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Introducing FAMe™: Can improved teacher access to individualised classroom support information impact positively on levels of anxiety in autistic pupils?

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Introducing FAMe™: Can Improved Teacher Access to Individualised Classroom Support Information Impact Positively on Levels of Anxiety in Autistic Pupils?

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Abstract

There is much research evidence to suggest that the successful inclusion of autistic pupils in mainstream secondary schools is difficult to achieve and that these pupils remain particularly vulnerable to a wide range of negative academic and psychosocial outcomes. With a focus on anxiety, this article reports the initial findings of a participatory-styled system-impact evaluation study. Quantitative evidence of decreased pupil anxiety is demonstrated and validated with qualitative data. Implications for future education policy and practice are discussed.

Key Words: autism, Asperger Syndrome, anxiety, inclusion, Special Educational Needs and Disabilities (SEND), education, equality, FAMe™

Terminology

Recent changes to the diagnostic labelling system (DSM-5, 2013) have seen Autism Spectrum Disorder (ASD) and autism become the umbrella labels used to refer to all autistic spectrum conditions. We do not consider autistic persons to be 'disordered' (Beardon, 2007, 2008a; Leatherland and Chown, 2015), nor subscribe to a 'medical model' view of autism (e.g. Goodley, 2001; 2011; Oliver, 2004; Samaha, 2007; Snyder and Mitchell, 2006), so we use autistic/autism throughout this article to describe individuals considered to be on the autism

spectrum. As with the diagnostic label itself, there is no single way of describing autism that is universally accepted. It is recognised that individual preferences vary widely depending on a number of factors, including a person's relationship with/connection to autism and the discipline/model of disability to which they subscribe (Leatherland and Chown, 2015). A recent National Autistic Society (NAS) study (Kenny et al. 2015), explored the preferred terminology of 'individuals on the autism spectrum' when referring to themselves and/or being referred to. We have chosen to adopt the terminology endorsed by the majority, and use 'identity first' language, i.e. 'autistic' individual/pupil/population, throughout this paper. The non-autistic population is referred to as either the 'predominant neurotype' (PNT) (Beardon, 2008b), or 'non-autistic', though we recognise that outside of the autistic population a wide range of neurodiversity also exists (Armstrong, 2010).

Introduction

Introducing the Facts About Me (FAMe™) System, and with a focus on the correlation between FAMe™ implementation and anxiety, this article outlines the preliminary results of an ongoing PhD project. The FAMe™ System was designed in response to the author's personal experiences[1], and the further corroboration of these in autism and education research literature that indicate high levels of educationally based anxiety in the autistic pupil population (e.g. Ashburner et al., 2010; Bolic Baric et al., 2016; Charman et al., 2011; Keen et al., 2016; Osbourne and Reed, 2011; Ravet, 2011).

The FAMe™ System utilises the 'Marksheet' function of existing School Information

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[1] Julia Leatherland (FAMe™ System Designer and Principal Researcher) is a parent of five autistic children and has witnessed first-hand the environmental stressors autistic individuals are challenged to overcome on a daily basis at school

Management System (SIMS) software, to provide mainstream secondary teachers with easy access to information ('Facts') about the classroom-support needs and/or learning profiles of individual autistic pupils. Consideration was given, during system design, to the current limitations of schools' resources (Iadarola et al., 2015) and teachers' workload - recently described as 'unmanageable', by 82% of 4450 teachers who responded to a survey carried out by the Guardian Teacher Network (The Guardian 2016).

When the FAMe™ System is operational, teachers have continuous access to a 'SEND and FAMe™' tab which sits above the class register (Figure A). If an autistic pupil is in the class group, their FAMe™ information is displayed in the FAMe™ column within this tab. This FAMe™ information consists of three concise 'Facts' about the individual autistic pupil's self-identified classroom support requirements (Figure B). Teachers are not expected/required to remember this information, but rather to access it each time they teach an autistic pupil.

In this trial of the FAMe™ System, autistic pupils' 'Facts' were established through consultation between pupils and the principal researcher, during the pre-FAMe™ interview sessions (this process is described in more detail in the methodology section). If the FAMe™ System is to be used by schools in the future, it is anticipated that the now termly pupil SEND review meetings (DfE & DoH, 2015), in which pupils are encouraged to participate, could provide the perfect opportunity for staff and pupils to work together to generate pupils' 'Facts'. These can subsequently be updated to reflect changes in primary need (Morewood, 2011).

Fig, A. Teachers' Register View when FAMe™ System is Operational

Marksheet tab as it appears in register

Fig. B. Example contents of SEND and FAMe™ Marksheet Tab

The expectation is that, by raising their awareness of autistic pupils' profiles of need, teachers will be better enabled to create effective environments and practices that support learning and serve to protect these pupils from a range of negative outcomes (Aspect, 2012; Keen et al., 2016; Howlin and Moss, 2012). Rather than attempting to teach teachers what *'autism is'* (Milton, 2012), through FAMe™ we aim to facilitate teachers' understanding of the individual autistic pupils they teach. The outcomes for participating pupils were analysed, to identify the impact of FAMe™ implementation on their educational and emotional profiles.

Literature Review

The majority (70%) of autistic children in England today are educated in mainstream schools (DfE, 2014a). Autism is the most common primary need amongst pupils with a Statement of Special Educational Need or Education Health Care Plan (25%) (DfE, 2014b), evidencing that their needs often extend beyond those of the majority of children and young people which can be met through *'high quality teaching that is differentiated and personalised'* (DfE and DoH, 2015). There exists an expectation that **all** teachers should be able to create 'inclusive' classrooms for **all** pupils (DfE, 2014; DfE, 2015) however, few guidelines exist about how best to include the mainstreamed population of autistic pupils (e.g. Emam and Farrell, 2009; Lindsay et al., 2013; Morewood et al., 2011), who are reported to pose a unique challenge to teachers (e.g. Gibbons, 2008; House of Commons Education & Skills Committee, 2006; Jones et al., 2008; Pivik et al., 2002; Robertson, Chamberlain and Kasari, 2003). Amongst learners with special educational needs and disabilities (SEND), autistic pupils are understood to be particularly vulnerable to a range of negative outcomes related to their quality of life (QoL) and academic success (e.g. Ashburner et al., 2010; Charman et al., 2011; Morewood, Humphrey and Symes, 2011; Osborne and Reed, 2011). As many as 84% of

autistic children and adolescents have a co-occurring mental health problem (Magiati et al., 2016; White et al., 2009; Selles et al., 2015; Van Steenel et al., 2011) - such as depression, anxiety, and Obsessive Compulsive Disorder (OCD) - which is thought to develop in part through their experiences in the education system (NAS, 2010) - with high rates of academic under-achievement (54%) also reported in this population (Ashburner, Ziviani and Roger, 2010; Keen et al., 2016). This compares to prevalence rates of around 10% and 8% respectively in non-autistic children (NAS, 2010; Ashburner, Ziviani and Roger, 2010). While a correlation between education and suicidal ideation and attempts has yet to be determined, such risks are identified in the literature for both autistic children (Mayes et al., 2013) and autistic adults (Cassidy et al., 2014). In general terms, there is also evidence to suggest that poor school performance increases risk of suicide in adulthood (Kosidou et al., 2014). Kanwar et al. (2013, p.929) conclude their paper pertaining to links between anxiety and suicide by stating 'this systematic review and meta-analysis provides evidence that the rates of suicides are higher in patients with any type of anxiety disorders excluding OCD'. Since there appears to be identified links between anxiety and suicide (Sareen et al., 2005), we assert that any mechanism for reducing risk of anxiety has significant implications for autistic pupils.

The heterogeneous nature of autism (e.g. Attwood, 2007; Beardon, 2012; Beardon and Worton, 2011; NAS, 2014; Rosqvist, 2012), contributes to the complexity of providing autism-friendly learning experiences (Batten et al., 2006; Pivik et al., 2002: Singh and Elsabbagh, 2014) in classroom environments that enable successful participation (Macbeath et al., 2011; Ravet, 2011). Many teachers possess a limited understanding of the way autism impacts on an individual pupil's experiences of their environments, relationships, and/or

their cognitive style and learning abilities (e.g. Charman et al., 2011; Falkmer, Parsons and Granlund, 2012; Hebron and Humphrey, 2014; Leatherland and Chown, 2015; Jones et al., 2008; NAS, 2016a). Such understanding is crucial if teachers are to appropriately differentiate the curriculum and tailor classroom strategies to address individual pupil's needs (Barnard et al., 2000; Falkmer, Parsons and Granlund, 2012). A good teacher, through good practice, might be able to address some of the more obvious challenges (DfE, 2015), but no teacher can be expected to simply 'intuit' the wide and complex array of subtle difficulties experienced by individual autistic pupils (Ravet, 2011; Singh and Elsabbagh, 2014). Individualisation is considered essential if outcomes for autistic pupils are to be improved (Bevan-Brown, 2010; Falkmer, Parsons and Granlund, 2012; Hebron and Humphrey, 2014; Reed, Osborne and Waddington, 2012). However:

'finding ways to provide balanced support for individual needs at a time when financial conditions have deteriorated, resulting in larger classes and more students with special needs in each class, is truly a challenge for the educational system' (Bolic-Baric et al., 2016, p.192).

A successful campaign (#everyteacher) led by leading UK autism charities (Ambitious about Autism (AaA), 2016; NAS, 2016a) has effected a commitment from Government to include a specific focus on autism in future initial teacher training (Espinoza, 2016). Whilst this represents a positive step towards improved autism awareness in schools, it will not address the training needs of current teachers, many of whom report lacking both the knowledge to teach autistic pupils (60%) and confidence in their ability to do so (44%) (NAS, 2016a). In addition, while autism training is welcomed, it is unlikely to address all issues within education for all autistic pupils. Teachers have requested more accurate and accessible

information about the needs of their autistic learners (e.g. Miller, 2002; Wilkinson and Twist, 2010) and researchers have indicated that providing them with such information is likely to have a positive impact on pupil outcomes (e.g. Charman et al., 2011; Macbeath et al., 2011). Our aim is that, by enabling teachers to access their autistic pupils' FAMe™ information, the FAMe™ System will begin to bridge the gap between teacher knowledge and pupil need (Kasari and Smith, 2013; Parsons et al., 2013; Parsons and Kasari, 2013).

Methodology

The FAMe™ Project is an ongoing evaluation of the FAMe™ System's potential to change current autism pedagogy and impact positively on a range of outcomes, relating to well-being and academic success, for autistic pupils attending mainstream secondary schools. Recognising that these pupils are the only true 'experts' (Milton 2014; Waltz, 2006) who can tell us about their secondary school experience, and what classroom accommodations they need to reduce stressors, the research was undertaken with a commitment to attend to and reflect the voices of its autistic participants (Milton, Mills and Pellicano, 2014; Ne'eman, 2011). Grounded in the principles of participatory research (e.g. Jivraj et al., 2014; Stone and Priestley, 1996), a pragmatic mixed methods approach (e.g. Creswell and Plano Clark, 2007; Denscombe, 2008; Hammersley, 2008; Johnson and Onwuegbuzie, 2004; Nuthall, 2004) was employed to collect quantitative and qualitative pupil and teacher data, using a combination of: pre- and post-FAMe™ semi-structured pupil interviews; pupil self-report measures; and online teacher and Special Educational Needs and Disabilities Coordinator (SENDCO[2])

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[2] A SENDCO is responsible for the day-to-day operation of the school's SEND policy. All mainstream schools must appoint a teacher to be their SENDCO. The SENDCO will co-ordinate additional support for pupils with SEN and liaise with their parents, teachers and other professionals who are involved with them.

surveys (Figure C). This mixed methods design produced a breadth and depth of data set (both quantitative and qualitative) allowing for triangulation of data and a robust platform upon which to determine validity of results.

Respecting that autistic individuals often process information differently to the PNT population (Ashburner et al., 2013; Minshew et al., 1997; Preece and Jordan, 2010; Williams and Hanke, 2007) and that visual/pictorial presentation can aid comprehension (Arthur-Kelly et al., 2009; Dockrell and Lindsay, 2011; Morris, 2002; Rao and Gagie, 2006), all information packs were provided in both long and short (easy-read) formats and included images as well as text wherever possible.

Fig. C. Data Collection Methods

	Pupils	**Teachers**	**SENDCOs**
Pre-FAMe	**Meeting 1.** **Semi-Structured Interview** With a focus on experiences of school and what teachers do that is helpful/unhelpful in the classroom **Development of 3 'Facts About Me' (pupil)** Based on what each pupil would like their teachers to do differently and/or know about them **Completion of Self-Report Measures**	**Online Questionnaire** With a focus on experiences of teaching autistic pupils; confidence in ability to understand and meet pupils' support needs; experience of accessing pupil SEND information; and potential usefulness of an easy access information system (FAMe™)	

Post-FAMe	Meeting 2. **Semi-Structured Interview** With a focus on experience of teachers' FAMe™ system use and impact on/difference made to pupil when teachers used their 'Facts' to change their classroom practice **Updating/Changing Facts About Me** if necessary **Completion of Self-Report Measures** (repeat of same measures used in meeting 1)	**Online Questionnaire** With a focus on experience of teaching autistic pupils using FAMe™ System e.g. whether the 'Facts' provided new information/frequency FAMe™ information accessed/change in classroom practice; impact on confidence in ability to understand and meet pupils' support needs; ease of use of FAMe™ System; and suggestions for further development	**Online Questionnaire** With a focus on impact of FAMe™ on their understanding of autistic pupils' needs; usefulness of information collected from pupil self-report measures; changes to SEND provision for pupils; and desire to continue with FAMe™ System use within school

As new and/or unfamiliar situations are known to create and/or increase anxiety for many autistic individuals (Gillott and Standen, 2007), participants' parents were emailed information at various stages of the project to share with their children, which included, but was not exclusive to: an animated video explanation of the project (https://youtu.be/IWZSaTZrO8U), which was narrated by and included photographs of the principal researcher; visual interview schedules; and details of the date and room in school where interviews would take place.

Individual pupil's FAMe™ information - the three 'Facts' about them that they most want their teachers to know and attend to in the classroom - was gathered during the pre-FAMe™ interviews. A variety of specifically designed visual materials (e.g. photo prompts and sketch sheets) were made available to aid discussion and support pupil-researcher communication, taking into account the need for alternative communication methods often required by autistic individuals (Preece and Jordan, 2010; Rao and Gagie, 2006). Once prepared for entry

into the FAMe™ System, FAMe™ information was sent via parental email for participant verification. Any requests for amendments were actioned prior to making the information available to teachers through the school register system for one school term (April-July 2016). The following are examples of FAMe™ information generated by pupils:

- Please break down my instructions for me - I can't take in a lot of information at one time

- Please check that I have understood the task before I start

- Please write my homework down for me in my planner / provide me with a homework sheet

- Please only ask me to speak in front of the class if I put my hand up to show I am happy to do so

- Please help me find a group to work with - I find the activity of getting into groups difficult and stressful

In this article, we report results from the preliminary quantitative pupil-data analysis, identifying score differentials obtained from pupils' pre- and post- FAMe™ self-report measures. Measures selected focus on issues relating to QoL (i.e. anxiety, depression and self-esteem), which are widely understood to be negatively impacted by school experiences (Ashburner et al., 2010; Charman et al., 2011; Morewood, Humphrey and Symes, 2011; NAS, 2016a; Osborne and Reed, 2011). Results will be contextualised using quotations from the post-FAMe™ pupil interviews, a narrative analysis of which will be reported elsewhere.

Recruitment and Participants

FAMe™ Project information packs were emailed to SENDCOs of all council maintained mainstream secondary schools in Sheffield (n=22) - excluding those with a specialist autism

provision (n=4)[3]. SENDCOs were invited to contact the principal researcher for more information and, of those who did so (n=5), 3 agreed to trial the FAMe™ System in their school and subsequently facilitated pupil recruitment.

To protect pupil anonymity, FAMe™ Project information and consent forms were posted via school to the homes of pupils with a known (by school and by the pupil) diagnosis of autism in years 7-10. Contact between researchers and parents/participants was only established once parent and pupil consent forms (which provided details of parental email addresses) had been returned to school.

In total 24 autistic pupils were recruited. One pupil subsequently withdrew consent and one was withdrawn by the principal researcher following the first interview when evidence of informed consent could not be established (the pupil did not seem aware of the project or her involvement in it, and did not remember completing the consent form. She presented with signs of anxiety at being in an unfamiliar situation e.g. asked repeated questions/stated repeated information whilst pacing the room, and so the session was brought to an end). Participants were offered the choice of taking part in a face-to-face interview at school or home - either alone or with a familiar adult (TA/parent/carer) present - or being interviewed via an email exchange. All chose to attend interviews in school without additional support. One participant took part in both pre- and post-FAMe™ interviews but chose not to complete the pre-FAMe™ self-report measures - his data is included in the narrative analysis

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[3] It is assumed, by the principal researcher, that the classroom experiences of/support available to autistic pupils attending schools with a specialist/integrated autism provision are likely to be qualitatively different from those attending mainstream schools without such specialist resources. These 4 schools were therefore excluded from the recruitment process to retain as much homogeneity within the data set (in terms of school placement) as possible.

only. During the term in which the project took place, one participant moved into specialist provision and one began attending twilight sessions (individual teaching after normal school hours) only (this was as a result of information that came to light during her initial interview). A further participant was attending a work experience placement during the post-FAMe™ interview period and did not respond to an invitation to attend.

Self-Report Measures

Self-report measures were administered by the principal researcher following the semi-structured interviews with pupils. Pupils were offered a break between the two elements of the session when drinks and snacks were made available. Pupils were given the choice of completing the measures independently or having the items read to them. They were encouraged to ask for clarification of any questions that they were unsure how to interpret. It was explained that the questionnaires focused on their thoughts and feelings and assurances were given that there were no right or wrong answers.

The Beck Youth Inventory (BYI-II-Revised, Beck et al., 2005) is a widely used measure of adolescent mental health which shows robust reliability and validity (Beck et al., 2005) and has been used in previous research with autistic youth (Ichikawa et al., 2013; Mandy et al., 2016). The BYI-II Anxiety and Depression subscales (BAI and BDI) were selected to measure levels of pre- and post- FAMe™ mental health. These 20 item self-report scales are easy and quick to administer and score, and have been shown to be sensitive to changes in anxiety and depression over a relatively short time period making them appropriate intervention evaluation tools (PearsonClinical, 2016). The scales can be completed independently (requiring a reading age of 7 years) or read out loud by the administrator.

Applicable to children between the ages of 9-16, the Myself As a Learner Scale (MALS, Burden, 1998) was developed as a means of focusing directly on school students' perceptions of their learning abilities. Containing 20 items, participants are asked to rate how applicable each statement was to them. As with the BYI-II, items can be completed independently or read by the administrator. Standardised scores enable researchers to compare participants with a normative population sample and establish whether individuals and/or groups demonstrate a high/low or average academic self-concept - a construct shown to be flexible and open to the influence of teaching style or other contextual factors (Burden, 2005).

Designed by the principal investigator specifically for this project, the How I feel at School Questionnaire asked pupils to consider their experiences at school over the past week and rate their in-class anxiety, interest in lessons and understanding of the work presented to them on a sliding scale with emoticons illustrating each rating to accommodate visual learner preference (Beresford et al., 2004; Dettmer et al., 2000; Preece, 2002). The pre-FAMe™ questionnaire included an item asking pupils to rate how they thought they would feel if teachers used their FAMe™ information, which was replaced, post-FAMe™, with an item relating to their perception of change since the FAMe™ system was introduced.

Ethics

Ethical approval from Sheffield Hallam University's ethics committee was sought and granted prior to commencement of the project. However, some further discussion of ethical issues is warranted at this juncture. As a participatory-styled research project with double-vulnerable participants, i.e. *children* (Alderson and Morrow, 2011), and *autistic* (Harkema and

Coffee, 2014), ethical consideration of participants' needs were of paramount importance. While Thomas and O'Kane argue that *'ethical problems in research involving direct contact with children can be overcome by using a participatory approach'* (1998, p.336) and participatory-based studies are promoted for use in autism research (MacLeod et al., 2014), the nature of this study meant that no presumptions could be made. Embedded throughout, the principle of ensuring that participants were fully supported and protected from risk of harm was continuously reflected in practice. Taking into consideration the particular vulnerabilities of autistic youth, potential risks were identified from the outset, including risk of: increased stress due to social interaction (de Bruin, et al., 2007), difficulties with communication (Allen and Lewis, 2014) and power dynamics - both adult to child (Harcourt et al., 2011) and adult researcher to participant with autism (Stone and Priestly, 1996). Steps taken to eliminate these included what might be regarded as 'standard' ethical components, e.g.: assuring families that their ongoing school relationships would not be affected by their participation/or not in the project; reiterating participants' right to withdraw at each stage; informed consent from both parent/carer and participant; and anonymised and secure data. 'Additional' steps to reflect the participants' needs (Research Autism, 2015) included: presenting all information in a variety of media (Nicolaidis et al., 2015); introducing the principal researcher via email, photograph and video prior to the initial meeting (NAS, 2016b); providing alternatives to face-to-face interviews (Davis et al., 2012); and, anticipating the possibility of distress during interview, ensuring a member of school support staff was available at all times. The interviewer's duty of care was discussed with pupils and it was made clear how and to whom any information pertaining to harm-to-self or others would be disclosed outside the interview.

Analysis and Results

The results reported in this paper focus exclusively on self-reported pupil anxiety levels (according to frequency of experienced symptoms over the previous week -How I feel at School, or 2 weeks - BAI) and their perceived impact of teachers' use of the FAMe™ system on these.

Descriptive statistics are presented in Figures 1-3, to give an overview of the participants' anxiety levels pre- and post-FAMe™.

Raw BAI scores were converted into age and gender-specific standardised T-scores which can be grouped according to their clinical significance: average <55; mildly elevated = 55-59; moderately elevated = 60-70; extremely elevated >70 (Beck et al., 2005). Mean standardised T-scores of those pupils who participated in both rounds of data collection (n=18) were compared using paired sample two-tailed t-tests. Bootstrapping was used to eliminate doubts about t-test reliability due to the small sample size and the possibility of a non-normative sample distribution (Field, 2013).

Figure 1 illustrates the difference between individual pupil's pre-and post-FAMe™ anxiety scores measured on the BAI. The clinical cut off points for anxiety severity are shown. Self-reported anxiety levels fell post-FAMe™ for all but one pupil (94%) - whose anxiety was already well within the average range pre-FAMe™ (T = 34). The percentage of participants reporting clinically elevated anxiety symptoms pre-FAMe™ was 39% falling to 22% post-FAMe™. The overall difference in whole-group pre-post-FAMe™ anxiety levels was significant at p=0.001 (bootstrapped 2-tailed t-test) suggesting that the decrease in overall

group anxiety was not due to chance.

Fig.1.

Difference in individual pupil's pre- and post-FAMe™ anxiety scores - clinical severity levels
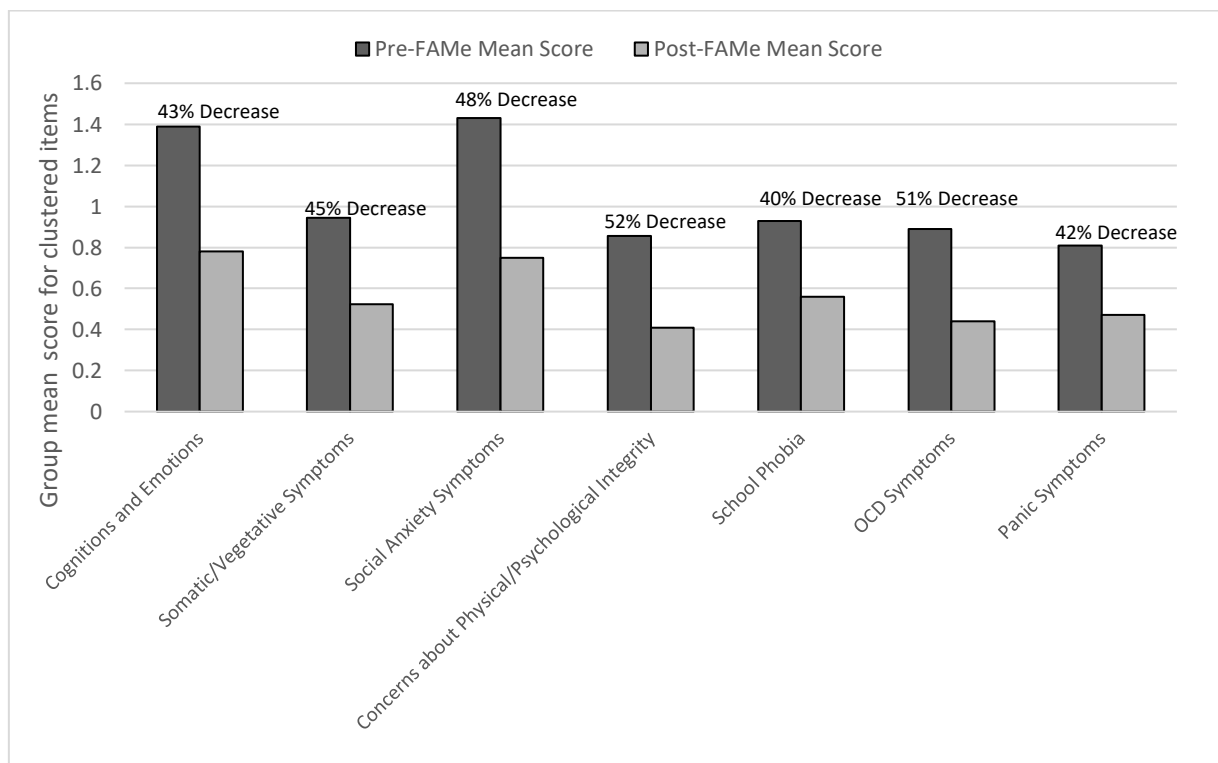
are shown
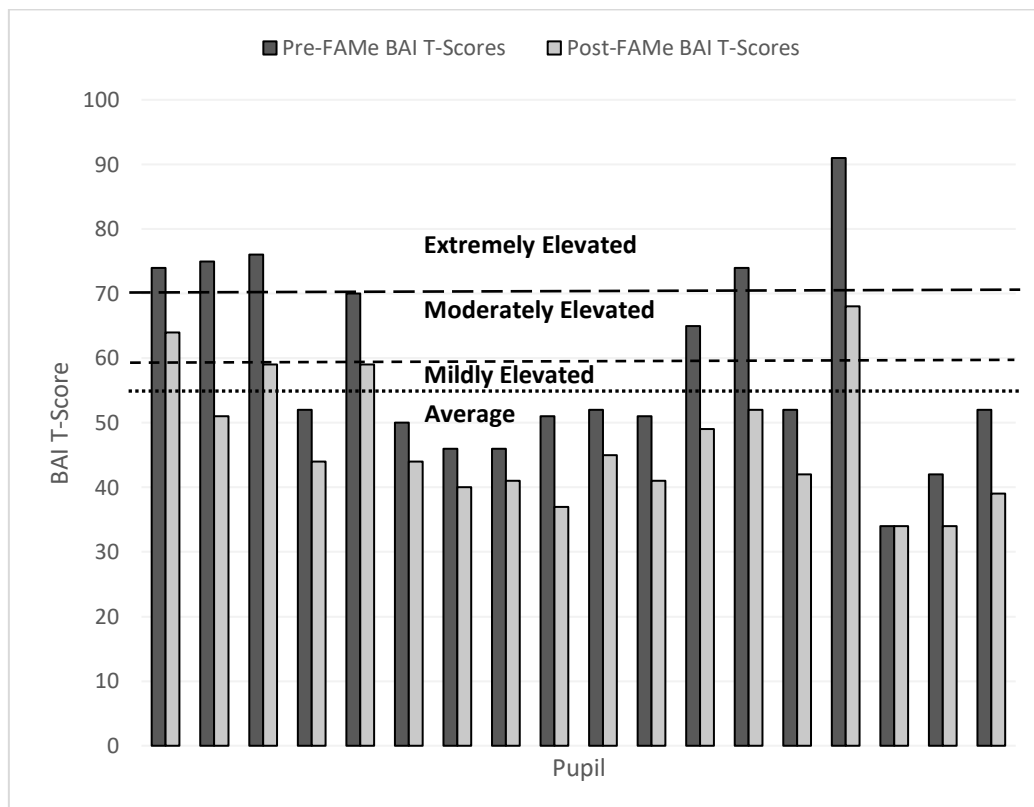
Collectively the 20 BAI items have been designed to measure a common core of negative

and anxious affect, characteristic of anxiety disorders in youth (Beck et al., 2005). In addition,

clusters of items are thought to be indicative of symptoms associated with specific anxiety

types/disorders (Beck et al., 2005). In order to ascertain whether the autistic pupils in this

study demonstrated higher levels of particular anxiety symptoms, and whether any symptom

type was more conducive to change, pre- and post-FAMe™ group mean scores for each

cluster of items were calculated. As may be expected, participants reported experiencing anxious cognitions and emotions (Gaigg, 2012), and social anxiety symptoms (Bellini, 2004; Kuusikko et al., 2008), more frequently than symptoms associated with other specific anxiety disorders, further demonstrating the efficacy of BAI's sensitivity to differentiate between clinical groups (Beck et al., 2005). A group mean post-FAMe™ reduction in frequency of ≥40% for all symptom clusters was reported. Results are shown in Figure 2.

Fig.2.

Difference in group mean reported anxiety symptom frequency between pre- and post-FAMe™ pupil assessments


Pupils were asked to rate how anxious they had felt in class over the past week on a sliding scale. Pre- and post-FAMe™ results are shown in Figure 3. The improvement in pupil-rated in-class anxiety mean scores, from pre- to post-FAMe™, was significant at p=0.002

(bootstrapped 2-tailed t-test) suggesting that the changes observed were not due to chance.

Fig.3.

Pre- and post-FAMe™ levels of in-class anxiety experienced by pupils in the week prior to assessment
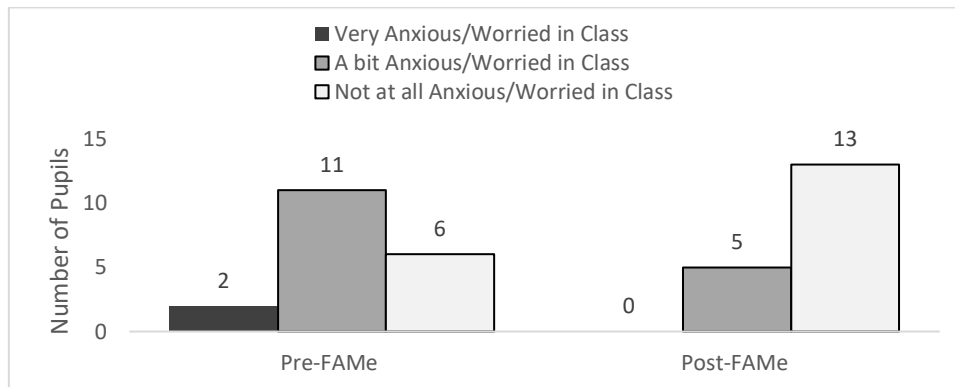
Pupils indicated whether they believed that their in-class levels of anxiety had decreased, stayed the same or increased as a result of their participation in the FAMe™ Project. Fifteen (84%) reported that they believed their in-class anxiety had decreased as a result of FAMe™.

Qualitative data generated in post-FAMe™ pupil interviews supports these results. The following are examples of pupil's verbal responses to the interview question, 'What difference has the FAMe™ System made to you?':

- *I'm becoming less anxious…a lot of things have been a lot better. I just became more confident…because of the facts*

- *[since the introduction of FAMe™]…some teachers have been doing things differently…It's made school less stressful and easier and more enjoyable*

- *In science I'm a bit more higher grade…it might be because it was more interesting…if I don't understand*

something she tells me it again but not in a way that when someone hasn't listened…doesn't shout at me…I feel like I'm able to work a bit better

- *They [teachers] have thought about the [seating] position where they put me…I'm doing the work a lot quicker than I was because I'm not being talked at all the time…they always make sure I've got it now [understood the work]…it's made a difference…I feel more comfortable*

Discussion

Increasingly UK legislation is requiring children's views to be sought and acted upon (Valuing people, DoH, 2001; Education Act, DfES, 2002; Children and Families Act Section 3, DfE, 2014) and the value of doing so has been recognised:

'We ought to listen more to the views of children when we are 'trying to get it right' for the 'flexible continuum of provision for children with SEN' espoused by the Government' (Bishton and Lindsay, 2011, p.182).

Whilst results from this small-group study cannot be generalised to the wider population of autistic pupils, early indications suggest that FAMe™ has the potential to effect significant positive impact on pupils' anxiety, both in-class and more generally. Qualitative data, collected during the post-FAMe™ pupil interviews, provide robust support for these quantitative findings e.g.:

'I've changed…I've changed the way I think about things…they [teachers] know [the facts]…it's made me less stressed' Girl, age 13.

It has been suggested that the act of asking a child their opinion is of less importance than

the results of having that opinion heard - that children need to see the change that comes about as a result (Bishton and Lindsay, 2011). As the function of the FAMe™ System is to effect change in autism pedagogy (result) through the communication of pupil voice (being heard), we hypothesise that this is likely to have contributed to the system's positive impact, e.g.:

'They've definitely acknowledged that [facts] …it's made class like a lot easier'
Boy, age 14.

'They just seem to get it now…I'm glad I took part'. Girl, age 12.

This hypothesis will be tested using the qualitative pupil-interview data which facilitates the exploration of potential mechanisms (e.g. Pawson, 2005; 2013; Pawson and Tilley, 2004; Wayne et al., 2008) involved in the changes reported here and those uncovered during analysis of the additional quantitative data sets (e.g. depression and academic self-esteem). Findings will add to the limited body of qualitative research which specifically captures the views of autistic young people (Bereford et al., 2004; Preece & Jordan 2010).

Whilst the full impact of FAMe™ has not yet been categorically analysed, early indications of local impact and the wider implications are clear. Collaboration between the principal FAMe™ researcher, Sheffield City Council Education Department and CAPITA - developers of SIMS software - has begun, to optimise the functioning of the FAMe™ System within teachers' registers and SIMS marksheets. The ultimate aim is that FAMe™ will be available to all teachers, providing the information about their autistic pupils they have been asking for (Miller, 2002; NAS, 2016a; Wilkinson and Twist, 2010). If the positive effects

reported here go on to be experienced by the majority of the autistic pupil/student population through replication of FAMe™ in other councils, there is potential for considerable impact at a National level. In addition, this impact is not expected to be exclusive to secondary mainstream schools. Primary education, further education, and higher education are all areas in which autistic learners may benefit from FAMe™ system implementation, and its use will support institutions to meet their lawful obligations under the Equality Act (2010) in relation to making reasonable adjustments for autistic pupils/students.

Conclusion

Early indications from this small-scale study have identified a significantly positive impact of FAMe™ system implementation for autistic pupils attending three mainstream secondary schools. Anxiety scores and symptoms were notably reduced post-FAMe™. As anxiety plays a considerable part in the lives of young autistic pupils and impacts negatively on educational progress (Ashburner, Ziviani and Roger, 2010; Keen et al., 2016), and links directly to suicidal ideation and attempts (Cassidy et al., 2014; Mayes et al., 2013), any system that reduces anxiety in autistic youth promises to be positively impactful and welcomed. While limitations have been identified and recognised within this paper, there is sufficient evidence to claim that FAMe™ is worthy of continued investigation and has the potential to be a valuable contributor to the reduction of anxiety in the autistic population.

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