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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 state-funded 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,

[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 education literature has predominantly focussed on the motivation of parents to 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.

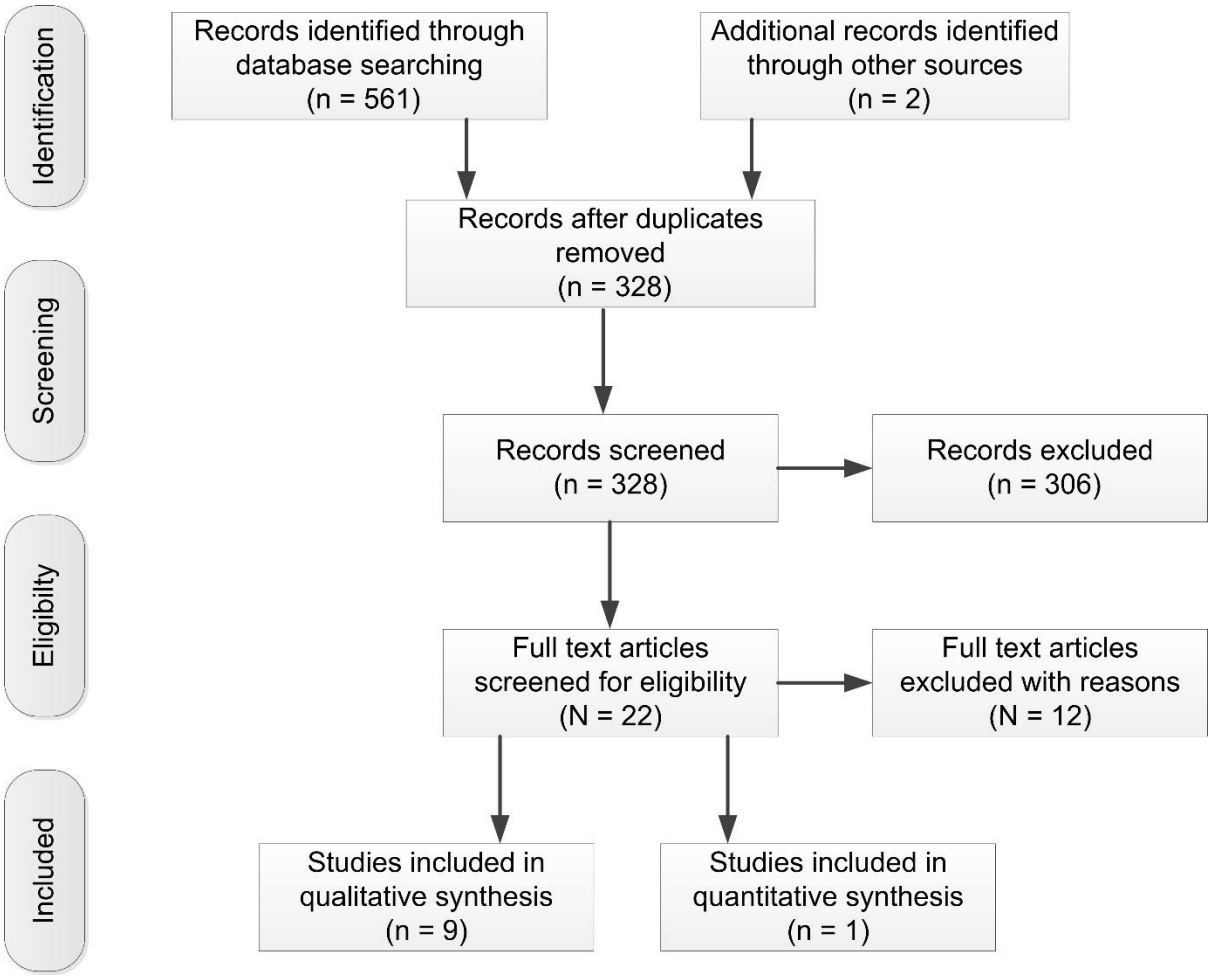
2.1 Search strategy and study selection

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

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

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

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

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

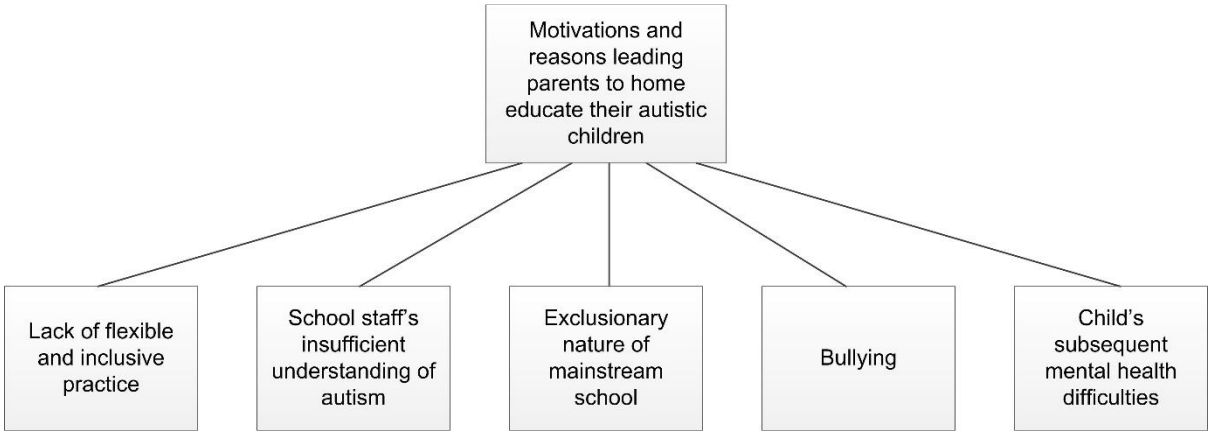
						documentary data sources.		for autistic children		
Simmons, (2016)	USA	Experiences of parents who home educate autistic children	114 parents of autistic children (61 home educated; 53 traditionally schooled)	Not included	6-18 years. Sex not specified	Quantitative online survey	Data were analysed using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

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

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

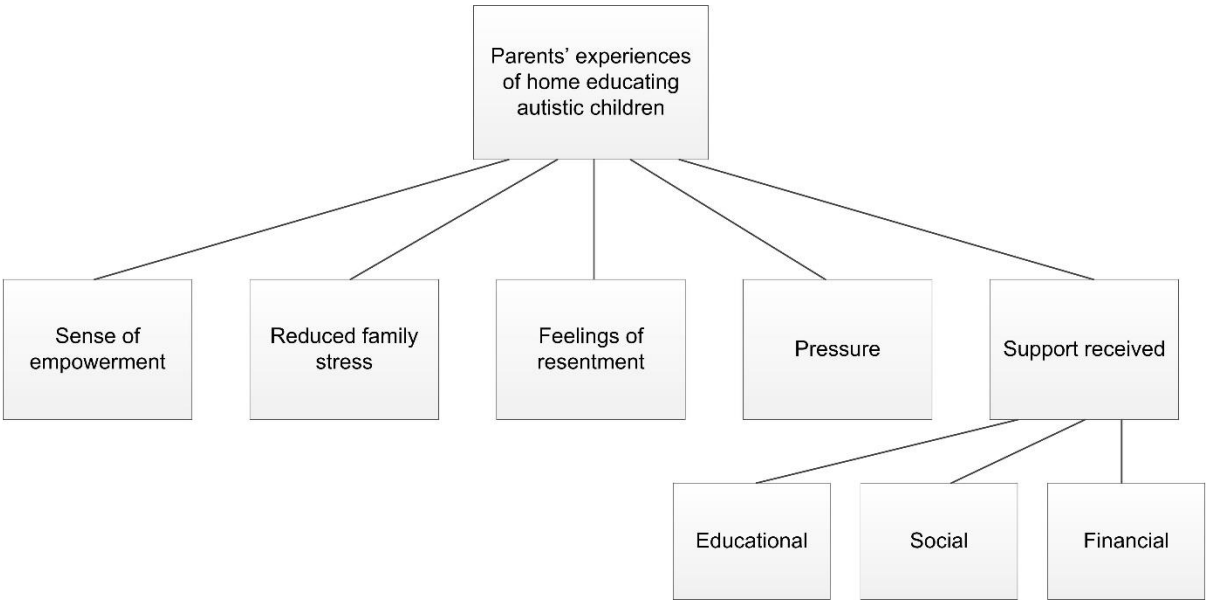
source of anxiety (Kidd & Kaczmarek, 2010). Two of the mothers in Kidd and Kaczmarek's (2010) study were advised by paediatricians to withdraw their children from school due to their level of anxiety. Children reaching 'crisis point' such as suicidal ideation and self-harm was the catalyst for parents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

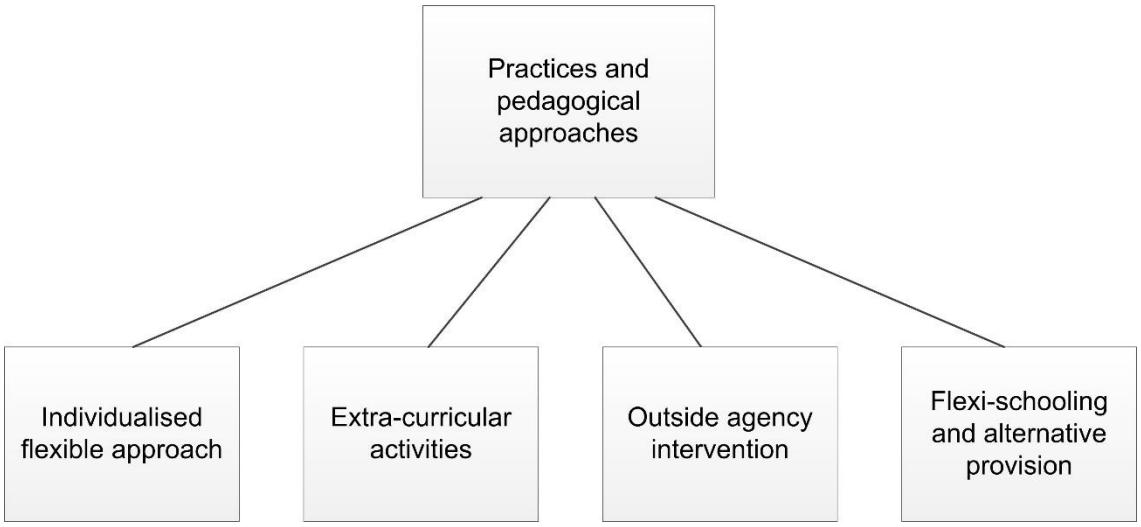
Social Support. For some mothers home educating community groups were a lifeline, "We also got involved with a homeschool group in our community, and that group provides social interaction and support for both boys and for me. Homeschooling was a winning decision for all of us." (Parent; Dolan, 2017). 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,

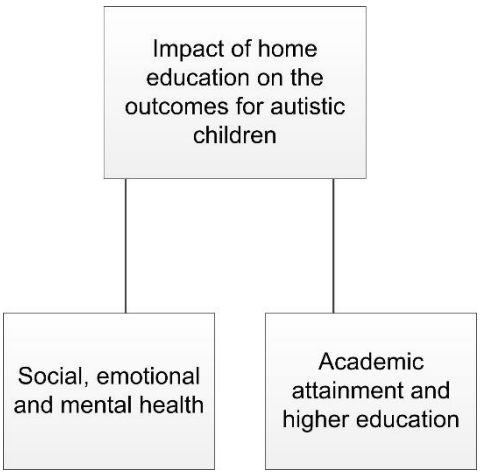
> I had planned to try to flexi-school but it's so difficult to set up. It's hard to find a head teacher that will do it to be honest. I'm not sure why because they would get full time funding for a part time place (Parent; Taylor, Kendall & Forrester, 2011).

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 flexi-schooling 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 meta-ethnography 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.

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