people (Ambitious about Autism, 2017). National statistics for England report that there are 95,363 autistic children and adolescents who attend statefunded mainstream schools, which is about 72% of the total number of school aged autistic students (Department for Education [DfE], 2019a).

For many parents, mainstream education is deemed the option that will give their autistic child a chance to have a 'normal life' (Roberts & Simpson, 2016). A child's right to integrate with their peer group, access the National Curriculum and have the shared cultural experience of mainstream schooling is a view supported by current UK educational policy which encourages the special educational needs (SEN) of children to be met within mainstream schools where possible (DfE, 2014). The philosophy of inclusive education as promoting the right of SEN children to not be segregated from their peers has become well established over the last 40 years, leading to an increasing number of autistic children experiencing an 'inclusive education' (Lawrence, 2017). However, whilst the philosophy of inclusion has good intentions the efficacy of inclusion is contentious. Effectively integrating autistic children within the systems of mainstream schools is still deemed a challenge to educators and it is widely acknowledged that autistic children are struggling, especially in high school (Goodall, 2018).

The transition from a small primary school with one class teacher to the uncertainty of a secondary school with lots of teachers, hundreds of students, large buildings, change in the curriculum, different rules and behaviour policies, high academic demands and sensory overload can be traumatic for some autistic children (Neal & Frederickson, 2016; Tso & Strnadová, 2017). The evidence suggests that challenges in social understanding increases the risk of autistic children experiencing bullying,

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¹ The terminology used in this paper is identity-first (i.e. autistic children) rather than person-first (i.e. children with autism). Identity-first language was found to be the preferred terminology by the majority of autistic people surveyed (Kenny et al., 2016). This is in line with research that highlights the unintentional bias perpetuated by scholars by referring to people, especially children, with the most stigmatized disabilities such as autism by person first language (Gernsbacher, 2017). Children without disabilities or less stigmatised disabilities are more frequently discussed in research through identity first language (i.e. blind children, gifted children etc.) (Gernsbacher, 2017).

peer rejection, and feelings of isolation (Cook, Ogden & Winstone 2016; Hedges et al., 2014). Furthermore, parents of autistic children who attend mainstream schools report higher levels of social anxiety in their children compared to parents whose autistic children attend specialist schools (Zainal & Magiati, 2016).

Teaching staff report feeling ill equipped in regards to their knowledge and training on teaching autistic children within the mainstream classroom (Majoko, 2016). For example, autistic children can find it difficult to regulate their emotions and behaviour leading to anxiety and stress often being communicated through 'meltdowns' which can be challenging for school staff to manage (Brede, Remington, Kenny, Warren & Pellicano, 2017). Autistic children are also at greater risk of school exclusion with over 45% experiencing it (Ambitious about Autism, 2016). The government's records indicate that 119,909 autistic children were excluded from school in 2017-2018 (DfE, 2019b). Following school exclusion, autistic girls report receiving little support from their school which further isolated them from education and increased their anxiety (Sproston, Sedgewick & Crane 2017). The challenges faced by autistic students and the subsequent impact on their mental health has led some parents to feel that they have no other choice than to withdraw their autistic children from the school system to be home educated (Kendall & Taylor, 2016).

Home education practices and laws vary across the world. Home education is permitted in most European countries as well as in Australia, Canada and the United States of America (USA) (Kunzman & Gaither, 2020). In the UK, parents who choose to home educate their child from the beginning of their education are not required to inform their local authority (LA) and parents who remove their child from a mainstream school are simply required to inform the head teacher (www.gov.uk/home-education). Therefore, the number of children being home educated in the UK is not documented; though estimates range between 45,250 and 150,000 with agreement that the number is rapidly rising (Kendall & Taylor, 2016). There are 2.5 million home educated children in the USA with an estimated increase of 2% to 8% per annum (Ray, 2019). Within this rise, an increasing number of parents are making the far-reaching decision to home educate their autistic children yet this remains an under researched area (Daniels, 2017). The home educate and the academic and social

outcomes for the general population of home educated children (e.g. De Carvalho & Skipper, 2019; Kunzman & Gaither, 2020) with limited exploration of the experiences of home educating parents (Catlin, 2019). Therefore, more autism specific information on what influences this decision, the experiences and practices of parents and the outcomes for autistic children is needed. As parents look for alternative ways to educate their autistic children, it is imperative to keep information in this field current and reflective of shifts in education. This would also inform school practice and policy. Research on the topic of home education and autism has evolved in recent years with interest in the area growing (e.g. Bower, 2019; Lawrence, 2017). Whilst the body of literature remains fairly small, a review of the literature to ascertain the current empirical understanding is both timely and appropriate. A thematic synthesis approach was adopted to draw together the experiences of parents across the studies to provide a more in-depth understanding than that gained from individual studies alone. Synthesising the themes from multiple studies assists in the interpretation of the data and strengthens the emerging implications. This approach helped to identify limitations and gaps in the existing literature and the future research needed to address them. The incorporation of quantitative and qualitative datasets in this review supports a better understanding of autism and home education as the breadth and depth of the phenomenon are explored. By bringing the voices of parents together, the review aimed to answer the following question: What are the experiences of parents who decide to provide home education for their autistic child and what do they identify as the outcomes? The thematic synthesis review has important implications for a range of stakeholders including national and local policy makers, schools, families and autistic children and young people which are timely as many families are home educating due to the current context of the coronavirus pandemic.

2. Method

A thematic synthesis approach was adopted which modelled Creswell, Hinch and Cage's (2019) qualitative synthesis. To ensure that all relevant studies were included, the method was developed a step further to synthesise quantitative data which demonstrates scale and qualitative findings which provide descriptive detail. Many systematic reviews in the autism field have incorporated quantitative and qualitative research (e.g. Mason at el., 2019; Mirzaei, Pakdaman, Alizadeh & Pouretemad, 2020) and the current review used a version of the evaluative review frameworks utilised by Tyrell and Woods (2018) in their systematic literature review on gathering the views of autistic children and

young people. To evidence a transparent, sequential process linked to original data, themes are illustrated by participant quotes and statistical data.

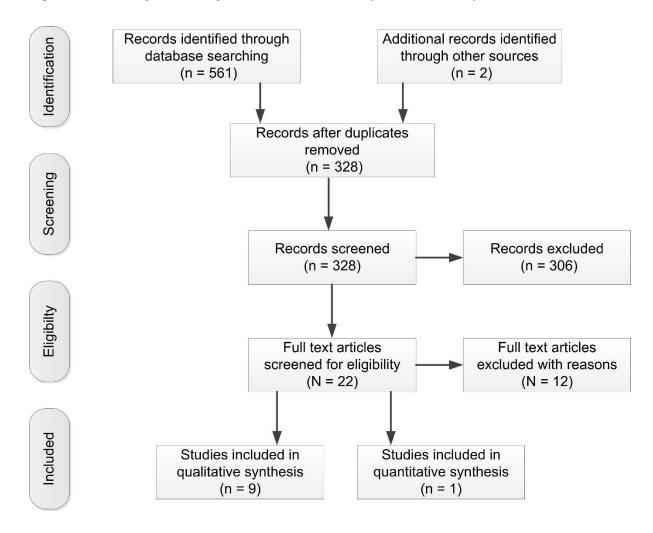
2.1 Search strategy and study selection

The following databases were searched between September 2019 and January 2020: PsychInfo; Applied Social Science Index and Abstracts; and Education Resources Information Centre. In addition, Google Scholar was utilised until saturation was reached with no new studies being identified. Key search terms included: autis* OR asperge* AND home schooling OR home education. Other spellings of the key terms were used including: ASD, ASC, homeschool and home-education. The key terms were trialled across the databases to determine if they identified a set of pre-identified papers which established that the terms were suitable. As this field of research is in its infancy a date range was not applied. The review adhered to the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) (Moher, Liberati, Tetzlaff & Altman, 2009). Please refer to Figure 1 for an outline of the PRISMA process for this review.

2.2 Inclusion criteria

The inclusion criteria were: 1) English-language article; 2) published in a peer reviewed journal or a doctoral thesis; 3) an empirical investigation collecting either qualitative or quantitative data; 4) the primary focus being on factors related to autism and home education; 5) including a participant sample of parents of whom at least 50% must have an autistic home educated child; 6) AND/OR a participant sample of children or young people, at least 50% must have autism and be home educated. The inclusion criteria was straightforward to operationalise and studies that did not meet all of the inclusion criteria were excluded. For example, three studies (Arora, 2006; De Carvalho & Skipper, 2019; Parsons & Lewis, 2010) were not included due to the inclusion criterion of a participant sample of parents of whom at least 50% must have an autistic home educated child. One quantitative study was screened and included due to its high quality and relevance.

Fig. 1. PRISMA diagram. The figure illustrates the search process and study selection.



2.3 Quality appraisal

Ten studies met the full inclusion criteria and were assessed for methodological quality using Gough's (2007) Weight of Evidence (WoE) A 'methodological quality' and WoE C 'focus of the study'. The robust evaluative framework used to assess the methodological quality of quantitative and qualitative studies is described in (Woods, Bond, Humphrey, Symes & Green, 2011). Quantitative studies could score a maximum of 16. Studies were then categorised as low (scoring 0-5), medium (6-10) or high (11-16) quality research. Qualitative studies could score a maximum of 14. Studies were then categorised as low (scoring 0-5), medium (6-10) or high (11-14) quality research. The first author coded all of the papers and the second author coded 25% of the papers to ensure inter-coder reliability. The quality criteria of differing scores were debated until the inter-rater reliability percentage agreement was 100% for each of the three papers that were dual coded. The study of autism and home education is

in its infancy and so quality assessment was used as a tool to identify good quality research rather than as a method of exclusion. For WoE C studies were appraised on their relevance to the current review question. Studies were awarded: 1 point for discussion of the decision to home educate; 1 point for reflection on the experience of home educating; 1 point for discussion of outcomes.

2.4 Data extraction and synthesis

Data extraction began with general details of the papers including: citation details; phenomena investigated, participant sample, methodology and findings. Themes identified by the author were recorded alongside participant quotes and statistics. Qualitative and quantitative findings were synthesised and inductively categorised on the basis of similarity in meaning.

3. Results

3.1 Overview of the included studies

In total, 10 studies were included in this review (see table 1). All of the studies took place between 2011 and 2019. The origin of the studies was as follows: UK (n = 5), USA (n = 3) and Australia (n = 2). Nine out of the 10 studies used qualitative methods and one study used quantitative methods; four studies were doctoral theses; all studies included parent participants; and two studies included autistic children and young people as participants. The majority of respondents were mothers but the age range of the focus children was wide. Dolan's (2017) study included seven mothers and five autistic young people, who had been home educated for at least their high school years before studying university courses. This study provided interesting insights into the transition into higher education from home education for autistic young people and as one of only two studies that included the perspective of autistic young people it was important to include the study in this review. Daniels (2017) also included child participants who were aged 5-11 years.

Simmons's (2016) doctoral thesis comprised two studies. One study evaluated an intervention to increase on-task time for autistic students studying at home which was not relevant to this review and therefore not included. A second large-scale quantitative study provided a useful comparison of the experiences of home educated and traditionally schooled autistic children. This study highlighted the perception that home education can be beneficial for autistic children. The quantitative study provided numerical data and the qualitative studies unpacked the detail of what worked well for these families.

3.2 Methodological quality

All studies scored highly for the execution of data collection. The studies did not generally score highly for emergent theory related to the problem which may be correlated to the exploratory nature of the studies. Nine out of 10 studies scored well using the quality assessment measure (table 1). The doctoral theses scored particularly highly which is likely due to available word count allowing for detailed explanation.

The research samples were predominantly parents which is necessary as it is parents who tend to make the decision to withdraw their children from school and home educate. Their experiences need to be shared to increase understanding of the risk factors leading to this decision and the support that they need to successfully educate their children. However, only two studies included the perspective of the autistic individuals. The voice of the child is needed as it is the children and young people who are best placed to identify what they perceive to be the barriers and supportive factors in mainstream schools and how leaving school impacted them. It is empowering for vulnerable young people to have a platform in which they can share their experiences and influence change. For the potential positive and negative factors of home education to be fully understood the perspectives of multiple stakeholders including children need to be listened to. Furthermore, the autistic community has highlighted that they want to be fully involved in the research concerning them and so further efforts should be made in future studies to include autistic people and incorporate their views into every part of the research process. (Nicolaidis at al., 2019).

 Table 1. Characteristics of primary included studies

Reference	Country	Research	Parent	СҮР	Age and	Design	Analytical	Findings	Quality	Relevance
		focus	Participants	participants	sex of		approach		Assessment	Assessment
					СҮР				Score:	Score:
									Weight of	Weight of
									Evidence A	Evidence C
Bower,	UK	Motivations	2 mothers	Not	8 year	Semi-	Thematic	Bullying and	Medium	Low
(2019)		and	who share	included	old male	structured	analysis	teachers' lack		
		experiences	an autistic			interviews		of		
		of families	son					understanding		
		who home						of autism led to		
		educate in						parents to		
		Northern						home educate		
		Ireland								
Daniels,	UK	Motivations,	8 families:	10 children	5–11	Background	Thematic	Multiple factors	High	Medium
(2017)		practices	15 parents		years. 3	parent	analysis	influenced		
		and	(8 mothers:		female: 7	questionnair		parents'		
		pedagogical	7 fathers);		male	e, semi-		decision to		

		approaches				structured		home educate		
		used by				interviews,		including child's		
		parents to				observation		dislike of		
		home				of home		school and		
		educate their				education		teachers' lack		
		autistic				practice and		of		
		children				follow up		understanding		
						parent		of children's		
						telephone		needs. Parents'		
						interview		pedagogical		
								approaches		
								had similarities		
								to child-centred		
								approaches		
Dolan,	USA	Exploration	7 mothers;	5 students	18-22	Semi-	Cross-case	Parental	High	Low
(2017)		of success of	and 1		years. 1	structured	synthesis	support during		
		home	roommate		female: 4	interviews,		home		
		educated			male	reflection		educating		
		autistic				diaries and		years and		

		students in				document		during		
		college				review e.g.		university		
						academic		resulted in		
						transcripts		students		
								succeeding in		
								university		
Hurlbutt,	USA	Experiences	10 parents	Not	7-25	Semi-	Open-coding	Parents	High	Medium
(2011)		of parents	from 9	included	years. 3	structured	procedure	decided to		
		who home	families (9		female:	interviews		home		
		educate their	mothers: 1		10 male.	with follow		education as		
		autistic	father)			up questions		schools were		
		children				via phone or		unable to meet		
						email		the needs of		
								their children.		
								Parents felt		
								they found a		
								form of		
								education that		

								worked for their		
								children		
Kendall &	UK	Experiences	7 mothers,	Not	6-14	Semi-	Thematic	Lack of	Medium	Medium
Taylor,		of mothers	6 of whom	included	years. All	structured	analysis	understanding		
(2016)		who home	had an		male	interviews		by staff, poor		
		educate their	autistic					school-parent		
		SEN children	child. 1					communication		
			mother had					and the impact		
			a child with					the school		
			dyspraxia					environment		
								had upon		
								autistic children		
								led parents to		
								home educate		
Kidd &	Western	Mothers'	10 mothers	Not	8-14	Semi-	Interpretative	Home	High	Medium
Kaczmarek	Australia	perspectives		included	years.	structured	phenomenol	education led		
(2010)		of home			Sex not	interviews	ogical	to		
		educating			specified.		analysis	improvements		
								in autistic		

		their autistic						children's		
		child						behaviour and		
								psychological		
								wellbeing		
Lawrence	UK	Experiences	5 mothers	Not	5-14	Semi-	Interpretative	Sharing	High	High
(2017)		of parents		included	years. 1	structured	phenomenol	education		
		who flexi-			female: 5	interviews	ogical	between		
		school their			males		analysis	home and		
		autistic						school can		
		children						benefit some		
								autistic children		
McDonald	Western	То	2 mothers	Not	4-14	Semi-	Constructivist	The flexibility	Medium	High
& Lopes,	Australia	understand		included	years. All	structured	grounded	and		
(2014)		how SIDE			male.	interviews,	theory	individualised		
		supports				participant	methods	approach of		
		parents who				observation,		SIDE created a		
		home				informal		good		
		educate their				interviews		educational fit		
		autistic child				and				

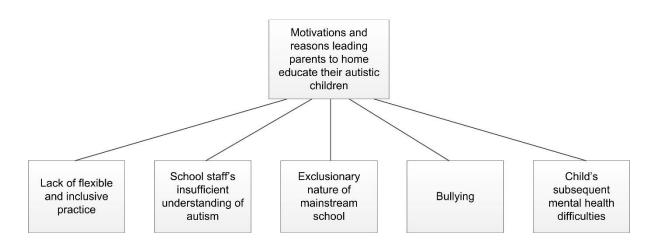
						documentary		for autistic		
						data		children		
						sources.				
Simmons,	USA	Experiences	114 parents	Not	6-18	Quantitative	Data were	Homes	High	High
(2016)		of parents	of autistic	included	years.	online survey	analysed	educating		
		who home	children (61		Sex not		using IBM	parents noted a		
		educate	home		specified		SPSS	positive		
		autistic	educated;				Statistics	increase in		
		children	53				v.22	motivation to		
			traditionally					learn, active		
			schooled)					engagement		
								and family		
								functioning as		
								well as a		
								decrease in		
								problem		
								behaviour of		
								their autistic		
								children		

Taylor,	UK	Perspectives	9 home	Not	6-15	Sample	Thematic	Personalised	Low	High
Kendall &		of parents	educating	included.	years.	formed from	analysis	nature of home		
Forrester,		who home	mothers. 8		Sex not	self-selection		education		
(2011)		educate their	out of the		specified.	on online		supported		
		SEN children	10 home			forums. 7		children. Lack		
			educated			semi-		of support from		
			children had			structured		education		
			autism			interviews		systems was		
						and 2		frustrating for		
						questionnair		parents		
						es based on				
						the interview				
						questions				

This review aimed to explore the experiences of parents who home educate their autistic children. As described above the data were thematically analysed. Four global themes emerged and each is graphically illustrated with a thematic map (Fig. 2- 5).

3.3 The motivations and reasons that led parents to home educate their autistic children

Fig. 2. Thematic map of the motivations and reasons that led parents to home educate their autistic children



Lack of flexible and inclusive practice to meet the child's educational and social needs. In the quantitative paper, parents on average identified six out of 12 reasons for home educating. The most common (over 50%) of reasons were: (a) dissatisfaction with educational placement: 74.58%, (b) dissatisfaction with educational programme: 74.58%, (c) need to fight for services: 62.71%, (d) child's negative feelings towards school: 62.71%, (e) concern about child's safety: 59.32%, (f) school's inability to manage behaviour: 57.63%, (g) negative interactions with educational professionals: 52.54% (Simmons, 2016). Across the qualitative studies, parents described how their children's cognitive differences required the curriculum and teaching approaches to be adapted but that their children's teachers were unable to modify and pushed for the child to do the adjusting (Kendall & Taylor, 2016).

Because he was having meltdowns all the time and because they weren't managing his environment or modifying the curriculum to suit his needs, they were still trying to get him to

write with a pencil, still trying to get him to play football games, still trying to get him to accept relief teachers without prior warning. All the things that set him off they continued to do and they had a behaviour management plan and there were consequences for his bad behaviour but they were not willing to change and it was always like, we'll cure him of this by giving him a string of consequences or punishing him (Parent; Kidd & Kaczmarek, 2010).

Children preferred to learn by rote and computer-based learning, however, it was felt that work was simplified rather than adapted and as a result children made limited progress (Kidd & Kaczmarek, 2010). Dissatisfaction with the educational programme was cited by the majority of parents as a motivating factor to home educate (e.g. Simmons, 2016). Schools reportedly found it difficult to provide for children who were exceptionally gifted in areas of interest such as algebra and quantum physics but who also had SEN (Hurlbutt, 2011; Lawrence, 2017). Parental frustration at the disproportionate time their children spent with support staff with limited access to a qualified teacher was reported (Kendall & Taylor, 2016; Lawrence, 2017). Parents expressed frustration at interventions and strategies not being implemented properly and abandoned quickly (Daniels, 2017). Therefore, a driving factor for parents to home educate was their ability to meet their own children's learning needs, adapt the environment and provide sensory breaks and down-time accordingly (Lawrence, 2017; McDonald & Lopes, 2014).

Parents' perception of school staff's insufficient understanding of and attitude towards autism
Insufficient understanding of managing challenging behaviour resulted in parents feeling schools were containing their children rather than teaching them (Lawrence, 2017). A lack of partnership between home and school contributed to the breakdown in school placements across the studies (Kendall & Taylor, 2016). Daniels' (2017) study identified a discrepancy between teachers' understanding of autism and their ability to transfer this into practice.

When he moved into Year 2 he had the SENCo as his teacher... I thought this would be great in terms of knowing how to support my son but she really didn't have a clue! She did not attempt to meet his needs. She saw him as defiant and told me, 'He won't break me you know, I'll break him' (Parent; Kendall & Taylor, 2016).

Parents reported experiencing hurtful comments that made them feel like 'social outcasts' (Kendall & Taylor, 2016). Negative interactions with educators was also identified in the quantitative survey (Simmons, 2016).

Exclusionary nature of mainstream school. Autistic children experienced social exclusion by their peers and teachers, classroom exclusion and school exclusion as a form of punishment.

As soon as they got the support of the TA it was excuse to get him out of the classroom... she had not trained in ASD and would take him into the corridor. He was really bright but was spending most of his time informally excluded (Parent; Kendall & Taylor, 2016).

School staff not supporting the social needs of autistic children was identified as a form of exclusion (Bower, 2019). Parents also felt that teachers were sometimes too quick to send their autistic children home, "They've no qualms with phoning me the minute anything goes wrong. They're not trying to sort it – they don't try to think, 'Well, we'll give it a few minutes and see whether he calms down.' It's like, as soon as he picks up a pencil and looks dangerous, that's it – the phone call" (Parent; Lawrence, 2017). Children regularly being sent home for situations that with better management could be avoided was stressful for parents (Daniels, 2017). A cycle of fixed-term exclusions was also frustrating for parents (Hurlbutt, 2011). Parents reported that exclusion significantly impacted on their children's' mental health, with inappropriate sanctions exacerbating mental health problems (Kendall & Taylor, 2016).

Bullying is a well-documented risk factor for autistic children's inclusion and was the predominate reason parents decided to home educate in Bower's (2019) study. Six out of 10 mothers in Kidd and Kaczmarek's (2010) study reported that their child was subjected to bullying, "Bullying started rearing its ugly head...so much so that I did actually come upon three boys; two were holding him down while the other kicked him. It was the worst day of my life" (Parent; Kidd & Kaczmarek, 2010). High school was reported to be a greater risk factor for bullying as social relationships become increasingly complex (McDonald & Lopes, 2014).

The child's subsequent mental health difficulties and family stress. The challenges described above meant that for the autistic children in these studies, the mainstream environment was a significant

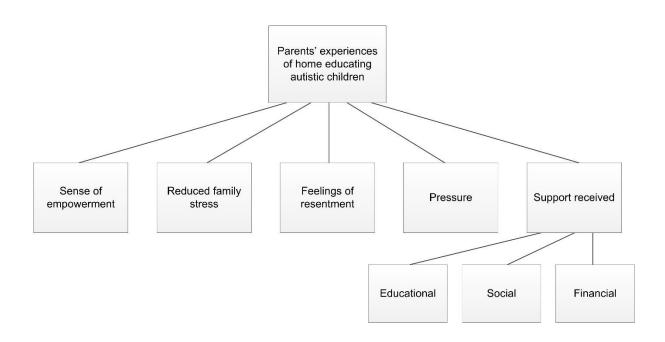
source of anxiety (Kidd & Kaczmarek, 2010). Two of the mothers in Kidd and Kaczmarek's (2010) study were advised by paediatricians to withdraw their children from school due to their level of anxiety. Children reaching 'crisis point' such as suicidal ideation and self-harm was the catalyst for parents to home educate,

And one day I was getting him (*child with ASD*) ready for school and he said, 'I hate my life I wish I was dead'...So I just took his shirt off and I said, 'Right you do not go to school anymore. We will think of something different'" (Parent; McDonald & Lopes, 2014).

Parents reported their children had 'meltdowns' after school which they attributed to their child 'holding it together' during the day (Kidd & Kaczmarek, 2010). Children communicated their wish to not attend school through head banging, crying and screaming (Kendall & Taylor, 2016). Ultimately the impact mainstream education was having on their children's mental health meant that all the parents in Kendall and Taylor's (2016) study felt that they did not elect to home educate rather they had no choice.

3.4 Parents' experiences of home educating their autistic children

Fig 3. Thematic map of parents' experiences of home educating autistic children



Sense of empowerment. Having agency and choice in their children's education led to a sense of empowerment for some parents (Kidd & Kaczmarek, 2010).

I find it selfishly the best thing I have ever done in my life. It's incredibly enjoyable... I have never done a job or anything like this, it's brilliant. With hindsight I was awful when he was at school. I was so unhappy and stressed. I'm a better mother now (Parent; Taylor, Kendall & Forrester, 2011).

The parents shared that putting their energy into something positive was a lot more rewarding than the energy used on disagreements with school. Families that had chosen to home educate were strengthened (Hurlbutt, 2011; Kidd & Kaczmarek, 2010).

Reduced family stress. Parents reported improvement in their own mental health and wellbeing as they had been experiencing high levels of stress as their children reached crisis point (Simmons, 2016; Taylor et al., 2011). One parent commented, "I actually have more time for my daughter, and family time because I'm not dealing with screaming and crying" (Parent; Lawrence, 2017). No longer having to communicate with education professionals and fight for services was a welcome relief to parents (Simmons, 2016; Taylor et al., 2011).

Feelings of resentment. A wide range of feelings were experienced by parents which demonstrates the complex and at times all-consuming role of being a home educating parent. As described above, some parents found it empowering but some reported feelings of resentment (McDonald & Lopes, 2014). Demonstrating the complex and at times all-consuming decision for parents a variety of feelings were experienced. Some parents found it empowering but some reported feelings of resentment (McDonald & Lopes, 2014). A parent explained, "it's also a lot more pressure on me...I could have had a life and had a job, or completed my studies" (Parent; Kidd & Kaczmarek, 2010). The resentment came from feeling forced due to a lack of flexible schools (Kendall & Taylor, 2016; Kidd & Kaczmarek, 2010; McDonald & Lopes, 2014).

Pressure. The dual roles of running a household and being a home educator was a considerable source of pressure for parents (Daniels, 2017; Kidd & Kaczmarek, 2010).

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 (Parent; McDonald & Lopes, 2014).

Being a full-time home educator meant that one parent was unable to work which was a substantial financial sacrifice for many families. However, all the parents in Kendall and Taylor's (2016) study agreed that despite the financial implications they were less stressed and happier home educating as their children were less stressed and happier.

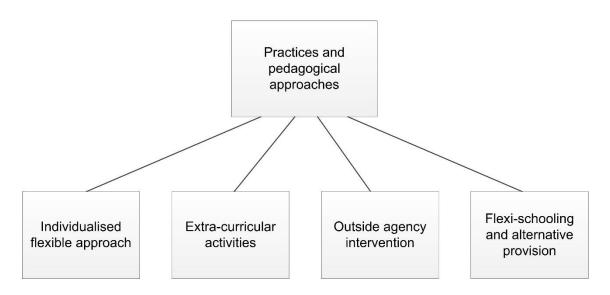
Educational Support. The parents who felt their only option was to home educate felt let down by the lack of support they received from school (Kidd & Kaczmarek, 2010). Some parents felt frustrated, "If he was in school he would get funding so it seems a bit of a cop out that there are no lending resources. It's all cuts here. Speech therapists don't work with him at all since he left school" (Parent; Taylor et al., 2011). Sourcing appropriate resources and materials was time consuming and expensive (Hurlbutt, 2011). Whilst some parents were concerned by the lack of monitoring they were also relieved to be left alone, "It is easier not to be bothered by the school" (Parent; Hurlbutt, 2011). Social Support. For some mothers home educating community groups were a lifeline, "We also got involved with a homeschool group in our community, and that group provides social interaction and support for both boys and for me. Homeschooling was a winning decision for all of us." (Parent; Dolan, 2017). Whilst others felt that their children were not welcome due to their autism and associated perceived disruptive behaviour, "I want support, I need support but it's finding it. I know there are homeschooling groups. Liam has such social problems that he would be uncomfortable and disruptive and the other parents may not be accepting of him" (Parent; Kidd & Kaczmarek, 2010). A lack of support meant that for home educating parents there was little possibility for time away from their children (Kidd & Kaczmarek, 2010). This was especially true for the mothers of children who could not tolerate strangers in the house and for single mothers. Not all of the mothers expressed needing time away from their child but it is likely that time to relax and engage in leisure activities is an important aspect of maintaining wellbeing for the majority of parents.

Financial Support. Parents across the studies reported that they did not receive financial help with resources, exams and specialist support, "It's costly! All resources have to be provided by me and just one spelling programme costs £55. GCSEs will cost hundreds in addition to text books." (Parent; Taylor et al., 2011). Many of the autistic university students in Dolan's (2017) study benefited from

counselling or psychology services; however, not all parents had the financial resources to access this.

3.5 Practices and pedagogical approaches used by parents to home educate their autistic children

Fig 4. Practices and pedagogical approaches



An *Individualised flexible approach* centred on the child's needs and interests informed the parents' approach to planning and teaching across the studies. The frequency that learning was described as child-directed was *almost never* for 5.17% of participants, *once in a while* for 37.93%, *frequently* for 41.40% and *almost all of the time* for 15.52% (Simmons, 2016). Functional skills were prioritised (Hurlbutt, 2011) and mornings were generally spent focussing on basic literacy and numeracy skills with more informal physical and social activities happening in the afternoons (Daniels, 2017).

At the moment, he's really into dinosaurs and things and so for his last birthday everyone's like, books of dinosaurs! And kids' books of dinosaurs are amazing. We are learning so much, because it's not just learning about that animal, you've got to read about them and you can find maths to do and science, all within it –but he's just thinking we're having a nice time together messing around, so it's like 'trick learning' on a Wednesday afternoon (Parent; Lawrence, 2017).

Parents welcomed the opportunity to develop their children's areas of particular strength (Hurlbutt, 2011). For some children this meant studying at university level (Taylor et al., 2011). A child-centred

pedagogy was described across the studies as parents adapted their plans to meet the child's needs and emotional state day by day (Daniels, 2017).

Extra-curricular activities. Community based learning was part of home education for the majority of parents' surveyed, it occurred almost all the time for 42.37% of participants, frequently for 42.37% and almost never for 15.25% (Simmons, 2016). Providing opportunities for the children to socialise was a priority for most parents. Children across the studies attended clubs, sporting activities, church groups, home education groups and days out to zoos, museums and galleries.

Outside agency intervention. The parents in Hurlbutt's (2011) American study had long lists of interventions that they had tried with their children including: speech therapy, occupational and physical therapy, music therapy, feeding therapy, social skills classes, chiropractic services, auditory integration therapy, applied behavioural analysis, early childhood special educational services, special diets, paying for private tutors/teachers and the Son-rise programme. Access to the services was dependent on whether they were covered by medical insurance or if parents could pay for them meaning not all children could access the support they needed,

He has gone to group therapy and individual therapy for seven years. It has actually been easier to find some services for our son now that he is an adult. We were actually told by one of his therapists when he was a teenager to have him arrested because then the judge could order services that we couldn't afford to pay (Parent; Dolan, 2017).

Interestingly, the parents in Daniels's (2017) British study did not list outside agency support as part of their provision.

Flexi-schooling and alternative provision. Flexi-schooling allows pupils to attend school part-time and to be home educated part-time; however, it is at the discretion of the head teacher whether to agree to this,

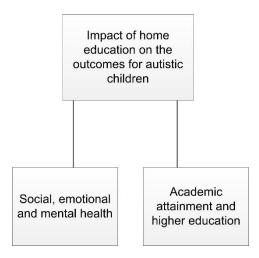
I had planned to try to flexi-school but it's so difficult to set up. It's hard to find a head teacher that will do it to be honest. I'm not sure why because they would get full time funding for a part time place (Parent; Taylor, Kendall & Forrester, 2011).

The parents in several studies felt that this could potentially provide a good balance and the flexibility that their child needed (Kendall & Taylor, 2016; Lawrence, 2017).

A second example of flexible provision that offered families a sense of balance was described in McDonald & Lopes's study (2014) which explored the incorporation of Australia's Schools of Isolated and Distance Education (SIDE) into home education programmes. SIDE centres aim to support geographically isolated students and children whose needs cannot be met in school for a range of reasons (McDonald & Lopes, 2014). When children are enrolled at SIDE an individualised education plan is developed which parents report alleviates some of the pressures of being solely responsible for their child's education (McDonald & Lopes, 2014). Whilst SIDE is a distance learning institution, both children in McDonald and Lopes's study were offered the opportunity to attend the main site several times a week to work one-to-one with a male special needs teacher. This allowed the boys to socialise, develop independence skills and access flexible and tailored tuition whilst giving their mothers some respite. This therefore felt like a better educational fit for these families.

3.6 The impact of home education on the outcomes for autistic students

Fig 5. Impact of home education on the outcomes for autistic children



Improved *social*, *emotional* and *mental* health was reported across the studies. Parents reported a drastic increase in motivation for 51.16% of participants; a drastic increase in active engagement for 53.49%; a drastic decrease in problem behaviour for 57.78%; a drastic increase in family functioning for 56.9%; a drastic decrease in stress for 52.54% (each item was completed on a 5-point Likert scale e.g. drastic decrease, slight decrease, stayed the same, slight increase, drastic increase) (Simmons,

2016). Mothers reported their children were displaying fewer 'autistic traits' such as head-hitting and meltdowns which are likely stress-related, "Since he has been home, days and weeks go by without him shouting. We haven't taken away those feelings of anxiety and at times fear but he is learning to deal with them. Now...he is just so happy!" (Parent; Kendall & Taylor, 2016). Parents also reported that self-harm was no longer an issue for their children (Kidd & Kaczmareck, 2010). Parents across the studies reported feelings of relief that their children were no longer experiencing high levels of anxiety and were flourishing (McDonal & Lopes, 2014). Parents were in agreement that their children's social skills improved with regular extra-curricular activities as they responded well to the structure, "He is now happy, healthy and confident. He is showing an interest in a huge range of subjects. He is socialising more and full of energy just like a child should be" (Parent; Taylor et al., 2011).

Academic attainment and higher education. Through the use of a personalised education plan, modified teaching strategies and flexibility, parents reported improvements in the volume of work their children produced and their subsequent progress (Kidd & Kaczmarek, 2010). Parents were pleased their children were able to reach their potential,

We're looking now for advanced algebra and the beginning of quantum physics...he's just built his own computer ... and he's doing Cyber Security [with the] Open University. That is a structure that really works for him because it's just so clear and he sees where he is and what he still has to do" (Parent; Lawrence, 2017).

McDonald and Lopes (2014) reported that both of the boys in their study who were home-schooled with the support of SIDE had positive outcomes and went onto further education. Dolan's (2017) study focussed on autistic university students who had been home educated as school aged children and found that strong systems of family support that were developed during the home educating years facilitated young people to be successful at university, "I was ready for college classes... Being homeschooled is what helped me start to like learning, and my mother encouraged me to pursue subjects I liked doing" (Young Person; Dolan, 2017). Support included love and care as well as practical support such as living at home whilst attending university.

4 Discussion and implications

This thematic synthesis review aimed to thematically synthesise the extant literature investigating autism and home education. These good quality studies offer valuable insight into what is known

about parents' experiences of home education and outcomes for autistic children. The review has implications for autistic children, their parents and schools as well as local authorities and national policy makers which are discussed below.

4.1 What are the experiences of families who home educate an autistic child?

Taken together, the findings from this review highlight the multiple challenges that autistic children face in mainstream school and the worrying impact that this can have on mental health and wellbeing (Neal & Frederickson, 2016; Zainal & Magiati, 2016). Whilst school can be a demanding environment for lots of children some of the challenges seem to be exacerbated for autistic students whose complex needs may not be fully understood by teaching staff (Goodall & MacKenzie 2019; Majoko 2016). Home education for the autistic children in these studies provided the individualised approach that enabled them to flourish. Flexible approaches have been identified in good autism education (Preece & Howley, 2018). Fewer sensory and social demands reduced anxieties and parents reported less depressive symptomology once they began home educating.

Overall the research on home education and autism is very positive with parents reporting improvement in their children's mental health. However, this could be related to sampling; the majority of parents removed their children from school at crisis point. Therefore, when the cause of the anxiety is taken away it is likely that the anxiety will lessen. Additionally, participants were mainly recruited through support groups and were self-selecting volunteers. There are two elements here which reduce the representativeness of the samples. First, participants who attend or join support groups and who volunteer for research may be different to those who do not. Second, parents who were finding success in home educating may have been drawn to volunteering to participate in research. Whereas parents who were struggling at home with their children may have been reluctant to participate. The data collected was predominantly based on the parents' perceptions of their own experiences and as with other qualitative research findings these may not necessarily generalise to the wider population. As with all research, this study needs to be understood within the context of its limitations; however, it still needs to be acknowledged that these good quality studies have similar findings and draw similar conclusions.

Parents in this research expressed concern about the disproportionate time their autistic children spent with support staff rather than qualified teachers. Whilst many children would be unable to cope academically, socially or emotionally without a high level of adult support, there is also evidence that separate instruction delivered by untrained teaching assistants is ineffective and undermines the inclusion, learning, socialisation and independence of SEN students (Sharma & Salend 2016).

Despite not receiving the same pedagogical training as teachers there is reportedly an expectation in schools that teaching assistants can work with children with complex cognitive profiles (Webster & Blatchford, 2019). Additionally, enduring concerns have been raised on the limited training that teachers receive on meeting the needs of SEN children (Webster & Blatchford, 2019). With specialist schools on the decline, the current expectation for schools to be inclusive is likely to remain (Webster & Blatchford, 2019).

Bullying was a common motivating factor for parents to home educate. Autistic children may be particularly vulnerable to bullying due to characteristics associated with autism (e.g. higher-order theory of mind abilities and communication difficulties), decreasing the likelihood of protective factors of bullying (e.g. friends and supportive peers) (Schroeder, Cappadocia, Bebko, Pepler & Weiss, 2014). Frequent victimisation (i.e. one or more incidents per week) of autistic children is associated with mental health problems including higher levels of anxiety and self-harm (Cappadocia, Weiss & Pepler, 2012). Autistic individuals are also at greater risk of depression, self-harm and suicidal ideation (Hirvikoski et al., 2016; Raja, 2014). Loneliness has been identified as a potential contributor to depression and self-harm with suggestions that supporting autistic people to feel connected to others may be beneficial to improving their mental health (Hedley, Uljarević, Wilmot, Richdale, & Dissanayake, 2018). Most autistic children have a desire for friendship but need support in facilitating and maintaining relationships (O'Hagan & Hebron, 2017).

A clear finding from this review is that home education can be a positive experience for families. For children who have had a difficult school experience resulting in anxiety, self-harm and school avoidance these symptoms can be alleviated through home education. Positive outcomes for communication and interaction were reported as well as good educational outcomes with some young people going on to study at university level. This supports the wider home education literature that indicates in regards to academic achievement, home educated children consistently score well above the national average of mainstream educated children (Guterman & Neuman, 2019; Ray, 2013). The

finding here of positive social outcomes for home educated autistic children is again in line with the general home education literature (De Carvalho & Skipper, 2019). Research suggests that home educated children are involved in more extra-curricular and social activities and their social skills are equivalent or further developed than their mainstream educated peers (Cui & Hanson, 2019; Hamlin, 2019).

Whilst the majority of parents were pleased with their decision to home educate, due to the detrimental impact school was having on their children's mental health as well as causing their families considerable stress, they also felt they had no other option. Parents reported little help from school or local authority/state departments. Furthermore, Hurlbutt's (2012) survey of 52 special education teachers revealed a perspective that parents do not have the skills or knowledge to teach and children would miss out on academic and social opportunities. However, the evidence presented in this review would suggest some parents perceive that they are able to meet their child's educational and social needs in flexible and creative ways leading to positive outcomes for the child. Interestingly the teachers in Hurlbutt's (2012) study did not address the many ways that learning in schools can be challenging for autistic children who often have a visual learning style with preference for concrete concepts and who find the focus on auditory learning and abstract concepts difficult (Zenko, 2014). As reported by the parents in this review, difficulties with gross and fine motor skills are a common characteristic of autism (Garrido, Petrova, Watson, Garcia-Retamero & Carballo, 2017), and can make writing and physical education undesirable which again can lead to conflict in schools. Sensory issues can make the busy spaces, florescent lighting and loud noises of schools a stressful environment leaving autistic children too tired and distracted to engage with learning. For the teachers in Hurlbutt's (2012) study to not address these points and acknowledge how some families may be able to provide a more suitable learning environment in the home highlights that school staff require further support to develop their understanding of autism. It also likely that negative teacher perceptions on home education could increase the risk of marginalising this group by reducing motivation to collaborate with parents who home educate. For example, a teacher in Hurlbutt's study (2012) commented that if a child who had been removed from school were to be re-enrolled "it wouldn't be well received".

Home education is a huge investment by parents who would likely benefit from increased support to source resources, cover the cost of exams and access specialist education services. A need for

greater emotional, social and financial support including respite for parents who home educate children with special education needs has been identified in this review and in the wider SEN literature (Maxwell, Doughty, Slater, Forrester & Rhodes, 2020). However, in a climate of government budget cuts, how this is achieved requires further consideration.

Flexible provision such as SIDE and flexi-schooling were identified as ways to provide the personalised curriculum and social opportunities that autistic children need as well as respite for parents. Such models encourage the acceptance and accommodation of different cognitive and behavioural profiles. This supports the wider autism literature on alternative provision in the UK. For example, a centre for autistic children experiencing emotionally based school avoidance focussed on developing individual strengths and promoting good mental health through a flexible approach and positive relationships (Preece & Howley, 2018).

Whilst many benefits of home education have been identified, it is not a viable option for all families. More needs to be done to support autistic children in school so they can thrive academically and emotionally and therefore avoid reaching 'crisis point'. The factors that led to school-placements breaking down in the studies reviewed here were not unique to the home education literature. Similar themes have emerged in the autism and school exclusion literature (Sproston et al., 2017) and in autism and emotionally based school avoidance research (O'Hagan, 2020). Current available evidence (e.g. Preece & Howley, 2018; Whitaker & Preece, 2013) suggests that protective factors to successful schooling for autistic children include trusting relationships with school staff, positive peer relationships, good home-school communication, a flexible a personalised approach to teaching and learning, an environment adapted to reduce sensory overload and anxiety, quiet calm spaces for autistic children to work in, proportionate access to qualified teaching staff, appropriate intervention to meet communication and interaction needs and sufficient time for teaching staff to plan for individual needs.

4.2 Implications for policy and practice

Several implications for professionals have been identified. Ongoing training for school staff on what it means to provide an equitable, flexible and inclusive education is warranted. This also needs to include how adults can help facilitate friendships and positive peer relationships for autistic children to protect them from loneliness and bullying. Increased awareness, understanding and support for home

education at a local schools level and national government level would hopefully reduce the stigma and pressures experienced by parents.

Whilst the level of support desired by home educating families varied and families did not wish to be excessively monitored, they did want some form of social, educational and financial support. Home educating families particularly hoped for support with sourcing and paying for resources and with the cost of exams. The implication here is that the money local authorities save when a child leaves the school system could support children to receive the resources that they need at home. Additionally, families also found it more difficult for their child to access additional services such as speech and language therapy when they withdrew from school. Given the complex communication needs of many autistic children, local authorities should consider providing support and guidance to families on how to access additional services. Local authorities supporting families in a meaningful way could have the dual benefit of reducing family stress and enabling local authorities to keep open communication with families which would support their child protection responsibilities.

4.3 Implications for research

This thematic synthesis review has identified several high quality papers in the field of autism and home education. The papers have predominantly focussed on the perceptions of the adults in the children's lives; and whilst the evidence suggests that home education has been beneficial for children in reducing their stress and anxiety it would be useful to further listen to the child's voice and their understanding of their own lived experience. Young people are best positioned to understand the pressures of mainstream schooling and research can be a source of empowerment to the autistic community. Therefore, further efforts should be made in future studies to include autistic people and incorporate their views into every part of the research process. Researchers need to be skilled in overcoming challenges such as: gaining the views of 'hard to reach' children (Hardy & Hobbs, 2017); interpreting children's views (Ingram, 2013); and ensuring that views are used in a co-productive non-tokenistic manner (Lundy, 2007). Autistic children may need more flexible ways to participate in research such as through the use of: pictures; photographs taken by the student; completing an oral, written or electronic diary; visual tools; pictorial questionnaires and scales; and focus groups (Tyrrell & Woods, 2018).

For the parents in this review and in the wider literature, home education can be a wonderfully rewarding experience and a relief to see their children flourishing (Catlin, 2019). However, being both parent and teacher means there is little time or space for respite and therefore home education is tiring for all parents, not just those of autistic children (Lois, 2013). Good mental health is a prerequisite for the resilience undoubtedly needed to sustain such an all-consuming role for many years. Therefore, how this could be supported through arrangements such as flexi-schooling or alternative provision warrant further exploration.

The research in this field comes from predominantly qualitative studies which provide fascinating insight into lived experiences. However, further quantitative studies are needed to develop a breadth of understanding. For example, the parents in these studies report good academic outcomes for their children which is likely related to removing school related anxieties which were a barrier to learning. To explore this hypothesis, quantitative research into the academic achievement of this group could develop understanding of ways that highly anxious children can access education. Comparative research into the outcomes for children who are home educated full time and those who access flexischooling may also be beneficial when considering the possibilities of provision offered to autistic children. As the number of home educated children is rising, longitudinal data capturing the benefits and challenges as well as the outcomes into adulthood would support families to make informed decisions.

4.5 Study limitations

This review aimed to examine the experiences of parents who home educate autistic children and has successfully provided an overview of the studies in this area. There are possible limitations to be considered. First, as an emerging field of research the number of studies is small and so the breadth and depth of this phenomenon requires further exploration. Due to the limited available research all studies meeting the inclusion criteria were included regardless of methodological quality. However, only one study was categorised as low-quality and six were categorised as high-quality reflecting reliability and validity of this research. The theses all scored highly which is likely related to the available word count. Shorter papers may be disadvantaged which the quality appraisal framework does not take into account. This thematic synthesis brought together quantitative and qualitative findings which had been generated from different analytical approaches of varying quality. Therefore,

there is an element of subjectivity to this approach. There are alternative approaches such as metaethnography however, as the nine qualitative studies all utilised an analytical approach that generated themes, a thematic synthesis approach stayed true to the data. Inter-rater reliability measures were used for the assessment of methodological quality in order to ensure rigour. As the first author undertook the literature searches and thematically coded and synthesised the data, the validity of the approach may have been further strengthened by inter-coder reliability checks at these stages. However, in relation to the analysis it is acknowledged that thematic analysis is considered to be a process of reflexive interpretation rather than extraction of meaning which therefore recognises the researcher's active role in identifying and interpreting meaning (Braun & Clarke, 2019). Due to this being a small scale study, it was not registered in a database for systematic reviews.

5 Conclusions

The decision by parents to home educate their autistic child tends to be influenced by the child's social experiences at school, whether their educational needs have been met and the interplay this has with the child's mental health. Parents who have felt empowered by home educating their autistic children and who have received appropriate support in the form of emotional, social and financial resources, are in a good position to provide their child with a flexible, balanced and individualised education leading to positive academic and life outcomes.

References

APA. (2013). *Diagnostic and Statistical Manual of Mental Disorders (DSM 5)*. Washington, DC: American Psychiatric Association.

Ambitious about Autism. (2016). When will we learn? London, UK: Ambitious about Autism.

Ambitious about Autism. (2017). What is Autism?

https://www.ambitiousaboutautism.org.uk/understanding-autism/about-autism/what-is-autism accessed 8 March 2017.

- Arora, T. (2006). Elective home education and special educational needs. *Journal of Research in Special Educational Needs*, *6*(1), 55-66.
- Bower, C. (2019). 'Um, I was getting bullied at school because I didn't believe in god': one family's experience of autism, school and home education. *International Journal of Inclusive Education*, 1-14.

- Brede, J., Remington, A., Kenny, L., Warren, K., & Pellicano, E. (2017). Excluded from school:

 Autistic students' experiences of school exclusion and subsequent re-integration into school. *Autism & Developmental Language Impairments*, *2*, 2396941517737511.
- Cappadocia, M. C., Weiss, J. A., & Pepler, D. (2012). Bullying experiences among children and youth with autism spectrum disorders. *Journal on Autism and Developmental Disorders*, *42*(2), 266–277.
- Catlin, M. L. (2019). *The Experience of Being a Homeschool Mother: A Heuristic Inquiry* [Unpublished doctoral dissertation]. Capella University.
- Cook, A., Ogden, J., & Winstone, N. (2016). The experiences of learning, friendship and bullying of boys with autism in mainstream and special settings: A qualitative study. *British Journal of Special Education*, *43*(3), 250–271. https://doi.org/10.1111/1467-8578.12143
- Cresswell, L., Hinch, R., & Cage, E. (2019). The experiences of peer relationships amongst autistic adolescents: A systematic review of the qualitative evidence. *Research in Autism Spectrum Disorders*, *61*, 45-60.
- Cui, J. & Hanson, R. (2019). Homeschooling in the United States: Results from the 2012 and 2016 Parent and Family Involvement Survey (PFI-NCES: 2012 and 2016). U. S. Department of Education. Washington, DC: National Center for Education Statistics.
- Daniels, R. M. (2017). Exploring the motivations and practices of parents home educating their children with ASD [Unpublished doctoral dissertation]. University College London.
- De Carvalho, E., & Skipper, Y. (2019). "We're not just sat at home in our pyjamas!" A thematic analysis of the social lives of home educated adolescents in the UK. *European Journal of Psychology of Education*, *34*(3), 501-516.
- DfE. (2019a). Special Educational Needs in England: January 2019. Retrieved from https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2019.
- DfE. (2019b). Permanent and Fixed Period Exclusions in England: 2017 to 2018. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_dat a/file/820773/Permanent_and_fixed_period_exclusions_2017_to_2018_-_main_text.pdf.

- DfE. (2014). Special Educational Needs Code of Practice: For 0 to 25 years. Retrieved from https://www.gov.uk/government/consultations/special-educational-needs-sen-code-of-practiceand-regulations.
- Dolan, C. (2017). An Investigation into the Experiences of Homeschooled Individuals with

 Autism that Led to Success in the On-Campus College Environment: A Case Study

 [Unpublished doctoral thesis]. Liberty University.
- Garrido, D., Petrova, D., Watson, L. R., Garcia-Retamero, R., & Carballo, G. (2017). Language and motor skills in siblings of children with autism spectrum disorder: A meta-analytic review. *Autism Research*, *10* (11), 1737-1750.
- Gernsbacher, M. A. (2017). Editorial Perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry*, *58*(7), 859-861.
- Goodall, C. (2018). Inclusion is a feeling, not a place: A qualitative study exploring autistic young people's conceptualisations of inclusion. *International Journal of Inclusive Education*, 1-26.
- Gough, D. (2007). "Weight of evidence: a framework for the appraisal of the quality and relevance of evidence." *Research papers in education* 22, (2): 213-228.
- Guterman, O. & Neuman, A. (2019). Reading at home: Comparison of reading ability among homeschooled and traditionally schooled children. Reading Psychology 40, 169-190.
- Hamlin, D. (2019). Do homeschooled students lack opportunities to acquire cultural capital?
 Evidence from a nationally representative survey of American households. *Peabody Journal of Education*, 94(3), 312-327.
- Hardy, J., & Hobbs, C. (2017). Introduction. In J. Hardy & C. Hobbs (Eds). Using qualitative research to hear the voice of children and young people: The work of British educational psychologists (pp. ix x). Leicester: The British Psychological Society.
 - Hedges, S., A. Kirby, M. Sreckovic, S. Kucharczyk, K. Hume, and S. Pace. (2014). "Falling Through the Cracks': Challenges for High School Students with Autism Spectrum Disorder." The High School Journal 98 (1): 64–82. doi:10.1353/hsj.2014.0014.
 - Hedley, D., Uljarević, M., Wilmot, M., Richdale, A., & Dissanayake, C. (2018). Understanding depression and thoughts of self-harm in autism: a potential mechanism involving loneliness.

 *Research in Autism Spectrum Disorders, 46, 1-7.

- Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016).

 Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208, 232–238.
- Hurlbutt, K. S. (2011). Experiences of parents who homeschool their children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *26*(4), 239-249.
- Hurlbutt, K. (2012). Special Education Teachers' Perceptions and Beliefs Regarding Homeschooling Children with Autism Spectrum Disorders. *Online Submission*, *27*(1), 1-9.
- Ingram, R. (2013). Interpretation of children's views by educational psychologists: Dilemmas and solutions. *Educational Psychology in Practice*, *29*(4), 335-346.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community.

 Autism, 20(4), 442-462.
- Kendall, L., & Taylor, E. (2016). 'We can't make him fit into the system': parental reflections on the reasons why home education is the only option for their child who has special educational needs. *Education 3-13*, 44(3), 297-310.
- Kidd, T., & Kaczmarek, E. (2010). The experiences of mothers home educating their children with autism spectrum disorder. *Issues in Educational Research*, *20*(3), 257-275.
- Kunzman, R., & Gaither, M. (2020). Homeschooling: An updated comprehensive survey of the research. *Other Education*, *9*(1), 253-336.
- Lawrence, C. (2017). Can sharing education between home and school benefit the child with autism? [Unpublished doctoral dissertation]. Sheffield Hallam University.
- Lois, J. (2013). Home is Where the School is: The Logic of Homeschooling and the Emotional Labor of Mothering. New York: New York University Press.
- Lundy, L. (2007). 'Voice' is not enough: conceptualising Article 12 of the United Nations Convention on the Rights of the Child. *British educational research journal*, *33*(6), 927-942.
- Majoko, T. (2016). Inclusion of children with autism spectrum disorders: Listening and hearing to voices from the grassroots. *Journal of autism and developmental disorders*, *46*(4), 1429-1440.
- Mason, D., Ingham, B., Urbanowicz, A., Michael, C., Birtles, H., Woodbury-Smith, M., ... & Parr, J. R. (2019). A systematic review of what barriers and facilitators prevent and enable physical healthcare services access for autistic adults. *Journal of autism and developmental disorders*, *49*(8), 3387-3400.

- Maxwell, N., Doughty, J., Slater, T., Forrester, D., & Rhodes, K. (2020). Home education for children with additional learning needs—a better choice or the only option?. *Educational Review*, *72*(4), 427-442.
- McDonald, J., & Lopes, E. (2014). How parents home educate their children with an autism spectrum disorder with the support of the Schools of Isolated and Distance Education. *International Journal of Inclusive Education*, *18*(1), 1-17.
- Mirzaei, S. S., Pakdaman, S., Alizadeh, E., & Pouretemad, H. (2020). A systematic review of program circumstances in training social skills to adolescents with high-functioning autism. *International Journal of Developmental Disabilities*, 1-10.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of internal medicine*, *151*(4), 264-269.
- Neal, S., & Frederickson, N. (2016). ASD transition to mainstream secondary: A positive experience?

 Educational Psychology in Practice, 32(4), 355–373.

 https://doi.org/10.1080/02667363.2016.1193478
- Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., ... & Joyce, A.
- (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as coresearchers and study participants. *Autism*, *23*(8), 2007-2019.
- O'Hagan, S. (2020). *Autism, Anxiety and Enabling Access to Education* [Unpublished doctoral thesis]. The University of Manchester.
- O'Hagan, S., & Hebron, J. (2017). Perceptions of friendship among adolescents with autism spectrum conditions in a mainstream high school resource provision. *European Journal of Special Needs Education*, *32*(3), 314-328.
- Parsons, S., & Lewis, A. (2010). The home-education of children with special needs or disabilities in the UK: views of parents from an online survey. *International Journal of Inclusive Education*, *14*(1), 67-86.
- Preece, D., & Howley, M. (2018). An approach to supporting young people with autism spectrum disorder and high anxiety to re-engage with formal education—the impact on young people and their families. *International Journal of Adolescence and Youth*, *23*(4), 468-481.
- Raja, M. (2014). Suicide risk in adults with Asperger's syndrome. The Lancet Psychiatry, 1, 99–101.

- Ray, B. D. (2013). Homeschooling associated with beneficial learner and societal outcomes but educators do not promote it. *Peabody Journal of Education*, *88*(3), 324-341.
- Ray, B. D. (2019). Research facts on homeschooling: General Facts, statistics and trends. Retrieved from http://www.nheri.org/research/research-facts-on-homeschooling .html. Accessed 12th March 2020.
- Reilly, L. (2007). *Progressive modification: how parents deal with home schooling their children with intellectual disabilities.* Unpublished PhD, Crawley, WA: University of Western Australia.
- Roberts, J., & Simpson, K. (2016). A review of research into stakeholder perspectives on inclusion of students with autism in mainstream schools. *International Journal of Inclusive Education*, *20*(10), 1084-1096.
- Schroeder, J. H., Cappadocia, M. C., Bebko, J. M., Pepler, D. J., & Weiss, J. A. (2014). Shedding light on a pervasive problem: A review of research on bullying experiences among children with autism spectrum disorders. *Journal of autism and developmental disorders*, *44*(7), 1520-1534.
- Sharma, U., & Salend, S. J. (2016). Teaching assistants in inclusive classrooms: A systematic analysis of the international research. *Australian Journal of Teacher Education*, *41*(8), 7.
- Simmons, C. A. (2016). *Evidence-based practice for homeschooled children with ASD* [Unpublished doctoral dissertation]. University of Georgia.
- Sproston, K., Sedgewick, F., & Crane, L. (2017). Autistic girls and school exclusion: Perspectives of students and their parents. *Autism & Developmental Language Impairments*, *2*, 2396941517706172.
- Taylor, E., Kendall, L., & Forrester, G. (2011). *No school like home and no home like school: parents'*responses to the Badman report and its recommendations. British Education Research

 Association Annual Conference, Institute of Education, London.
- Tso, M., & Strnadová, I. (2017). Students with autism transitioning from primary to secondary schools: parents' perspectives and experiences. *International Journal of Inclusive Education*, *21*(4), 389-403.
- Tyrrell, B., & Woods, K. (2018). Gathering the views of children and young people with ASD: a systematic literature review. *British Journal of Special Education*, *45*(3), 302-328.

- Webster, R., & Blatchford, P. (2019). Making sense of 'teaching', 'support' and 'differentiation': the educational experiences of pupils with Education, Health and Care Plans and Statements in mainstream secondary schools. *European Journal of Special Needs Education*, *34*(1), 98-113.
- Whitaker, P., & Preece, D. (2013). Understanding the perspectives of children and parents: A foundation for developing partnership. In M. Howley & D. Preece (Eds.), *Supporting pupils on the autism spectrum: Whole-school training materials and resources for SENCOs.* London: Optimus Press.
- Woods, K., Bond, C., Humphrey, N., Symes, W., & Green, L. (2011). Systematic review of Solution Focused Brief Therapy (SFBT) with children and families. *London: Department for Education*.
- Zainal, H., & Magiati, I. (2016). A Comparison Between Caregiver-Reported Anxiety and Other

 Emotional and Behavioral Difficulties in Children and Adolescents with Autism Spectrum

 Disorders Attending Specialist or Mainstream Schools. *Journal of Autism and Developmental Disorders*, 1–11. https://doi.org/10.1007/s10803-016-2792-7
- Zenko, C. (2014). Practical solutions for executive function challenges created by the unique learning styles of students with Autism Spectrum Disorder (ASD). *Perspectives on School-Based Issues*, *15*(4), 141-150.