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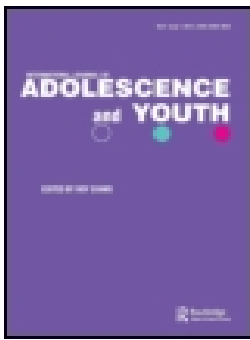
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# An approach to supporting young people with autism spectrum disorder and high anxiety to re-engage with formal education – the impact on young people and their families

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## ABSTRACT

School refusal is an important factor impacting upon poor outcomes for adolescents and youth. Individuals with autism spectrum disorder (ASD) experience characteristic difficulties regarding social interaction and communication, rigidity of thinking and sensory sensitivities. These difficulties, coupled with the heightened anxiety that many on the spectrum experience, place them at particular risk of school refusal. This study investigates activity undertaken in one UK local authority, where provision was developed to help such students to re-engage with formal education. Data were collected at three points through the first year of the provision's existence. Findings show all students were successfully supported to attend the provision and re-engage with formal education. Factors supportive of re-engagement are presented and considered in the light of an ecological model of support for school refusers and what is considered as 'good practice' in autism education. It is suggested that the factors identified are indicative of good practice across both areas of activity.

## ARTICLE HISTORY

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## KEYWORDS

Autism spectrum disorder;  
anxiety; school refusal

## Introduction

The range of factors leading to school absenteeism and refusal in young people can be multiple and complex, (Kearney, 2008) and there is insufficient evidence to consider any one intervention as the 'treatment of choice' to support re-engagement with education (Maynard et al. (2015). As disengagement from learning impacts achievement and may result in poor outcomes including unemployment and social exclusion, it is important to identify ways to re-engage those young people who have fallen out of formal education. Nuttall and Woods (2013) have developed an ecological model of successful reintegration, which identifies four main areas as 'systems' within the model: internal psychological factors within the young person, appropriate support for these factors, support for the family and the role of professionals and educational systems. One group of young people particularly at risk of disengaging from formal education are those with autism spectrum disorder (ASD). The complexity of ASD characteristics and the resultant issues with anxiety can result in significant school-related anxieties (Tyler, 2016) which then impact school attendance and engagement with school-based learning, as well as taking a toll on families.

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## Autism

The UK National Autistic Society (2016) indicates that 1 in 100 people are affected by autism spectrum disorder (ASD), defining the condition as *'a lifelong developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them.'* ASD is characterised by difficulties and differences in social interaction, communication, repetitive and restricted behaviours, activities and interests (American Psychiatric Association, 2013). Many individuals with ASD also experience sensory processing differences including sensory hyper-sensitivity, hypo-sensitivity and problems with sensory integration (Bogdashina, 2006; Leekam, Nieto, Libby, Wing, & Gould, 2007). Whilst the defining characteristics of ASD are well-established, it is important to note that each individual is unique in how ASD affects him or her. Moreover, whilst there are identified core areas of difficulty which result in individual needs, the strengths and interests of each individual are just as important to identify, as these frequently are the starting point for developing individualised interventions (Wittemeyer, English, Jones, Lyn-Cook, & Milton, 2012; English, Daly, & O'Brien, 2015).

## ASD and anxiety

ASD frequently co-occurs with other disorders and conditions, including mental health issues. Of particular relevance to this research is recognition that anxiety disorders are common amongst individuals with ASD, with approximately 40% having symptoms of at least one anxiety disorder, compared with 15% of the general population (Galanopoulos, Robertson, Spain, & Murphy, 2014). In a review of 40 studies, White, Oswald, Ollendick, and Scahill (2009) report that between 11 and 84% of children with ASD also exhibit anxiety symptoms and that *'anxiety may worsen during adolescence'* (p. 216). High levels of anxiety symptoms are identified in relation to: social anxiety; generalised anxiety, separation anxiety; specific phobias and obsessive-compulsive disorder (Gillott, Furniss, & Walyerm, 2001; Hallett et al., 2013).

Whilst there is increasing awareness of the risks of anxiety for individuals with ASD, overlaps between characteristics of ASD and anxiety symptoms is problematic (Kuusikko et al., 2008). White et al. (2009, p. 219) suggest that *'anxiety disorders, such as social phobia and obsessive-compulsive disorder, are rarely diagnosed in people with spectrum disorders due to a general clinical consensus that such symptoms are better explained by the ASD itself.'* More specifically, Bellini (2004, p. 83) argues that the relationship between social skills and social anxiety is *'reciprocal in nature'*. The complexity of the relationship between characteristics of ASD and levels of anxiety has implications in practice; for example, professionals report difficulties in identifying the boundaries and overlaps between a condition such as ASD and mental health problems such as anxiety and depression (Rose, Howley, Fergusson, & Jament, 2007). Thus, the complex nature of ASD and anxiety may be misunderstood and left unaddressed thereby increasing further risks for individuals, which have implications for school attendance and engagement in formal education.

## Implications: school attendance and engagement in formal education

Tyler (2016) suggests that *'given the nature of the condition, young people with ASD have much to be anxious about in a school setting'*. The consequences of co-morbid ASD and severe anxiety are not clearly defined, yet they are likely to have direct implications for individuals and their families. Of particular relevance to this study are the risks of non-attendance at school and subsequent disengagement from formal learning. Although the extent of non-attendance amongst this group of students has not been identified, disability is identified as a risk factor for absenteeism (Kearney, 2008) and Munkhaugen, Gjevik, Pripp, Sponheim, and Diseth (2017) identify that school refusal behaviour is significantly higher in children and adolescents with ASD than in typically-developing students. Archer, Filmer-Sankey, and Fletcher-Campbell (2003, p. v) investigated causes of school phobia and school refusal, defining school phobia as *'acute anxiety about attending school, students who cannot face school'*. Whilst their

research does not explore ASD in particular, results identified '*the main causes of the problem at school appeared to be social anxiety*' (p. vi). A variety of school factors are also identified as contributory factors including: school environment and structure, complexity of secondary schools, relationships with teachers and peers, social isolation, transition, fear of subjects and academic pressures, inappropriate provision unsuited to students' needs (Archer et al., 2003; Pellegrini, 2007). The cycle of non-attendance for extended periods has been found to lead to subsequent problems in school, such as poor academic outcomes and poor achievement in adult life (Pellegrini, 2007). Pellegrini (2007) go on to suggest that extended periods of non-attendance are caused both by 'within-child' factors, such as individual cognition and affect, and environmental factors, such as social contexts and school demands. Nuttall and Woods (2013) develop this ecological concept further, and suggest an ecological model for understanding non-attendance and successful reintegration.

Given the nature of ASD and social anxiety, it is perhaps not surprising that some individuals are absent from school for extended periods and thus become disengaged from formal education. In addition, the environmental factors, particularly in relation to school settings, are essential to consider. Batten, Corbett, Rosenblatt, Withers, and Yuille (2006) argue that the spectrum of needs requires a '*flexible continuum of provision*' and the '*right school for each child*'. Given that inappropriate provision, which is not aligned to needs, is a potential factor in contributing to non-attendance (Archer et al., 2003) this suggests that some individuals with ASD may need an alternative approach to enable them to attend and engage (Appleby Payne, 2010). Archer et al. (2003) suggest there is a need for '*gradual reintegration*' and the use of strategies based on '*analysis of individual need*' (p. 27). In the case of those with ASD, this implies that any approach to enable individuals to re-engage with formal education will require knowledge and understanding of the nature of the individual's autism, the impact on anxiety and provision which is more closely aligned with their particular needs.

## The research study

### The Centre

The impetus for this study originated in one local authority in which a number of students with ASD and severe anxiety were identified due to prolonged non-attendance in schools and lack of engagement with formal education. New provision was identified (referred to pseudonymously throughout as 'the Centre') in order to:

... set up something to specifically meet the needs of children who have got autism and anxiety. They're often called the bedroom children or the bedroom students. And we've had that with children with mental health difficulties before... So the idea was creating a safe, autism-friendly environment where young people could access education appropriate to meet their needs. Not only their educational needs but also their social and emotional needs...  
(Professional – the Centre)

The Centre was located in a Victorian primary school building near a town centre, and was managed within a service for students who cannot attend mainstream school due to a diagnosed complex medical and/or mental health condition. One teacher worked in the class on a full-time basis, supported by a senior colleague and by specialist subject teachers as appropriate.

Seven students with ASD and high anxiety (six males, one female, aged 14–16 years) attended the Centre during the academic year. All had previously been absent from school for between 8 months and 2 years, and had previous negative experiences of school which led to them disengaging from education. Factors identified by families and professionals as contributing to non-attendance/engagement with schools included late diagnosis of ASD, resulting in needs not identified and therefore not addressed; lack of understanding in schools; poor transitions from primary to secondary settings; social isolation and bullying; environmental factors such as size of secondary school, number of students and sensory issues such as noise; lack of appropriate support; and the complexity of family contexts. Families reported battles in trying to secure a diagnosis and to identify the nature of individual needs and also the fight to find appropriate provision and interventions. This was often a lengthy process,

beginning in primary school, and requiring families to work with a variety of professionals from different disciplines in their efforts to find help for their child. During this period, family members explain that levels of anxiety increased which resulted in high levels of anxiety and distress for the whole family. As the process evolved, individual students became fearful of leaving the house and eventually spending most of their time in their bedrooms.

This study was designed to address the following research questions. What was the impact of 'the Centre' on helping young people with ASD and high anxiety re-engage with formal education within the first year of its existence; to what extent has the project had an impact on these young people's emotional wellbeing; and what impact indicators and practice methods can be identified to inform and support future practice?

## **Methods**

An evaluative case study methodology (Palaiologou, Needham, & Male, 2016) was adopted to undertake this study. A mixed methods snapshot evaluation approach was used to enable triangulation of data (Torres, Preskill, & Piontek, 2005). Initial data were collected in September 2015, with further data collected at 2 agreed data points (14–18 December 2015, 25–29 April 2016). Methods used were as follows.

### ***Semi-structured interviews and focus group***

An initial focus group meeting was held with Centre staff in September 2015, before the start of the school term. A total of 21 individual interviews were undertaken in December 2015 and April 2016: seven interviews with staff from the Centre, nine with family members, and seven with related professionals (staff from the local authority's ASD outreach team, or link staff from the schools at which students were on roll).

### ***Questionnaires***

Semi-structured questionnaires were given to students in December 2015 and April 2016. Five students were attending the Centre in December 2015; however, three were still in the introductory process, so only two questionnaires were distributed at this point. Two further students began the introductory process in March 2016. Again, it was felt inappropriate to survey these students in May 2016; therefore, five questionnaires were distributed. Response rate was 100%; all respondents were male.

### ***Document analysis***

A range of documentary evidence was made available to us. This included attendance data, Individual Learning Plans (ILPs) and the General Well-Being Scale (Heubeck & Neill, 2000; Veit & Ware, 1983) used at the Centre.

## **Ethics**

Ethical approval for the research was granted by the university's Research Ethics Committee, and the research was carried out in accordance with the British Educational Research Association's Ethical Guidelines for Education Research (British Educational Research Association, 2011). Informed consent was obtained from all adults and students who participated in the study; parents of all students at the Centre also gave permission for their children's participation. Participants were aware that they could withdraw from the process at any time. All participants have been anonymised in this report, and direct quotes have been selected to ensure that sources are not identifiable.

## Analysis

Attendance data, student questionnaires and other quantitative data were analysed using descriptive statistical analysis. Transcripts of the interviews and focus group were analysed using QSR NVivo 10 software. Thematic qualitative analysis was undertaken to identify key themes identified by respondents.

## Findings and discussion

In this section, we present findings with regard to student attendance and engagement then report on the impact of the Centre on families. Factors contributing to positive outcomes are identified and discussed in relation to an ecological model of reintegration (Nuttall & Woods, 2013) and good practice in autism education (Charman et al., 2011).

### Impact of the Centre regarding students

#### Attendance and engagement

A major concern regarding these students was their prolonged lack of attendance in school or any other educational setting, and their subsequent lack of engagement with formal education. Concerning attendance and engagement, data scrutinised comprised attendance figures; ILP records, interview transcripts (professionals and family members) and student questionnaires.

Attendance, transition and curriculum targets were set and achievement recorded for five students from September 2015 to April 2016. Exemplar outcomes and targets for three students are shown in Table 1. Achievement against individual targets for all five students is summarised in Table 2.

Attendance targets were fully or partially met for all five students: marked progress given their prolonged non-attendance in schools. Whilst attendance for one student was identified throughout his ILP as *sporadic*, this was impacted by family crisis. Improved attendance was also identified by parents.

He just literally locked himself in his bedroom all the time, and he didn't come out...and you know, I know it's only a few hours a week he's coming [to the Centre], but at least he's coming out.

Transition targets set by staff relate closely to attendance. Progress in this area was also positive, with three students meeting their transition targets in full, working towards going on to further education college placements. Whilst two students did not meet all targets, nevertheless they made significant progress compared with their previous experiences.

Individual engagement was evident in relation to curriculum targets. Students clearly re-engaged with school-based learning at the Centre, with four students meeting targets and one demonstrating progress towards engaging with the curriculum. ILPs indicated that students engaged with core curriculum subjects, examinations and subjects of particular interest to individuals, with three students taking GCSE exams in summer 2016. In addition, students were engaged in vocational and life-skills curriculum activities (e.g. carpentry, animal welfare) according to their interests.

Overall the Centre was successful in enabling students to attend, to make transitions and to engage. Attendance and engagement progress was attributed by professionals and family members to a number of factors including personalised, student-led timetabling, the autism-friendly environment, effective management of demands, quality of relationships, small group size and staff attributes.

#### Wellbeing

The staff at the Centre placed importance on the individual student's wellbeing, viewing this as essential for re-engagement with formal education. Staff used the General Well-Being Scale (Heubeck & Neill, 2000; Veit & Ware, 1983) which was completed by five students who all indicated increased psychological wellbeing and decreased psychological stress (see Table 3). Positive progress towards attendance, transition and engagement targets corresponded with progress in relation to wellbeing for all students, all of whom reported increased wellbeing and reduced psychological stress.

The following comment is illustrative of the positive impact for students:



**Table 1.** Outcomes and targets students A, B and C.

Student	Intended outcomes	Sample targets
Student A (age 16 years)	Re-engage with teaching at the Centre to prepare for exams Prepare for transition - integration for next stage in education	Attendance: attend all planned sessions at the Centre and a vocational setting Transition: attend vocational setting in readiness for college Curriculum: exam preparation Personal & social: <ul style="list-style-type: none"> <li>• be ready on time</li> <li>• take structured social breaks to meet other young people and access places around the building</li> <li>• agree choice for credits to translate into curriculum experiences</li> </ul>
Student B (age 16 years)	Engage with teaching at the Centre Prepare for transition to next stage of education	Attendance: attend 4 – 5.5 h daily Transition: <ul style="list-style-type: none"> <li>• become accustomed to attending the Centre daily</li> <li>• attend college interview</li> </ul> Curriculum <ul style="list-style-type: none"> <li>• exam preparation</li> <li>• complete all tasks set</li> </ul> Personal & social <ul style="list-style-type: none"> <li>• engage with other students in Centre classroom</li> <li>• integrate fully into lessons with other students (different classroom)</li> <li>• take one-page profile to college interview</li> </ul>
Student C (Age 14 years)	Engage with teaching at the Centre	Attendance: initially to attend the Centre 1 h per week, increase when appropriate Transition <ul style="list-style-type: none"> <li>• transfer all home teaching sessions to the Centre</li> <li>• be willing to meet other students at the Centre</li> <li>• to engage with other students in the classroom</li> </ul> Curriculum <ul style="list-style-type: none"> <li>• engage in lessons starting 1 h per week &amp; increasing</li> <li>• complete tasks set in subject lessons</li> <li>• complete some tasks independently</li> </ul> Personal & social <ul style="list-style-type: none"> <li>• be in the Centre classroom alongside other students and communicate with them if appropriate</li> <li>• earn credits to use to enrich curriculum opportunities</li> <li>• decide how to 'spend' credits</li> </ul>
	Participate in socialising with students	



**Table 2.** Student achievement against individual targets.

	Student A (%)	Student B (%)	Student C (%)	Student D (%)	Student E (%)
Attendance targets fully/partially met	100	100	100	100	100
Transition targets fully/partially met	60	100	100	100	66
Curriculum targets fully/partially met	77	100	100	100	100

**Table 3.** Students' general wellbeing (General Well-Being Scale: Heubeck & Neill, 2000; Veit & Ware, 1983).

	Student A (%)	Student B (%)	Student C (%)	Student D (%)	Student E (%)
Increased psychological well-being	+30	+70	+70	+100	+40
Decreased psychological stress	-80	-60	-90	-20	-50

... one in particular has just, you know, he's so settled, I walk in and he asks if I want tea and he helps make soup for their lunches and, you know, he's really, really settled here. And another young person just has, from what you read about him on paper he's a completely different young person now... (Professional – the Centre)

The students themselves also wrote positively of their experiences at the Centre:

It's all good, I love it at the Centre.

Honestly, I think the Centre has given me so many opportunities that I am so grateful for.

### **Impact on families**

It is well established that the presence of ASD in the family can lead to elevated parental stress (Hayes & Watson, 2013), and that it can have a profound impact on family functioning, wellbeing and quality of life (Mouzourou, Santos, & Gaffney, 2011). This can be heightened when the child is out of school, or where school-family relations are strained. By contrast, effective support can moderate stress and lead to improvements both in school and at home (Dunn, Burbine, Boers, & Tantleff-Dunn, 2001; Tehee, Honan, & Hevey, 2009). The family members to whom we spoke identified a number of positive impacts upon the family that had been brought about by their involvement in the Centre project: these included access to support and information, access to training, meeting other families and the opportunities for mutual support that this created. Overall, families reported a reduction in their levels of anxiety and an improvement in their situation.

Communication between staff at the Centre and families was regular and frequent, sometimes by telephone but mostly in person. This good communication led to parents feeling well supported. Parents shared information about their situations with staff and this led to action being taken to address their needs, e.g. group training in anxiety management being provided by the external professionals at the Centre site. Parents were also provided with information about sources of external support such as befriending schemes. Parents of children with ASD can often find themselves extremely socially isolated (Woodgate, Ateah, & Secco, 2008) and meeting other families who were in similar situations to their own was identified by parents as extremely important and supportive.

To meet other parents that are going through exactly the same thing... Because unless they've been through it then they have no idea because it's just horrible to see your kids go through what they are going through.

Because they seem to understand the different little things going on with (our children), that other people just don't seem to get... And our anxiety, I mean, the anxiety is just unbelievable.

As their children re-engaged with formal education and life became more structured, parents reported improvements in their child outside the classroom.

But he's so different at home now. He'll come and sit downstairs. Before he just always used to sit in the bedroom, he wouldn't come down, he wouldn't interact with any family, which he's started doing that now.

He's gained his confidence to the point where he actually managed to walk from my mum's house round to his friend's house on his own which he could never... he couldn't even leave the house before.

The Centre also gave parents time to do things without their child with ASD being there – in some cases for the first time in years – and allowed them to focus on their other children, other issues – or simply to *'get an hour to go and do what I need to do! To do stuff he won't usually do, so that's quite nice'*. All families felt that their child attending the Centre had a positive impact on their family life.

### **Factors contributing to positive outcomes**

The data identifies that the project had a positive impact both with regard to helping young people with ASD and high anxiety to attend school and re-engage with formal education, and upon their overall wellbeing. Analysis identified six main themes within the data. These were:

- the development of an appropriate learning environment
- a focus on the individual
- an eclectic approach
- consistency
- effective communication
- effective collaboration.

### **Development of appropriate learning environment**

Consideration of the learning environment was identified from the outset as important. The small size of the building and small group sizes, compared with a secondary school or college environment were considered important by professionals and family respondents alike.

I think it's about the young people beginning to trust education again because for some of them it's been a very difficult experience. And I think the whole set up of the room is very - I'd say very 'nurturing'. I don't mean nurturing in a cuddly way but I mean quite nurturing in that it's small, it's contained, the colouring's low level, it's work based, I hope what it lets them do is achieve rather than think they're failing all the time. (Professional – autism outreach service)

It's quiet. There's hardly - there's not many people in there as well, he can't cope with too many people. Once he gets to know them and if they're not too loud it's okay, he can deal with that. (Family member)

The classroom organisation and layout were informed by the TEACCH 'structured teaching' approach and in particular the need to address physical structure through clear purposes of space and defined boundaries (Mesibov, Shea, & Schopler, 2005; Mesibov & Howley, 2016). Clearly defined areas were created in the classroom, including individual work stations, group working and socialising spaces, a small kitchen area and a quiet place for students to retreat to when required. This provided students with clear structure, but was utilised in a flexible way according to individual needs:

I think the way the room is laid out, the way it's explained, you know there's work stations so they can go and sit and work on their own if they need to, you know, I think that's been helpful. (Professional – Autism Outreach)

In response to the student questionnaire statement 'the organisation of the Centre classroom helps me to concentrate and to learn', three of four students indicated this was the case *'always'* and one student *'sometimes'*, with two students referring in particular to feeling safe. Some aspects of the classroom environment had been utilised by students differently to initial expectations. Staff adapted accordingly, demonstrating flexible ways of working.

We had to think about the dining table, this wooden circular table. Everyone walks in and goes straight to that and sits down. We thought that would be the dining area, the social - but no, everyone walks straight to it and sits down... I think it's because they like the look of it - a kettle and cups is quite friendly isn't it? It's not near the door, it's quite into the room, away from where anybody's listening to them from in the corridor; it's quite safe. And I think just because it's nice and light and welcoming... they just naturally sit there. (Professional – the Centre)

### ***Focus on the individual***

An individualised approach, which includes working with interests, is widely regarded as good practice in ASD (e.g. Charman et al., 2011; Mesibov & Howley, 2016). Staff at the Centre implemented individualised approaches which incorporated student interests.

We have the freedom and the capacity to understand each student individually and within the limits of what we've got over there we offer them what we can. But we tell them what we can give, we tell them what we can offer when we understand what they want and need. And that's a little bit of dancing about at first until we both understand. And we don't move forward, we don't push until we understand what that student wants and needs and it's on their terms but it's also on our terms.

One-page profiles (Sanderson, 2014) were introduced to identify the needs, strengths and interests of each student, and the support strategies which they find most helpful. Individualised targets were set in four areas – curriculum, transition, personal/social and attendance – and were clearly defined in ILPs. Curriculum targets were set according to need, such as examination subject targets for some individuals, engaging in lessons for other individuals. Students could accumulate 'credits' which they could exchange for curriculum activities linked to specific interests. Transition and social/personal targets were similarly individualised, ranging from attending college interviews to being able to work with other students at the Centre. Attendance targets took account of specific individual difficulties, such as levels of anxiety and family circumstances. Staff used a validated general wellbeing scale (Heubeck & Neill, 2000; Veit & Ware, 1983) to assess individual levels and monitor progress in these areas.

Integral to this individualised approach were relationship-building strategies which staff also adopted based on individual needs. A calm and patient approach, with lower demands, was considered important for building relationships by staff and family members:

Well I think it's their patience, it was their unending patience, and power of talking to him, to give him confidence to make that decision, not to be worried about it, that he was with people he could trust and he didn't have to worry, so off he went, and he had a great day. (Family member)

Staff values and attitudes towards each student underpinned the Centre approach. Staff built positive relationships with students through one-to-one conversations, involving students in decisions and making choices, and the use of negotiation and explanation. Involving students was achieved by giving them time and space to think about what they wanted and providing a level of choice and agency regarding curriculum subjects.

I think it was one day last week he wouldn't come in, so I just went and sat in the car with him... and explained to him that I'm not going to make you come in if you don't want to. I just need to know whether you are going to come next lesson or not on Thursday, and if you are I need to know what we're going to do. We're doing all about the periodic table, so I said, 'Let's choose which elements'. I took him the paperwork. I said, 'you chose which elements we're going to study and then I'll know to have the work ready if you're going to come in'. So, we chatted a little bit and then I said, 'Right, I'd better go then, so are you coming in in Thursday?' He said, 'Oh yes, oh yes, I'll be coming in'. So, you have to find out how each one works and that's what I love about it. I've got the freedom to understand each one and how to work with them. (Professional –the Centre)

### ***Eclectic approach***

Given the unique nature of needs in each individual with ASD, no single intervention is sufficient to meet all needs (Jones et al., 2008) and ASD good practice involves a 'toolbox' of strategies in order to meet individual needs (Charman et al., 2011). Staff working at the Centre used a variety of approaches when working with individual students which are recognised as good practice in the education of students with ASD. Staff provided students with clear expectations, rules and boundaries:

We've said to them, 'If you come here you do as we ask; there are rules, we've all got to get on, you have to work with the rules, we don't break rules for anyone unless there's an exceptional reason. We talk to them about the expectations of behaviour. Well tell them that whatever we do we will not restrain, we never touch them, it's not our ethos. They know that if they choose to leave the building we will not give chase, that we will phone parents but we will not go after them. They all know that... so we're very clear.... (Professional – the Centre)

Flexibility was central to the team's approach, both with regard to the students' experience –

We don't try to squeeze them into a set curriculum because that's why they've not survived at school. (Professional – the Centre)

– and with regard to the team's working practice.

We try to be creative in our thinking, we try our best to be able to afford different things for young people, to give them new experiences, so there is nothing that would faze us and we would bend over backwards to try and make that an integrated part of that programme. (Professional – the Centre).

### **Consistency**

Consistency of staffing helped students and families feel secure and contributed to the development of relationships. Consistency of approach helped provide structure and predictability.

And anybody at work...I said, 'When you come into the Centre you'll have to do things how we do it or you can't come. We can't have two different ways. We all use the same vocabulary, 'I need you to do this, you need to do that', you don't say 'Will you?' You've got to use that language or you can't join us. (Professional – the Centre)

The Centre's clarity of purpose and focus was particularly important here. Initial confusion regarding eligibility criteria and referral routes was ironed out in the first few months. This enabled student numbers to be maintained at a realistic level, and introduction processes to be handled at the individual student's pace. Staff within the Centre were also clear about their individual roles and parameters.

And that's the other thing, isn't it? Do what you're good at, don't interfere in what you're not, you'll do more harm than good. That's why we never do counselling, we never give medical advice. We're teachers, do what you're good at. (Professional – the Centre)

### **Effective communication**

Effective communication and positive working relations were established with key professionals, such as the schools where the Centre's students were 'on roll' and with local autism-specific practitioners such as the autism outreach team.

She's just – (the Autism Outreach worker) is just brilliant support, someone who I can talk to and she - how can I put it? She wants it to work, you know, she thinks this is a great idea so she does want it to work...so I think she's giving as much time to it as she possibly can. (Professional – the Centre).

Whitaker (2007) writes of the importance of understanding parental perspectives, developing effective communication and working in partnership with families. All of these issues were addressed positively at the centre. Staff spoke of their commitment to open, honest communication with families.

We don't hide anything from them...And my thing to them is, 'Okay, if you come here we will always tell you the truth. You might not like it and you might find it hard and you might go home distressed and you might want to scream at us. That's your choice, but we will always tell you the truth. (Professional – the Centre)

Parents acknowledged that this approach was helpful and that communication was effective. They spoke positively about the staff team at the Centre, and the staff's skills. They also spoke positively of the environment at the Centre, the structure provided for their child, the opportunities for their child to engage in social interaction, their child's attendance and engagement with formal education, and the way that their child's interests were addressed.

### **Effective collaboration**

Working together effectively with others is vital in the field of ASD. Charman et al. (2011), reporting on their research into indicators of good practice in autism education, identify that there was

broad recognition that meeting the many core and associated cognitive and behavioural needs of children and young people with autism required external expertise. Joint working between school staff and other professionals on learning and behaviour was widespread (p26).

The Centre's collaborative approach and effective communication were identified by team members, external professionals and parents alike, and contributed to the development of effective partnership working, with shared goals and a shared focus.

**Table 4.** Comparison of Nuttall and Woods (2013) ecological model, Charman et al.'s (2011) elements of good practice in autism education and the Centre's approach.

Ecological model (Nuttall & Woods, 2013)	Good practice in autism education (Charman et al., 2011)	Centre's approach: factors contributing to positive outcomes
Internal psychological factors in individual young people:	Ambitions and aspiration for individuals	Focus on the individual: strengths, interests, needs, levels of anxiety, wellbeing
• Aspiration & motivation	Appropriate monitoring of progress	Flexibility according to individual needs
• Confidence and self-esteem		Individualised relationship-based approaches
• Feelings of safety, security & sense of belonging		
Appropriate support for those factors	Tool-box of strategies Adapting the curriculum	Appropriate learning environment
	Effective communication	Eclectic approach
Support for the family	Positive relationships with families	Consistency of approach
	Staff knowledge and training	Effective communication
Role of professionals	Involving other professionals and services	Focus on individual family circumstances and experiences
		Effective communication and partnership with families
		Consistency of staffing
		Values and attitudes
		Flexibility in working practice
		Positive relationships
		Effective collaboration with other professionals and educational settings

That's working really well, the fact that we're actually, you know, thinking the same thing. We're meeting and we have discussions of what we want to do and where we want to go, so that works really well. (External professional)

Relationships with students' families, and an understanding of their needs and perspectives, has also long been identified as crucial to successful provision in ASD (Schopler, Mesibov, Shigley, & Bashford, 1984; Whitaker & Preece, 2013). The Centre achieved positive outcomes within these areas.

### ***An ecological model embedded with autism good practice***

The key factors which emerged from our analysis can be interpreted and explained in relation to an ecological model such as that proposed by Nuttall and Woods (2013) and to the elements of 'good practice in autism education' identified by Charman et al. (2011). In the Centre's approach the factors which contributed to positive outcomes for individual students with ASD and their families correspond with the ecological model's four systems; moreover, the strategies implemented at this Centre parallel autism good practice (see Table 4).

This suggests that an ecological approach is effective in identifying the factors which contribute to disengagement in individuals with ASD. Such a model needs also to incorporate the particular complexities of ASD and the uniqueness of each individual. The Centre's approach is illustrative of the need for a holistic approach and reflects an understanding of the unique needs of the young person, the unique needs of their family and knowledgeable staff with a willingness to collaborate with all who need to be involved for the young person to attend and participate in meaningful learning within the school environment.

### **Conclusions**

The work of the Centre provides insights into potential advances in meeting the needs of young people with ASD who have disengaged from formal education. The range of factors leading to disengagement from formal education and school-based learning in individual young people with ASD are not dissimilar to those who do not, in that those factors are likely to be multiple and complex. Essentially the key characteristics of ASD, together with high levels of anxiety, are key contributors to subsequent disengagement. Both this disengagement, and approaches that can support individuals to re-engage, can be interpreted and understood through an ecological model which incorporates the uniqueness of the individual, together with support for families and collaboration with other professionals and educational settings.

We suggest that the work undertaken at the Centre, and the factors contributing to positive outcomes, are indicative of the integration of both good practice in autism education and good practice with regard to supporting school refusers to re-engage with education. The successful outcomes identified within the Centre indicate that a clear and constructive focus on these issues has been effective in enabling students with ASD and high anxiety to re-engage with formal education. It is acknowledged that this study has focused only on one setting and one cohort of students, and that further research is needed within this field to identify whether the factors identified at the Centre are identified as being of importance with regard to other similar learners.

### **Disclosure statement**

No potential conflict of interest was reported by the authors.

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## References

- American Psychiatric Association. (2013). *The diagnostic and statistical manual of mental disorders* (Fifth Edition (DSM-5)). Arlington, TX: American Psychiatric Association.
- Appleby Payne, A. (2010). From exclusion to inclusion: Planning for successful reintegration into a special school. *Good Autism Practice*, 11, 16–22.
- Archer, T., Filmer-Sankey, C., & Fletcher-Campbell, F. (2003) 'School phobia and school refusal: Research into causes and remedies: LGA educational research programme (Research Report 46). Berkshire: National Foundation for Educational Research.
- Batten, A., Corbett, C., Rosenblatt, M., Withers, L., & Yuille, R. (2006). *Make school make sense, autism and education: The reality for families today*. London: National Autistic Society.
- Bellini, S. (2004). Social skill deficits and anxiety in high-functioning adolescents with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 19, 78–86.
- Bogdashina, O. (2006). Autistic accounts of sensory-perceptual experiences – Should we listen? *Good Autism Practice*, 7, 3–12.
- British Educational Research Association (2011). *Ethical guidelines for education research*. London: BERA.
- Charman, T., Pellicano, L., Peacey, L., Peacey, N., Forward, K., & Dockrell, J. (2011). *What is good practice in autism education?*. London: Autism Education Trust.
- Dunn, M. E., Burbine, T., Boers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37, 39–52.
- English, A., Daly, M., & O'Brien, A. (2015). *Schools autism competency framework*. London: Autism Education Trust.
- Galanopoulos, A., Robertson, D., Spain, D. & Murphy, C. (2014) 'Mental health and autism.' *National Autistic Society: Your autism magazine*, 8, Winter [Accessed 23 August 2016]. Retrieved from <http://www.autism.org.uk/about/health/mental-health.aspx>
- Gillott, A., Furniss, F. & Walyerm, A. (2001) 'Anxiety in high-functioning children with autism.' *Autism: International Journal of Research and Practice*, 5, 277–286.
- Hallett, V., Lecavalier, L., Sukhodolsky, D., Cipriano, N., Aman, M., McCracken, J., ... Scahill, L. (2013). Exploring the manifestations of anxiety in children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43, 2341–2352.
- Hayes, S., & Watson, S. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43, 629–642.
- Heubeck, B., & Neill, J. (2000). Confirmatory factor analysis and reliability of the mental health inventory for Australian adolescents. *Psychological Reports*, 87, 431–440.
- Jones, G., English, A., Guldberg, K., Jordan, R., Richardson, P., & Waltz, M. (2008). *Educational provision for children and young people on the autism spectrum living in England: A review of current practice, issues and challenges*. London: Autism Education Trust.
- Kearney, C. (2008). School absenteeism and school refusal behaviour in youth: A contemporary review. *Clinical Psychology Review*, 28, 451–471.
- Kuusikko, S., Pollock-Wurman, R., Jussila, K., Carter, A., Mattila, M., Ebeling, H., ... Moilanen, I. (2008). social anxiety in high-functioning children and adolescents with autism and asperger syndrome. *Journal of Autism and Developmental Disorders*, 38, 1697–1709.
- Leekam, S., Nieto, C., Libby, S., Wing, L., & Gould, J. (2007). Describing the sensory abnormalities of children and adults with autism. *Journal of Autism and Developmental Disorders*, 37, 894–910.
- Maynard, B. R., Brendel, K. E., Bulanda, J. J., Heyne, D., Thompson, A. M., & Pigott, T. D. (2015). Psychosocial interventions for school refusal with primary and secondary school students: A systematic review. *Campbell Systematic Reviews*, 11, 12.
- Mesibov, G.B. & Howley, M. (2016) *Accessing the curriculum for learners with autism spectrum disorders: Using the TEACCH programme to help inclusion* (2nd ed.) London: Routledge/Taylor Francis.
- Mesibov, G. B., Shea, V., & Schopler, E. (2005). *The TEACCH approach to autism spectrum disorders*. New York, NY: Springer.



- Mouzourou, C., Santos, R., & Gaffney, J. S. (2011). At home with disability: One family's three generations narrate autism. *International Journal of Qualitative Studies in Education*, 24, 693–715.
- Munkhaugen, E. K., Gjevik, E., Pripp, A. H., Sponheim, E., & Diseth, T. H. (2017). School refusal behaviour: Are children and adolescents with autism spectrum disorder at a higher risk? *Research in Autism Spectrum Disorders*, 41–42, 31–38.
- National Autistic Society. (2016) *What is autism?* [Accessed 2 August 2016]. Retrieved from <http://www.autism.org.uk/about/what-is.aspx>
- Nuttall, C., & Woods, K. (2013). Effective intervention for school refusal behaviour. *Educational Psychology in Practice*, 29, 347–366.
- Palaiologou, I., Needham, D., & Male, T. (2016). *Doing research in education: Theory and practice*. London: Sage.
- Pellegrini, D. (2007). School Non-attendance: Definitions, meanings, responses, interventions. *Educational Psychology in Practice*, 23, 63–77.
- Rose, R., Howley, M., Fergusson, A., & Jament, J. (2007). Mental health and special educational needs: Exploring a complex relationship. *British Journal of Special Education*, 36, 3–8.
- Sanderson, H. (2014). Using one-page profiles to personalise care. *Nursing Times*, 110(23), 19–20.
- Schopler, E., Mesibov, G. B., Shigley, R. H., & Bashford, A. (1984). Helping autistic children through their parents: The TEACCH model. In E. Schopler & G. B. Mesibov (Eds.), *The Effects of Autism on the Family*. New York, NY: Plenum.
- Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities*, 22, 34–42.
- Torres, R. T., Preskill, H., & Piontek, M. E. (2005). *Evaluation strategies for communicating and reporting: Enhancing learning in organisations* (2nd ed.). London: Sage.
- Tyler, S. (2016) 'Attending to school refusal.' *SEN magazine* [Accessed 3 August]. Retrieved from <https://senmagazine.co.uk/articles/articles/senarticles/school-refusal-how-can-we-help-those-with-asd-attend-school>
- Veit, C., & Ware, J. (1983). The structure of psychological distress and wellbeing in general populations. *Journal of Consulting and Clinical Psychology*, 51, 730–742.
- Whitaker, P. (2007). Provision for youngsters with autism spectrum disorders in mainstream schools: What parents say – And what parents want. *British Journal of Special Education*, 34, 170–178.
- Whitaker, P., & Preece, D. (2013). Understanding the perspectives of children and parents: A foundation for developing partnership. In M. Howley & D. Preece (Eds.), *Supporting pupils on the autism spectrum: Whole-school training materials and resources for SENCOs*. London: Optimus Press.
- White, S., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review*, 29, 216–229.
- Wittemeyer, K., English, A., Jones, G., Lyn-Cook, L., & Milton, D. (2012) *Schools Autism Competency Framework*. London: Autism Education Trust.
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). 'Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, 18, 1075–1083.