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Parents' perspectives on flexischooling their autistic children

Abstract

The aim of this study was to explore the perceived advantages identified by parents who flexischool their autistic children. 'Flexischooling' is a term first used by Roland Meighan (1988) to describe '[the] notion of a part-time arrangement whereby school and family share responsibility in an agreed contract and partnership'. In this study it is used to describe an arrangement where autistic pupils undertake part of their full-time education at school, and part at home. In line with the National Autistic Society recommendations and research into the preferences of the autistic community (Kenny et al., 2016), 'autistic person' is used in preference to 'person with autism' in this article.

The research reported on five case studies of parents – all mothers – who have withdrawn their autistic child from school to homeschool for some of that child's education, but who keep their children on school roll and continue to pursue active involvement for their children with school. Their motives were explored as to why they did not wish either full time at-school education or fulltime at-home education for their children. Semi-structured interviews were used to examine the mothers' motivation. Results suggested that the mothers are responding to perceived challenges which face their individual autistic children in school. They are responding to a perceived value which they still feel exists for their children at school, and they are responding to perceived advantages of homeschooling and their involvement in their autistic children's education. Implications for the education of children with autism are discussed.

Keywords: Flexischool; autism; homeschool; parents; education

Introduction

Autistic children in the UK may attend a variety of school options for their compulsory full-time education, including mainstream schools, specialist schools or specialised units attached to mainstream. They may also be home educated (homeschooled). Numbers of home educated children in England are unclear as there is no requirement for parents in the UK to register their home educated children (Badman, 2009). However, responses to Freedom of Information requests from 190 local authorities showed over 36,000 children as home educated in the UK in 2015, a 65% increase in recorded cases in the previous six years (BBC news, December 2015).

In the UK parents are responsible for providing an education that is 'efficient', 'full-time' and 'suitable' (Section 7, the Education Act 1996) for their child, either through

attendance at school or otherwise. Motivation for home education is itself diverse and may include philosophical, religious or pedagogical concerns (Badman, 2009). It may also be because parents are concerned for the welfare of children with Special Educational Needs or Disability (SEND) (Badman, 2009; Hopwood et al., 2007). There are some 'very convincing case studies of hardship, anxiety and misunderstanding' (Badman, 2009, p.24) amongst children with SEND which lead to parents withdrawing their children from school 'in despair that their needs were not being adequately met' (ibid., p. 24).

Parents of children with SEND may not be 'electing' to home educate at all, but may rather be home-educating as a 'least bad option' (Badman, 2009, p.25). Parsons and Lewis (2010) rejected the term 'elective' in their research into home education, arguing that use of it 'implies a positive and informed choice' where there is a difficulty 'in the assumption that deciding where and how to educate children, especially those with SEN or disabilities [SEND], is a real choice for parents' (Parsons and Lewis, 2010, p. 84).

Including children with autism into mainstream school may be particularly challenging (Wing 2007; Norwich, 2005; Norwich and Lewis, 2005). There remains a lack of agreement as to best practice in the education of autistic pupils (Parsons et al., 2011; Lindsay, Proulx, Thomson & Scott, 2013; Lindsay, Proulx, Scott & Thomson, 2014). Evidence suggests that young autistic people are struggling in schools, particularly in mainstream schools, experiencing issues with isolation and loneliness (Chamberlain, Kasari, Rotheram-Fuller, 2007), peer rejection (Frederickson, Jones & Lang, 2010; Humphrey & Symes, 2010) negative self-perception (Hebron & Humphrey, 2013) and bullying (Cappadocia, Weiss, & Pepler, 2012; Humphrey & Symes, 2010). One in four autistic children is not in the type of school preferred by their parents (Lynch and Irvine, 2009), and less than half of autistic children in a recent survey reported that they are happy in school (APPGA, 2017).

It is not clear what proportion of parents who withdraw their children with SEND from school to home educate would welcome some continued access to school for their children, were it to be made available. Badman (2009) identified that some of the parents in his study were keen to maintain contact with the mainstream education

sector, welcoming visits by the Local Authority and making use of drop-in centres, resources and materials as available. His recommendations included extending to these children access to school libraries, sports facilities and specialist facilities. These suggestions built on earlier recommendations (Arora, 2006) for children with SEND who have been withdrawn from school by their parents to have some continued access to school should their parents wish it. Parsons and Lewis (2010) suggested provision of a mix of school and home-based options. Other research suggested that 'some parents [number not specified] said that they would welcome flexi-schooling with part-time attendance at school' (Kendall and Taylor, 2016, p.303), acknowledging the fact that flexischooling is at the discretion of the head teacher. One parent (Parent 'A') reported, 'I had planned to try to flexischooling but it's so difficult to set up. It's hard to find a head teacher that will do it to be honest. (Kendall & Taylor, 2016, p. 303).

Badman's 2009 review made recommendation to 'extend ... opportunities of Flexischooling' (p. 20). Arora's 2006 review of the literature on home-education with reference to special educational needs similarly recommended an option where the LEA and school work with the family as part of a 'flexible education plan'. Her suggestion is that school should 'retain some responsibility to provide advice, resources and regular monitoring of these children' as part of a 'well-coordinated arrangement in which children remain on the roll of the school, even if they are partly or wholly educated at home' (p. 63):

Homes and schools [could] work together to ensure that children's needs are met ... [through] a system of part-time attendance at school, in which the parents and the school take responsibility for delivering different parts of the curriculum in the different locations [Aurora, 2006, p. 26].

There has been little research undertaken into the motivation of parents of autistic children specifically to withdraw their children from school and even less into the motivation for some of these to retain some contact with school through flexischooling. This study therefore investigates parental report on their understanding of the benefits which flexischooling brings to their child. It highlights their perceived problems with school for their children, their perceptions of school's continued benefits for their child and their understanding of the benefits that their

own increased involvement through the at-home element of their child's education may bring.

Method

The study explores the case study experiences of five mothers who have withdrawn their autistic child from school for some of their schooling. It is a study of 'real-life' or 'life-world' experiences (Dowling, 2007), interested in describing phenomena as they appear to those experiencing the phenomena (Tuohy et al., 2013). It takes a viewpoint that the participants are 'experts in their own experiences' (Reid, Flowers and Larkin, 2005, p. 20).

Participants were selected purposefully through the online Facebook group 'Flexi-schooling Families UK'. This group is closed in that members are required to join in order to see or make posts, and these posts are moderated by the group managers. Permission from the group moderators was gained before request for volunteers to this study was made. The sample size for the study is small consisting of five parents (all mothers) who have withdrawn their children from school for part of those children's education. This sample size is in line with IPA recommendations (Smith, 2004; Reid, Flowers and Larkin, 2005; Smith, Flowers and Larkin, 2009).

The researcher used a semi-structured interview to enable participants to articulate their reasons for choosing this form of education. These interviews were recorded, transcribed and returned to the participants for verification. An initial 'summary' analysis of each of the interviews was then written up into a short report, designed to reflect the interpretation of that interview back to each participant in order to test for validity of interpretation.

The researcher then analysed each interview for content about the participants' perceptions of, and rationale for, flexischooling. This content was synthesised to produce data on the participants' perspectives, both positive and negative, of their chosen educational approach.

Participants

Participants in this study were the mothers of the following children:

'A', aged 7, diagnosed with autism at age 6 who attends a mainstream primary school for an hour and a half each day and for the rest of the time is educated at home.

'B', aged 12, diagnosed with autism at age 4 who attends a mainstream secondary school with autism unit attached for one hour twice a week and the rest of the time is educated at home.

'C', aged 10, diagnosed with autism at age 7 who attends a mainstream primary school for four days a week and on Wednesdays is educated at home.

'D', aged 14, diagnosed with autism at the age of 4 who attends a small private school for four days a week, and on Wednesdays is educated at home.

'E', aged 7, diagnosed with autism at age 2 who attends a non-autism-specific special school in the mornings and an autism group run by his mother in the afternoons.

Results

Problems with school

Participants express their concerns about their child's social, behavioural and academic issues with full-time attendance in school. Each has taken the decision to flexischool after their child had previously had negative experiences in the full-time education system.

These concerns are framed primarily with reference to the child's response. There are reports of the children feigning illness – specifically headaches and stomach ache – or of actually becoming ill: one child reportedly 'crashing' and sleeping for 18 hours each day. The parents give specific reasons for this as follows:

Sensory issues - such as the inability to filter sounds or by 'complete sensory overload'

Fear ('he was so frightened of things that the other children seemed to be fine with')

Lack of orientation so that the child became lost ('he was unable to get from one lesson to another and ended up alone in the library ... unable to ... ask for help')

Prosopagnosia ('he doesn't recognise any faces').

They also report concerns that their child was managing the challenges of school by shutting down ('If it's too much, he just switches off. He goes off into his ... world and it's like a fog'), and that a lack of disruptive behaviour meant that the school was not aware that there was an issue ('You could literally just sit him down and forget he was there'). One parent reports, 'because he didn't at that time start kicking and punching and shouting, it got missed'. There are repeated concerns both that their child's general academic needs are not being met ('I don't think he's going to learn anything'), and that their child's autism-specific needs are not being addressed ('he needed Speech and Language therapy, he needed OT therapy, particularly sensory therapy which they were not equipped, or not skilled, to deliver').

Parents report concerns about their children's behaviour at home after a full day at school. They report difficulty communicating with their child, and the effect that their child's behaviour has on wider family life:

I had no contact. None. It was like, I could barely get him to come down for - to eat. He wasn't talking to anybody. He was very, very short and very aggressive toward [his sister].

Another parent reports on how difficult it was to give their child the 1:1 time which she felt he needed during weekends and evenings, given the demands of family life.

The parents report communication issues regarding the schools. They express concerns that they do not 'know what he was doing in school' and that 'communication with school was not open enough'. Parents are concerned that the teaching their children were receiving in school was not appropriate to their needs. One reports that she was 'not sure that the teaching techniques they used there were the best' and her that she had concern about the 'lack of understanding of the teaching staff'. Another expresses concern that her son's support was delivered by withdrawing him from class to spend time with a TA, and 'teaching assistants aren't teachers'.

Advantages of school

Despite their many concerns, all parents in this study express a wish for their child to retain access to school for part of their education. These include potential positives for their child of attending school, together with perceived negatives regarding their own ability to deliver full-time home education. Latter concerns include practical reasons such as the need to work, and also a lack of confidence in their ability to teach their children. One parent articulates, 'I wanted to homeschool him, but I knew that I couldn't. I have to work, and, I don't know... It's just not something I could do'.

Participants remain confident about the advantages of some school attendance for their child. This is framed primarily in terms of social advantages, specifically those of community. One parent reports that she feels that her son needs '... to be part of his community – part of the community he [will] grow up in'. It is also important to some parents that school gives their child an opportunity to form bonds with an adult from outside the family. Relationships with peers are also described, one parent indicating that she feels that 'school is important ... with the social aspect and the shared experiences'. Another says that school enables her son to 'still get the group and get what it's like to listen in a classroom and do teamwork'. One parent articulates why this works better on a part-time basis, saying that her son has 'a great need to be in with other kids, but ... just can't handle the amount of time'.

Another parent expresses her belief in a need for social contact from the opposite angle. She feels that it is important that, if her son went to school, 'the children would get to know him from a very early age'. She argues that this exposure has helped his peers to accept him. 'He's recognised, they feel comfortable with him, he feels comfortable with them.'

A further strength of some school attendance is articulated in terms of 'staying in the system'. One parent describes this as 'having that foothold' and expresses that being part of the school system means continued access to exams, to the university application process and to work experience.

Advantages of home

The participants express clear advantages about the at-home element of these children's education which are more than simply 'not school'. These are frequently expressed in terms of time to spend together. For example, one reports, 'We're usually cuddled up together, you know, and on the ipad, and we make lots of jokes

together' and another that there is value to 'just standing in the kitchen and going through how you make pancakes and letting him do it and whisking the thing'. One mother says of their time together that 'we do all sorts: we go to museums, we try out whatever ... You're with him, you're talking that whole time and that is an important time, really, because it's uninterrupted as well'. This time together is articulated as being salvaged from other demands of family life. One parent explains that when her other child is at school, her son is able to sit in the front of the car with her on trips, which enables interaction. Another indicates that her autistic child is more able to interact with her when her other son is absent, and that it also gives potential for relationships to develop within the family: 'If he's got enough down-time in the week he's going to have more energy for [his sister]'. This ability to join in with usual family activity is clearly valued. 'He sees the kind of mechanics of life, of what's needed to live in a house and in a family' and 'I do think this is important for all children to kind of know their place within the family and know their importance'.

The impact on family life is expressed further. One parent says that she has 'more time for my daughter, and family time, because I'm not dealing with screaming and crying [from my son]' and another that time away from school makes her autistic child happier, and 'if he's happier it just ricochets through the whole family'.

Participants express their gratitude that the additional time with their child has enabled them to understand their child's autism better. One says that 'I think I learn stuff about him every day. The way his brain works – it's just fascinating to me, really' and another, 'I've learnt a lot more than I was ever taught'. As one mother expresses, 'I've got to a much better understanding of my son ... through this process than I would have done otherwise. I think, whether you like it or not, you have to become an expert on autism, so you may as well hit it head on'.

Discussion

The parents in this study are responding to personal, and frequently fluid, situations. There is little indication of a considered philosophy behind what they are doing; it is more the case that they are reacting to a situation to which they see little alternative.

Nevertheless, there is clarity in their responses about the perceived advantages of what they are doing. They are clear that they are responding to their child's needs, most usually to their child's distress, but also to their own perception that their child's

childhood should not be wasted, and that there is a great deal that their children need to learn during this time. 'It's just me doing it because I don't want him to not have a job when he comes to work, you know?'

They indicate their belief that they as parents are able to understand their child's communication better than it is understood at school. They are aware that social communication difficulties are a core element of autism, and that they need to intercede for their child to overcome these difficulties. They also show awareness that they are able to respond to these communications where busy school schedules may struggle to do so. As one indicates, if her child says, "Mum I'm not okay" she is able to stop that activity or go home, which is not the case in school.

Some participants are pragmatic about the reasons for the flexischooling, aware that in a sense they have merely formalised something that was happening already: 'I think it's much better than for a lot of children who are getting sent home anyway because they can't cope with it, or physically not being able to go in'. Others see it as a practical way of avoiding destructive behaviour: 'I don't have so many meltdowns at home as I do if he's at school'.

There is nonetheless an impression that the parents in this study are active in their support of their children and see the education that they have evolved – part home, part school – as being valuable in its own right. Some recognise its practical value for their children, suggesting, '[his education] is kind of segmented into pieces, into bite-sized chunks that are a little bit easier'. Others particularly value the increased communication opportunities between home and school which the provision supports: 'I think it's all about the rapport between the teacher and the parent, really'. One parent articulates this two-way communication as being a way to facilitate the whole education of the child: 'We could support what was going on in school and school would support what was going on at home'.

Conclusions

Shared education as described in this study ('flexischooling') operates in response to a perceived need at least as much as being by preference or elective. This need as perceived by the parents is both to protect their child from harm and distress, and in order to respond to that distress in the child. Parents as reported in this study are keen to respond to communication from their child, perhaps in reaction to the

reduced communicative elements of autism. They are confident in their own understanding of their child and report the need to respond to that understanding.

Although the rationale for the adoption of shared education is one of need, there is nevertheless confidence shown by these parents that the shared education that they are providing is in itself positive and is more than merely a relief from the perceived stress of school. Indeed, there is evidence that the parents feel that the sharing of education between home and school is facilitating the child's access to school, through providing support for the child to prepare and respond to these stresses. The most frequently reported advantage of the at-home element of flexischooling refers to facilitation of communication with the autistic child and the increased opportunity to build a relationship between parent and child. Parents report that the education provided in this way addresses individual needs within that autistic child, and also within the family as a whole. The sharing of the education between home and school for one child is reported as safeguarding the wider family dynamic – improving relationships between the autistic child and siblings, between the parent and other children and within the wider family such as grandparents.

Indeed, the facet of shared education which is reported most coherently is that it is acting as a 'bridge': between the child and parent, between the child's needs and what the school can offer, between the child and the wider family, and between the child's 'at home' world and that of 'at school'. The juxtaposition of these two worlds with their different social rules, expected behaviours, clothing requirements, languages and expectations is reported as a fundamental challenges for the autistic child. The parents report that the additional time provided through flexischooling enables them to work with their child to explain the different rules of the two environments and to 'bridge' between them.

The parents in this study show some insecurity in their role within flexischooling as educators in the academic sense. This is reported in terms of their lack of confidence in supporting the child with the academic curriculum. They also perceive themselves as unable to support their autistic child in the widening of social experience outside the family. They fear being 'out of the system' regarding accessing exams, school, university and job applications. This insecurity regarding their role is most often voiced in terms of fear for their child's future.

In contrast, the parents in this study show confidence about their role within flexischooling as parents. They express confidence that they understand and are protecting their autistic child and that they are working holistically to protect their child's position within, and the wider needs of, their whole family. In this their confidence as parents who are sharing one child's education extends to confidence as parents to their other children also. This confidence in their role is most often voiced in terms of satisfaction with their child's life in the present.

Implications for further research

This is a very small-scale study into an under-researched phenomenon. It is not known how many parents are flexischooling, nor how many of these have a child with autism. It is also not known how many parents with autistic children in full-time school would welcome the opportunity for part of that child's education to take place at home, nor how many parents who have chosen elective home education for their autistic child would take an opportunity for greater involvement in school for their child were it to be offered. Each of these merits further investigation.

Parents in this study are indicating that their children have struggled in full-time school. This is reflected in a recent survey by the National Autistic Society, which reports findings of an inquiry by the All Party Parliamentary Group on Autism (APPGA, 2017) that 70% of the children surveyed said that their peers did not understand them and half that their teachers do not know how to support them.

However, the parents in this study are indicating that they continue to value elements of school and wish for their children to be able to access at-school education, even on a part-time basis. They are also indicating that they perceive their input into their child's education to be positive – for their child, for themselves and for their wider families. The value of parental involvement in the education of autistic children itself merits further investigation.

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