

# The bullying of autistic children: A review of anti-bullying interventions, and a feasibility study examining the relationship between bullying victimisation and psychosis-like experiences.

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#### Declaration

This thesis is submitted for the Doctorate in Clinical Psychology at the University of

Sheffield. It has not been submitted for any other degree or to any other academic

institution.

#### **Structure and Word Counts**

#### Literature Review

Without references and tables: 6,771

With references and tables: 11,497

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#### **Overall Abstract**

Bullying of autistic children by their peers is prevalent. This is a significant concern given research linking childhood bullying with adverse mental health outcomes, in both autistic and neurotypical groups. The first section of this thesis is a scoping review, which aimed to establish what interventions have been developed to reduce the bullying of autistic children. The second section reports an investigation of the feasibility of examining the relationship between bullying victimisation and psychosis-like experiences (PLEs) in autistic children.

Following a systematic literature search 10 studies were identified for inclusion in the scoping review. Broadly, interventions focussed either upon skills-development for autistic children, or the promotion of contact between autistic children and neurotypical peers. There was heterogeneity in the research designs used and outcome measures employed. Overall, the evidence base is in its infancy and there is a need to develop and evaluate multicomponent interventions involving autistic children, neurotypical peers, staff and schools.

A quantitative cross-sectional design was used to investigate the feasibility of testing the relationship between bullying victimisation and PLEs in autistic children, and to test the preliminary hypothesis of association between these variables. Parents completed a battery of online questionnaires about their children (N=53). Hierarchical multiple regression was used to test the relationship between the variables of interest, while controlling for: age, sex, family history of psychosis and internalising difficulties. It was found that there is a lack of suitable questionnaires for measuring PLEs in autistic children, and that recruiting a large sample via a clinical service may not be feasible. Preliminary hypothesis testing failed to establish a statistically significant relationship between bullying victimisation and PLEs in autistic children. However, this should not preclude future work in this area.

vi

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# List of Contents

Access to Thesis Form	ii
Declaration	iv
Structure and Word Counts	V
Overall Abstract	vi
Acknowledgements	vii
List of Contents	viii
Section 1: Literature Review	1
Abstract	2
Practitioner Points	3
Introduction	3
Method	8
Results	12
Discussion	31
Conclusion	41
References	42
Appendix	54
Section 2: Empirical Study	55
Abstract	56
Practitioner Points	57
Introduction	57
Method	65
Results	75
Discussion	
Conclusion	90
References	91

Appendices105
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# Section 1: Literature Review

# Interventions for reducing the bullying of autistic children: A scoping review of

quantitative and qualitative evidence.

#### Abstract

**Objectives:** The bullying of autistic children is a significant concern, particularly given evidence linking childhood bullying with adverse mental health outcomes. There is therefore a need for interventions which reduce the extent to which autistic children are bullied by their peers. A scoping review was conducted to examine the literature evaluating interventions developed to reduce the bullying of autistic children. The aims were to describe what interventions have been developed and characterise what evidence exists regarding their efficacy.

**Method:** A systematic literature search of four databases (Scopus, PsycINFO, Medline and Science Direct) took place in February 2020. The search strategy used variations on the following terms: 'autism', 'bully', and 'intervention', and there were no date restrictions. Established frameworks for completing scoping reviews informed methodological decision making.

**Results:** Included studies (N=10) evaluated various interventions. Generally, interventions had a skills-development focus, or promoted contact between autistic children and neurotypical peers. A range of research designs were used, including cross-sectional and (quasi-) experimental studies. There was heterogeneity in the outcome measures used, however, there was a broad split between studies which administered knowledge or skills tests, and those which used questionnaires about bullying experiences. Among the studies which used questionnaires, some used standardised forms and others used newly developed, non-validated questionnaires.

**Conclusions:** Research evaluating interventions aimed at reducing the bullying of autistic children is in its infancy. There is a need to build upon the current evidence base and evaluate multicomponent interventions, which involve autistic children, neurotypical peers, staff and school culture.

2

#### **Practitioner Points**

- There is a lack of research evaluating interventions for reducing the bullying of autistic children, therefore, at this stage, it is not possible to make detailed recommendations for clinical practice.
- Practitioners may consider implementing an evaluated intervention. However, it was beyond the scope of this review to appraise the quality of studies and make recommendations as to which intervention should be favoured.
- Practitioners may consider generating practice-based evidence where they implement and evaluate interventions, or regularly use questionnaires that have not previously been validated for use with autistic children.

#### Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition, often diagnosed with reference to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V, American Psychiatric Association (APA), 2013). ASD is characterised by enduring difficulties with social communication and interaction alongside restricted or repetitive behaviours, which have a clinically significant impact on psychosocial functioning (APA, 2013). Prevalence of ASD among children in the United Kingdom (UK) has been estimated to fall between 0.3-1.6% of the population (Baron-Cohen et al., 2009; Mackay et al., 2016; Scott et al., 2002; Taylor et al., 2013). There is considerable discussion around the most appropriate term to use when describing individuals with a diagnosis of ASD. A study conducted with the autism community in the UK found that a broad range of terms are used (Kenny et al., 2016). Parents of individuals with ASD most commonly endorsed 'autistic', 'on the autism Given these findings the term used henceforth when referring to individuals with an ASD diagnosis will be 'autistic'.

Bullying has been described as "aggressive goal-directed behaviour that harms another individual within the context of a power imbalance" (Volk et al., 2014, p.328). This theoretically derived definition deemphasised the importance of repeated victimisation, acknowledging that single incidents or low frequency behaviours can cause significant harm. Bullying of autistic children is a significant issue across educational settings (Humphrey & Symes, 2010; Schroeder et al., 2014; van Roekel et al., 2010). Maïano et al. (2016) conducted a meta-analysis of bullying victimisation among autistic youth, calculating pooled prevalence with reference to 15 studies, comprising a total sample of 5,552 participants. It was found that 44% of autistic participants had been bullied by others. Moreover, comparison of autistic youth with neurotypical peers revealed that, while both groups were equally likely to perpetrate bullying, autistic children were three times more likely to be bullied by others. This pattern of findings, indicating a disparity between autistic youth and their neurotypical peers, was replicated by Hwang et al. (2018).

Studies have identified a number of factors which may impact the bullying of autistic children. Cappadocia et al. (2012) found that rates of bullying were negatively correlated with age and number of friendships, but positively associated with challenges in communication and parental mental health difficulties. A study by Sterzing et al. (2012) identified additional factors associated with an increased risk of autistic children being bullied by peers. Where children had a diagnosis of Attention Deficit Hyperactivity Disorder; non-Hispanic ethnic identity, or; more time spent in mainstream educational provision, they were more likely to be bullied. Heightened difficulties with social skills (at a broad level) were also associated with an increased risk of being bullied, however, so was greater conversational ability. Hebron and Humphrey (2014) used reports from parents and teachers to identify factors associated with the bullying of autistic children attending school in the UK. Jointly identified predictors of bullying by peers included behavioural difficulties and, in contradiction to the findings of Cappadocia et al. (2012), increased age. Teacher-reports highlighted that mainstream educational placement and use of public transport were associated with an increased risk of being bullied, while having a greater number of positive relationships reduced the risk of autistic children being bullied. Parent-reports indicated that greater parental confidence and engagement were associated with lower levels of bullying victimisation among autistic children. Additionally, a number of systemic and individual factors have been hypothesised to impact bullying perpetration by neurotypical children (Thomas et al., 2018). For instance, it has been found that perpetration of bullying is associated with negative attitudes towards peers who are bullied, and perceived expectations of friends (Rigby, 2005).

Bullying in childhood and adolescence has been extensively linked with mental health outcomes, both in neurotypical and autistic populations. Moore et al. (2017) reported the results of a meta-analysis of 165 studies conducted in the general population, concluding that there was substantial evidence for a causal relationship between being bullied in childhood and adverse mental health outcomes. There were particularly strong associations between bullying victimisation and internalising mental health difficulties (depression, anxiety and suicidality). In line with this, Cappadocia et al. (2012) found that the bullying of autistic children was associated with higher levels of internalising mental health difficulties, including anxiety and depression. The authors hypothesised that this relationship is bidirectional, i.e. that mental health difficulties may increase the risk of being bullied, in addition to being a potential consequence of victimisation. Similarly, Adams et al. (2014) found that self-reported experiences of being bullied were associated with internalising mental health difficulties (depression, anxiety and somatic symptoms) in male autistic adolescents.

The need for effective interventions to reduce the bullying of autistic children is clear, particularly given the rates of bullying victimisation in this group, and the impact that this can have upon mental health (Schroeder et al., 2014). Previous reviews have largely focussed upon interventions for neurotypical children. The present review will be the first to examine interventions which have been developed to reduce the bullying of autistic children.

A number of meta-analyses have been completed to evaluate the effectiveness of school-based anti-bullying interventions for neurotypical children. The findings of these studies have been mixed. An early meta-analysis of studies published between 1980 and 2004 evaluated interventions aimed at reducing bullying among children and adolescents in mainstream schools (Merrell et al., 2008). It was concluded that, while interventions increased participants' knowledge and improved attitudes, changes to behavioural outcomes were minimal. Ttofi and Farrington (2009) conducted a metaanalysis of studies published between 1983 and 2008. They concluded that there was a significant impact of school-based anti-bullying interventions on levels of bullying victimisation among participants. Particular elements of interventions were more strongly associated with reductions in bullying, e.g. school-wide parental training, and increased intensity and duration of anti-bullying programmes. Lee et al. (2015) concluded from their meta-analysis that school-based anti-bullying interventions have a small-moderate effect on victimisation. Significantly larger effect sizes were obtained in studies of interventions which featured emotional control training, peer counselling, or the establishment of a school-wide anti-bullying policy. A more recent meta-analysis concluded that anti-bullying programmes are effective in reducing bullying victimisation and perpetration, however, there were variations according to the specific

type of intervention evaluated, and the country in which studies were conducted (Gaffney et al., 2019).

The majority of reviews focus upon programmes developed for general school populations. However, one systematic review examined 'stigma-based' anti-bullying interventions, including two studies looking at interventions for autistic children (Earnshaw et al., 2018). Overall, it was concluded that there was significant heterogeneity in the interventions evaluated and methodologies used. The authors highlighted how studies rarely established the impact of interventions upon rates of bullying, rather outcome measurement typically focussed upon stigma-related factors such as prejudice and stereotypes, i.e. outcome measures were attitudinal rather than behavioural. Humphrey and Hebron (2015) conducted a narrative review of studies investigating the bullying of autistic children. They summarised prevalence statistics, risk factors for bullying victimisation and potential anti-bullying interventions. It was concluded that, in order to reduce the bullying of autistic children multi-component anti-bullying interventions should be developed, implemented and evaluated. The authors recommended that four key areas are addressed within any such intervention: (a) the skills and understanding of autistic children; (b) the attitudes and behaviours of their neurotypical peers; (c) the knowledge and skills of staff who work with the children (e.g. teachers) and; (d) development of a school culture which embraces diversity and models zero-tolerance of bullying.

The present scoping review will focus specifically upon evaluated interventions aimed at reducing the bullying of autistic children. The primary aim is to understand what interventions have been developed to reduce the bullying of autistic children, and to determine the extent to which any interventions address the four key areas identified by Humphrey and Hebron (2015). The secondary aim is to establish what evidence exists regarding the efficacy of any interventions, specifically to characterise the methodologies employed and the outcomes evaluated by relevant studies. Scoping review methodology was identified as the most appropriate, as it is well-placed to identify the types of evidence available in a specific area, and to examine how research is conducted (Munn et al., 2018).

#### Method

Methodological decisions were made with reference to available guidance on scoping reviews (Arksey & O'Malley, 2005; Peters et al., 2015) and a protocol was published on the Open Science Framework prior to commencing the review (Hastings, 2019). The five-stage framework for conducting scoping reviews proposed by Arksey and O'Malley (2005) was followed: (a) identifying the research question(s); (b) identifying relevant studies; (c) study selection; (d) charting the data, and; (e) collating, summarising and reporting the results.

#### **Research Questions**

The primary research question guiding the review was, 'What interventions have been developed to reduce the bullying of autistic children?'. As suggested by Arksey and O'Malley (2005) it was this research question that guided the methodological decisions made for the review, including the search strategy. The secondary research questions were 'What methodologies are used in studies of interventions aimed at reducing the bullying of autistic children?' and 'What outcomes are evaluated in studies of interventions aimed at reducing the bullying of autistic children?'.

#### **Identifying Studies**

Four academic databases were searched: Scopus, PsycINFO, Medline and Science Direct, and searches were also conducted on Google and Google Scholar. Efforts were made to identify grey literature, e.g. Scopus was used as this database holds records of conference proceedings, while the Ovid databases (PsycINFO and Medline) contain dissertation abstracts. The Google searches were also undertaken with the aim of identifying unpublished work. A broad selection of key words were used and there were no date restrictions, in order to increase the likelihood that all relevant studies would be found. The keywords were: *(autism OR autistic OR Asperger\* OR "autism spectrum\*" OR ASD OR ASC) AND (child\* OR adolescen\* OR student OR "school age") AND (bully\* OR "anti bullying" OR "peer victim\*") AND (intervention <i>OR program\* OR prevention OR skills OR therapy OR treatment OR training OR education OR mentor\* OR "peer mediated").* The search strategy was adapted according to the indexing of each database. Searches were conducted on February 2<sup>nd</sup> 2020. Additionally, the reference lists of selected studies were searched for further relevant publications.

#### **Study Selection**

The inclusion criteria for the scoping review were: (a) studies written in English; (b) studies evaluated interventions aimed at reducing the bullying of autistic children; (c) participants were children, and; (d) studies evaluated at least one outcome relating to bullying. Conceivably, interventions could be developed for autistic children or neurotypical peers, therefore it was not specified that participants of included studies were autistic. Studies solely examining outcomes relating to bullying *by* autistic children were excluded.

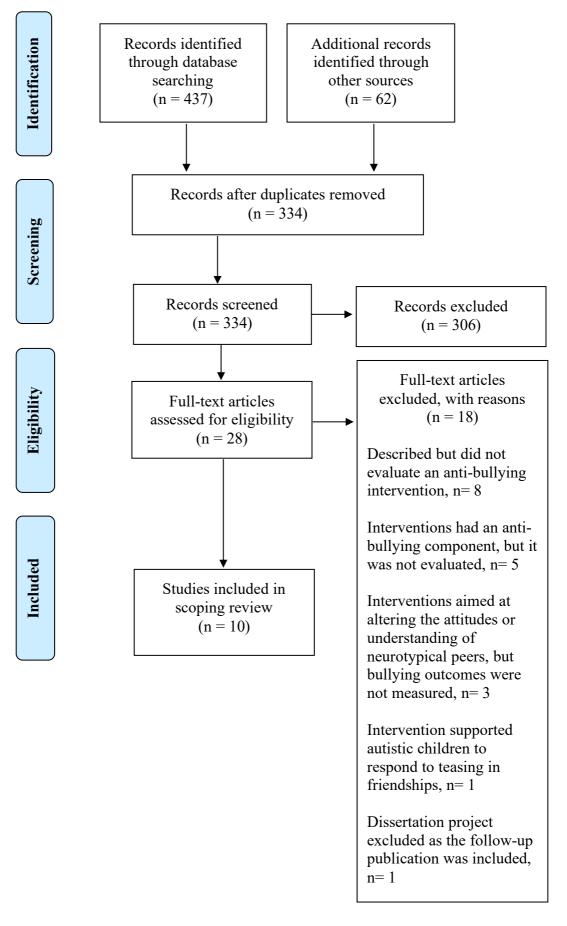
After searches had been conducted and duplicates removed, the titles and, where necessary, abstracts of the studies were screened for inclusion. Where a decision could not be made on the title and abstract alone, the article was read in full and compared against the inclusion and exclusion criteria. A total of 334 studies were screened, with

10 included in the scoping review. The process of study selection is depicted in Figure

1, an adapted PRISMA diagram (Moher et al., 2009).

#### Figure 1

#### PRISMA Diagram



#### **Charting Data**

In scoping reviews, data extraction is achieved by summarising relevant information in a charting table. The extraction fields described by Peters et al. (2015) were used to draft a charting table, which was published in the review protocol (Hastings, 2019). The charting table was updated based on information that became relevant during data extraction, and the headings used in other scoping reviews (Cheng et al., 2017; Di Rezze et al., 2016; Scanlan & Novak, 2015). The data extraction fields used within the charting table can be found in Appendix A.

#### **Reporting Results**

Arksey and O'Malley (2005) propose that scoping reviews should provide a state of the field overview of available evidence via a narrative account of studies. The purpose should not be to assess study quality or make conclusions about the generalisability of evidence. With these broad guidelines in mind, the methodology of Di Rezze et al. (2016) was replicated in reporting the results. Specifically, the studies were summarised in Table 1 (a condensed version of the charting table) and a narrative account of the literature was developed, which drew out relevant themes in order to answer the research questions posed by the review. This relied upon an iterative process of comparing the content of included studies with an existing conceptual framework. The framework used was the multicomponent approach described by Humphrey and Hebron (2015).

#### Results

Ten studies met the inclusion criteria and are summarised below. Table 1 provides an overview of the anti-bullying interventions evaluated by the included studies, methodological features and key findings.

# Table 1

# Studies Included in the Scoping Review

Study	Population who Received Intervention	Intervention	Methodology	Bullying Outcomes Evaluated	Key Findings Relating to Bullying of Autistic Children
Beaumont and Sofronoff (2008)	Children with an Asperger's diagnosis. Intervention group n=26 (23 male), 7-11 years (mean 9.6) Waiting List control group n= 23 (21 male), 8- 11 years (mean 9.8)	Junior Detective Training Program (Social Skills Training): Computer game; group skills sessions; parent training; teacher handouts. Setting: university. Eight sessions.	Randomized controlled trial (RCT). Six-week follow up.	Social cognition measure. Participants presented with a story, 'Dylan is Being Teased'(Attwood, 2004), and asked to generate ideas about how the character could cope with being bullied at school. Child response.	A mixed model MANOVA established that knowledge of anger management strategies in response to the 'Dylan is Being Teased' story was significantly better in the intervention group than the control group, following completion of the training programme. The authors highlighted "a strong trend for treatment gains to be maintained at 6-week follow-up" (p.749).
Bradley (2016)	Autistic children (ASD group) and neurotypical peers (NT group).	<b>Peer Mentoring</b> <b>Programme:</b> Peer mentor groups (4 students); fortnightly meetings; different	Quasi-experimental: pre/ post design. No follow-up.	Bullying questionnaire (as cited in Bradley, 2016); measured frequency of various types of bullying	A paired sample t-test showed a statistically significant post- intervention reduction in bullying frequency, as

ASD group n= 12 (8 male), 11-12 years (mean 11.7) topics discussed each session (bullying was one topic).

Setting: school.

NT peers n= 36 (12 male), age not reported

Fortnightly sessions over seven months.

experiences. Child report.

Semi-structured interviews with participants. reported by autistic children via the Bullying questionnaire.

At pre-intervention 10/12 autistic students had experienced at least one incident of bullying, while at postintervention 1/12 reported that they had been bullied.

During interviews autistic participants reflected that they felt more able to respond to bullying and more supported by others, and hypothesised that these factors had led to reductions in the level of bullying they experienced. Peers were identified as a source of Cook et al. (2019)

Neurotypical students and autistic peers.

NT group n=49 (20 male), 10-11 years (mean 10.4) ASD peers n=5 (5 male), all 10 years

**Musical Contact** Intervention: Mixed classes of NT students and autistic peers (contact group); social skills development: musical engagement (singing); encouraging communication between participants. No contact group received the same intervention, however, none of their autistic peers were in the classes.

Setting: school.

Eleven weekly sessions.

Quasi-experimental pilot study: contact/ no contact group comparison. Pre/ post comparison of data provided by the ASD group.

No follow-up.

Bullying Prevalence Questionnaire (Rigby & Slee, 1993); victim scale and bully scale. Child report.

NT group only: Response to vignette of a bullying scenario involving an autistic peer. Child response. Participants answered questions which contributed to scores for three scales: (a) judgements toward the autistic child in the vignette, (b) emotions in response to the autistic child in the vignette, and, (c) intended behaviours in response to the

support, where they had not been previously.

For neurotypical participants an independent samples ttest and Mann-Whitney U test revealed that there was not a statistically significant difference in tendency to be a bully (i.e. scores on the BPO bully scale), when comparing the contact and no-contact groups. A Mann-Whitney U test revealed that neurotypical participants in the contact group showed a significantly greater increase in prosocial emotions in response to the vignette than those in the nocontact group. Analysis of responses on the other

			bullying of the autistic child in the vignette.	scales relating to the vignette (judgements and intended behaviours) revealed no statistically significant between- group differences.
				For autistic children pre/ post comparisons indicated that there was a 19.7% decrease in tendency to be a victim (as measured using the BPQ victim scale). However, a Wilcoxon Signed-Rank analysis revealed that this was not a statistically significant change.
Neurotypical students. Sample characteristics not reported.	<b>Individualised Multi-</b> <b>Component Social</b> <b>Support Programme:</b> Training peer supporters (including some perpetrators of bullying)	Case study. No follow-up.	Qualitative feedback from David and his supporters.	It was verbally reported that there were significant reduction in bullying incidents following implementation of the

Etherington (2007)

	Intervention aimed to encourage change for an autistic child (David). N=1 (male), age at intervention not reported.	to understand autism, mentor David, and offer social support; wider- school education programme. Setting: school. Six-weekly training sessions to set-up the intervention; six-week education programme (only 5 of the planned sessions implemented).			programme, however, this was not measured objectively. Qualitative feedback from peer supporters was that they had a better understanding of David, and more compassion for him.
Liu et al. (2018)	Autistic children. Theory of Mind Performance Training (ToMPT) group n=26 (22 male), 10-18 years (mean 13.8)	Group interventions involving teaching and role play. ToMPT: developing emotional understanding and; belief attribution (bullying scenarios as examples).	RCT No follow-up.	Chinese version of the School Bullying Experience Questionnaire- C-SEBQ (Yen et al., 2012); measured severity of bullying victimisation and perpetration over the preceding month. Child and parent-reports.	Paired sample t-tests indicated that, following the ToMPT intervention, there was a statistically significant reduction in the severity of self- and parent-reported bullying victimisation, as measured by the C- SEBQ. Paired sample t- tests determined that,

	Social Skills Training group n=23 (21 male), 10-18 years (mean 13.6)	SST: practical skills; social courtesy; making friends (bullying scenarios as examples). Setting: not reported. Ten weekly sessions for both groups.			following the SST intervention, there was a statistically significant reduction in self-reported severity of bullying victimisation, but not parent-reported victimisation. A linear mixed effects model confirmed that the ToMPT intervention was significantly better than SST at reducing parent- reported bullying victimisation.
Milne et al. (2010)	Autistic children. Bullying skills intervention n=10 (sex not reported), 6-15 years (mean 9.9)	Virtual Agent Based Social Tutor: the bullying skills module asked participants to identify bullying situations and; ways of responding to these. Setting: not reported.	Quasi-experimental: pre/ post design. No follow-up.	Knowledge test: participants were asked four types of question to test knowledge of bullying skills. (a) 'strategy steps' tested how participants would behave in response to a bullying scenario, (b) 'is friendly' tested	A Wilcoxon Signed- Rank test established that there was a statistically significant improvement in scores on the knowledge test (average improvement 54%) following completion of the bullying skills module. Analysis of the

		Hour-long session split into three repeated rounds of the intervention. <i>Note.</i> Results relating to the managing anxiety module are not reported, as this was considered a separate intervention.		participants' ability to identify friendly interactions, (c) 'is bullying' tested participants' ability to identify bullying scenarios, (d) 'laughing test' asked participants to determine if scenarios constituted laughing <i>with</i> or <i>at</i> somebody.	separate question types in the knowledge test established that a statistically significant difference was found only in 'strategy' steps' questions. Improvement took place between pre-test and an interim test following round one of the intervention, however, there were no statistically significant improvements following two subsequent rounds.
Ranick et al. (2013)	Autistic children. N=3 (3 male), 6- 9 years (mean 7.3)	Multiple Exemplar Training: play-based intervention teaching participants to notice lies, particularly those told to exclude them or take their possessions.	Case series. Single case experimental design. One-month follow-up.	Accuracy at detecting deceptive statements, as observed by the researcher delivering the intervention; a proportion of sessions were also coded by an independent observer.	The percentage of deceptive statements accurately identified by all three participants improved following the intervention. Data was graphically represented; no inferential statistics

Hour-long session split

separate question types

		Setting: participants' homes. Twenty sessions.		Participants were judged to have detected deception if they responded that the therapist or peer confederate could not exclude them or take their possessions.	were used. Improvements generalised to novel deceptive statements and statements made by same age peer or sibling confederates. Improvements were maintained at one-month follow-up.
Rex et al. (2018)	Autistic children. N=6 (4 male), 8- 13 years (mean 10.0)	<ul> <li>Video-Modelling Intervention: videotaped scenarios; teaching assertive responses to exclusion, physical and verbal bullying.</li> <li>Setting: school.</li> <li>Intervention length variable for each participant (maximum 27 sessions).</li> </ul>	Case series. Single case experimental design. No follow-up.	Participants were asked how they would respond to bullying scenarios in the video models and an in-situ bullying simulation. Responses were coded on a four- point scale of 'appropriateness'. Responses were coded by the primary investigator and a proportion were also coded by a second rater.	There was an increase in the number of appropriate responses by participants in response to videos. All participants could demonstrate at least one assertive response to in- situ simulations of bullying, following the intervention. Data was graphically represented; no inferential statistics were used.

Segura (2012)	Autistic children. N=4 (4 male), 6- 10 years (mean 8.8)	Social Skills Programme: mixed classes (autistic children and NT peers) two- lessons on noticing, responding to and reporting bullying; video-modelling; role- play; between-session materials (social stories and practice monitoring cards). Setting: school. Three-times weekly sessions for 12 weeks, including baseline and follow-up.	Single case experimental design. Length of follow-up not reported.	<ul> <li>Bullying role-play scenarios, assessing behavioural responses of participants: staying calm, eye contact, voice, posture and response type (e.g. ignoring, telling somebody).</li> <li>Bully Victimisation Scale (BVS) (Reynolds, 2003); measures the severity of different types of bullying victimisation. Child report.</li> <li>Tough Kid Bully Blockers Survey (Bowen et al., 2008); measures "subjective experience of bullying" (p.56). Child report.</li> </ul>	Data for each participant was analysed separately using descriptive statistics and data overlap procedures. There were pre-post improvements in role- play performance, with the largest improvements noted in staying calm, and using an appropriate voice. Some of these improvements were maintained at follow-up. Averaged scores on the BVS reduced by one standard deviation. There was also a reduction in victimisation reported via the Tough Kid Bully Blockers Survey.
Sreckovic et al. (2017)	Autistic children.	Peer Network Intervention:	Case series. Single case experimental design.	BVS (Reynolds, 2003); measure of bullying	Descriptive report of BVS scores (raw scores

N=3 (3 male), all 15 years	participants placed in groups with NT peers; opportunities for	Bullying measures pre/ post intervention.	severity ('normal'; 'clinically significant'; 'moderately severe';	presented and no inferential statistics used). There was
	interaction. Setting: school.	No follow-up.	'severe'. Child report.	minimal change in BVS scores for two participants, however,
	Set-up: two meetings. Intervention: twice-			their pre-intervention scores were in the 'normal' range. The
	weekly meetings. Maintenance: once-			BVS scores of the third participant reduced
	weekly for three weeks.			significantly from 'severe' at baseline,
				finishing at 'normal' after the maintenance phase of the intervention.

*Abbreviations*: ASD= Autism Spectrum Disorder, BPS= Bullying Prevalence Questionnaire, BVS= Bully Victimisation Scale, C-SEBQ= Chinese version of the School Bullying Experience Questionnaire, MANOVA= multivariate analysis of variance, N= number of participants, NT= Neurotypical, RCT= Randomised Controlled Trial, SST= Social Skills Training, ToMPT= Theory of Mind Performance Training

#### **Participant Demographics**

A total of 226 children were included as participants in the studies, although one study (Etherington, 2007) did not report sample characteristics. Overall participant numbers for individual studies ranged from 3-54 (mean 22.6), within which there were 141 autistic children and 85 neurotypical participants. The mean age of participants in the studies ranged from 7.3-15 years, with a minimum reported age of 6 years and maximum reported age of 18 years. The majority of participants in the studies (67.6%) were male. However, Milne et al. (2010) did not report participant sex, therefore the 10 participants from this study were excluded from this calculation.

#### **Anti-Bullying Interventions**

Based upon the recommendations of Humphrey and Hebron (2015) four areas may be targeted in interventions aimed at reducing the bullying of autistic children. The authors advocated for multicomponent approaches involving each of the four targets: autistic children, peers, staff, and school culture. None of the studies included in the present scoping review evaluated an intervention which addressed all of these areas. Six of the ten studies evaluated interventions which involved two groups and the remaining four included one group. Autistic children were involved as participants receiving interventions in nine of the ten included studies, while neurotypical children were involved in five of the evaluated interventions. The groups involved in the interventions evaluated within each study are detailed in Table 2.

The majority of studies (n=6) evaluated training programmes aimed at supporting autistic children to develop their skills and understanding, such that they could more effectively manage interactions with peers. Interventions evaluated by two studies targeted a broad range of social skills, but incorporated subcomponents teaching participants how to notice and respond to bullying (Beaumont & Sofronoff, 2008;

Segura 2012). Liu et al. (2018) compared two interventions (theory of mind performance training, and social skills training); bullying scenarios were reportedly used as examples within both interventions but the exact capacity in which they were used is unclear. Interventions evaluated by three studies focussed solely upon training participants to identify and cope with bullying (Milne et al., 2010; Ranick et al., 2012; Rex et al., 2018).

Four studies evaluated interventions which promoted contact between autistic children and their neurotypical peers, with a primary or subsidiary aim of reducing the bullying of autistic children. One of these studies evaluated a peer mentoring programme wherein neurotypical participants discussed various topics, (including bullying) with autistic peers (Bradley, 2016). Two studies evaluated interventions which created additional opportunities for autistic children to interact with neurotypical peers, namely a musical contact intervention (Cook et al., 2019) and a peer network (Sreckovic et al., 2017). A final study evaluated an intervention developed to meet the needs of an autistic child who was being bullied by peers (Etherington, 2007). This was the only study in which there was an autism education programme targeting widerschool culture.

#### Table 2

Study	Targets of the Intervention				
	(Based on th	ne key areas described 2015)		and Hebron,	
	Autistic children	Neurotypical Peers	Staff	School Culture	
Beaumont and Sofronoff, 2008	$\checkmark$		$\checkmark$		
Bradley, 2016	$\checkmark$	$\checkmark$			
Cook et al., 2019	$\checkmark$	$\checkmark$			
Etherington, 2007		$\checkmark$		$\checkmark$	
Liu et al., 2018	$\checkmark$				
Milne et al., 2010	$\checkmark$				
Ranick et al., 2012	$\checkmark$				
Rex et al., 2018	$\checkmark$				
Segura, 2012	$\checkmark$	$\checkmark$			
Sreckovic et al., 2017	$\checkmark$	$\checkmark$			

#### Areas Targeted by Interventions

#### **Methodological Characteristics**

A diverse range of research designs were employed by the studies, however, authors predominantly used quantitative approaches, with the exception of Etherington (2007). Bradley (2016) used a mixed methods design, which incorporated thematic analysis of semi-structured interview data. Four studies used single case experimental design, wherein a pre-intervention baseline was established for each participant in order to create within-series experimental controls. These studies reported in-depth findings regarding the impact of interventions on a small number of participants (Ranick et al., 2012; Rex et al., 2018; Segura et al., 2012; Sreckovic et al., 2017). Three quasiexperimental studies conducted pre-post comparisons of outcomes data, however, there was no randomisation of participants into groups (Bradley, 2016; Cook et al., 2019; Milne et al., 2010). Two studies were randomised controlled trials. Beaumont and Sofronoff (2008) randomised participants into intervention or waiting-list control groups, while Liu et al. (2018) randomised participants to one of two intervention groups. Etherington (2007) gave a narrative report of a single case.

The majority of studies (n=7) did not conduct a follow-up to evaluate whether the effects of interventions endured over time. However, Ranick et al. (2012) incorporated a four-week follow-up period, while Beaumont and Sofronoff (2008) conducted a six-week follow-up. Segura (2012) reported results relating to a follow-up period but did not specify the length of follow-up.

#### **Study Outcomes**

#### **Bullying Outcomes**

A wide variety of outcomes were assessed in order to evaluate the impact of interventions upon autistic children, with some studies using multiple measures. Five studies used questionnaires to collect data about the type, frequency and/ or severity of bullying experienced by autistic children (Bradley, 2016; Cook et al., 2019; Liu et al., 2018; Segura, 2012; Sreckovic et al., 2017). Another category of outcome measurement was behavioural coding of participants' responses during role-play scenarios, to establish the extent to which they could implement strategies for coping with being bullied (Ranick et al., 2012; Rex et al., 2018; Segura, 2012). Other studies measured participants knowledge of coping strategies by asking them questions about vignettes illustrating examples of bullying (Beaumont & Sofronoff, 2008; Milne et al., 2010; Rex et al., 2018). A final method of collecting outcomes data was to seek qualitative

feedback from participants about their experiences of being bullied (Bradley, 2016; Etherington, 2007).

Whilst neurotypical peers were involved in interventions evaluated by five studies, outcomes (e.g. levels of bullying perpetration, attitudes towards autistic peers, or levels of empathy) were not typically recorded in this group. Indeed, three studies reported outcomes in relation to autistic children but not neurotypical peers who had been included in the intervention (Bradley, 2016; Segura, 2012; Sreckovic et al., 2017). Etherington (2007) collected qualitative feedback from neurotypical children, asking how they viewed their autistic peer, whom the intervention had been designed for. Cook et al. (2019) used questionnaires to measure neurotypical participants' experiences of bullying others and being bullied by peers. Neurotypical participants in this study were also asked to respond to vignette of a bullying scenario involving an autistic child.

Staff and school culture were the targets of intervention within studies conducted respectively by Beaumont and Sofronoff (2008), and Etherington (2007). However, outcomes were not measured in relation to these intervention targets.

#### Additional Outcomes

In addition to bullying-related outcomes, six of the included studies measured other variables. Five studies measured perceived effectiveness or acceptability of interventions (Bradley, 2016; Cook et al., 2019; Milne et al., 2010; Segura, 2012; Sreckovic et al., 2017). Three studies used additional outcome measures to assess participants' social skills (Beaumont & Sofronoff, 2008; Cook et al., 2019; Segura, 2012; Sreckovic et al., 2017). There were also various other outcomes assessed by individual studies. The additional variables measured by each study are summarised in Table 3.

# Table 3

# Additional Outcomes Measured

Study	Outcomes	Method of Assessment
Beaumont and Sofronoff, 2008	Social competence	Validated Social Skills Questionnaire (Spence, 1995)- parent and teacher reports
2000	Emotional regulation and social skills	Bespoke questionnaire designed for the purpose of the study- parent report
	Perception of emotion from facial expressions	Pre-existing questionnaire containing images of faces (Spence, 1995)- child response
	Perception of emotion from posture	Pre-existing questionnaire containing images of body postures (Spence, 1995)- child response
	Anxiety management	Participants were asked to respond to a vignette about how to manage anxiety (Attwood, 2004)- child response
Bradley, 2016	Self-esteem	Validated Harter self-esteem questionnaire (Harter, 1985)-child report
	Loneliness and social dissatisfaction	Validated Loneliness Questionnaire (Asher et al., 1984)- child report
	Qualitative feedback on experience of the intervention	Semi-structured interviews- child report

Cook et al., 2019	Pro-social behaviour Sympathy Acceptability of the intervention (neurotypical participants)	Social Behaviour Questionnaire (Tremblay et al., 1991)- modified by authors to be child report Child-Report Sympathy Scale (Eisenberg et al., 1996) modified to include a 1-5 Likert scale- child report Open-format questions- child response
Etherington, 2007	No additional outcome measures used	None
Liu et al., 2018	No additional outcome measures used	None
Milne et al., 2010	Participants' views of the effectiveness and acceptability of the intervention	Bespoke questionnaire designed for the purpose of the study
Ranick et al., 2012	No additional outcome measures used	None
Rex et al., 2018	No additional outcome measures used	None
Segura, 2012	Social interaction	Observation of social skills during free play sessions
	Social skills Acceptability and perceived effectiveness	Pre-existing Social Skills Improvement System (Gresham & Elliott, 2008)- teacher and parent report questionnaire Pre-existing Behaviour Intervention Rating Scale (Elliott & Gresham, 1991)- parent and teacher report

	Parent and teacher perceptions of the intervention	Pre-existing Social Validity Scale (as cited in Segura, 2012)- parent and teacher report
	Acceptability of the intervention	Pre-existing Child Consumer Satisfaction Survey (Block, 2012)- child report
Sreckovic et al., 2017	Social skills Reports of satisfaction with the intervention (autistic	Observed initiations and responses during social interactions with neurotypical peers Bespoke questionnaire designed for the purpose of the
	participants; neurotypical peers; parents; two members of school staff)	study

## Discussion

This scoping review aimed to answer three research questions by characterising studies which have evaluated interventions for reducing the bullying of autistic children.

# What interventions have been developed to reduce the bullying of autistic children?

Interventions evaluated within the existing literature can be split into three categories. The first category of intervention included programmes which aimed solely to develop the ability of autistic children to recognise and respond effectively to bullying. Three studies evaluated interventions with this focus. They used various methods of modelling bullying scenarios, specifically: a virtual tutor (Milne et al., 2010); play-based exemplar training (Ranick et al., 2013), and; videotaped role-plays (Rex et al., 2018). Participants were then trained in strategies (e.g. assertiveness) that they could use in response to the bullying scenarios. In each of the studies participants' responses to the bullying scenarios at pre- and post-training were compared in order to establish the impact of the interventions. However, given that autistic children can find it difficult to generalise skills across different contexts (de Marchena et al., 2015), it is a potential limitation that these studies did not assess whether participants were better able to recognise and respond to bullying in their daily lives. Furthermore, although Humphrey and Hebron (2015) describe how the understanding and skills of autistic children are an important target for anti-bullying interventions, there are drawbacks of using this approach alone. Indeed, it may be described as reactive rather than preventative, meaning that autistic children may continue to be exposed to bullying and the associated adverse outcomes.

The second category of intervention, also developed for autistic children, targeted a broader range of skills (e.g. social functioning), but had specific components aimed at developing participants' ability to recognise and respond to bullying. Five studies were excluded from the present review as, while a bullying component was incorporated into a wider intervention programme, no outcome measures relating to bullying were used (Block, 2012; Derosier et al., 2011; Laugeson et al., 2009; Shum et al., 2019; Tse et al., 2007). However, three of the included studies evaluated social skills programmes developed for autistic children, and used various methods of incorporating bullying-related skills teaching (Beaumont & Sofronoff, 2008; Liu et al., 2018; Segura, 2012). Two of these studies included other groups as part of their interventions. Beaumont and Sofronoff, (2008) involved staff (participants' teachers) by developing handouts, which gave recommendations as to how they could support the learning of children accessing the social skills intervention. Parents were also trained to support their children in using the social skills introduced in the intervention. Segura (2012) established mixed groups of autistic children and neurotypical peers, thereby including two of the four recommended targets for intervention.

Thirdly, there were interventions which aimed to reduce the bullying of autistic children by increasing opportunities for them to interact with neurotypical peers. Metaanalytic evidence indicates that intergroup contact reduces prejudice, thereby promoting positive intergroup outcomes (Pettigrew & Tropp, 2006). One study evaluated a peer contact intervention delivered via music lessons (Cook et al., 2019), while two studies evaluated peer-networks in which autistic children were given additional, structured opportunities to spend time with neurotypical peers (Bradley, 2016; Sreckovic et al., 2017). Etherington (2007) described a case study in which peer supporters of an autistic student were given training such that they could better understand him and offer mentoring. This was also the only study in which the intervention programme targeted school culture, which was done via delivery of six hour-long lessons about autism to the year group of the young person at the centre of the programme. This method of introducing change within the school culture may have impacted the extent to which children embraced diversity (though there were no formal measures of this). However, it only targeted one year-group and did not directly address the recommendation of Humphrey and Hebron (2015) that school-wide interventions encourage zero-tolerance of bullying.

In summary, the majority of evaluated interventions aimed to reduce the bullying of autistic children by supporting them to develop their skills and knowledge. Six of the studies included a second target for intervention, most frequently neurotypical peers, although one study involved staff and another targeted school culture. Generally, studies involving neurotypical children aimed to facilitate increased contact with autistic peers, either through peer networks or encouraging joint attendance of intervention sessions. With the exception of Etherington (2007), none of the studies implemented educational interventions for neurotypical peers. Lee et al. (2015) suggested that, in neurotypical groups, greater reductions in bullying victimisation have been associated with interventions that incorporate: training in emotional control, peer counselling and establishment of school-wide anti-bullying policies. That these areas are broadly consistent with the foci of interventions evaluated by the included studies is a potential strength within the literature. Targeting the knowledge and understanding of neurotypical peers in order to improve tolerance and acceptance, and reduce the bullying of autistic children would also be a legitimate target for intervention (Morewood et al., 2011). With the possible exception of Etherington (2007), none of the included studies took this approach, however, other authors have evaluated interventions aimed improving understanding and reducing stigma among neurotypical groups (Campbell et al., 2004; Gus, 2000; Staniland & Byrne, 2013). These studies were excluded from the present review as they did not investigate the bullying of autistic children. It is also of note that eight publications were excluded from the review

as they were descriptive, as opposed to evaluative (Biggs et al., 2010; Carrington et al., 2017; Good & Fang, 2015; Hong et al., 2015; Raffalli & Pomeroy, 2016; Raskauskas & Modell, 2011; Roberts & Webster, 2020; Walton, 2012). Multi-component interventions which involved each of the four key areas described by Humphrey and Hebron (2015) did not feature within the literature.

# What methodologies are used in studies of interventions aimed at reducing the bullying of autistic children?

Five of the studies included in the present review used single case methodology, including four which used single case experimental design (Ranick et al., 2013; Rex et al., 2018; Segura, 2012; Sreckovic et al., 2017). Etherington (2007) used narrative case study methodology, taking a descriptive approach to the reporting of results. Single case methodology has traditionally been considered the 'lowest rung' of the hierarchy of research evidence as it is associated with weaker internal validity and generalisability (Murad et al., 2016). However, single case methodology, particularly single case experimental design, can be a valuable source of evidence (Morley, 2018). Indeed, single case experiments can be conducted in a rigorous, well-controlled manner to reduce the risk of bias and are often more feasible to run than full-scale RCTs.

Three studies used quasi-experimental methodology, including two which compared outcomes for participants at pre- and post-intervention (Bradley, 2016; Milne et al., 2010). The third study (Cook et al., 2019) used a pre-post calculation for establishing outcomes among autistic participants, in addition to conducting group comparison for outcomes relating to neurotypical peers. While neurotypical participants in this study were not randomised into conditions, participants in two of the included studies were randomly assigned to groups (Beaumont and Sofronoff, 2008; Liu et al., 2018). All of these studies were larger in scale than those using single case methodology, however, participants numbers were still relatively low with numbers ranging from 10-54.

None of the included studies were longitudinal in design and just three incorporated a follow-up period (Beaumont & Sofronoff, 2008; Ranick et al., 2012; Segura, 2012). The use of (prolonged) follow-up periods would have enabled studies to establish the long-term effectiveness of anti-bullying interventions, in addition to providing an opportunity to identify any adverse outcomes that emerged over time (Llewellyn-Bennett et al., 2018).

# What outcomes are evaluated in studies of interventions aimed at reducing the bullying of autistic children?

Bullying-related outcomes were assessed in various ways among autistic participants. Five studies measured knowledge or skills acquisition following interventions aimed at enhancing the ability of autistic children to respond to bullying (Beaumont & Sofronoff, 2008; Milne et al., 2010; Ranick et al., 2013; Rex et al., 2018; Segura, 2012). The use of observational methods and behavioural coding (e.g. of children's responses to bullying scenarios during role play) arguably has more ecological validity than knowledge only tests. However, using either method alone does not allow researchers to determine the impact of interventions on the day-to-day bullying experiences of autistic children. Two studies gathered feedback on bullying experiences using non-standardised, discursive methods (Bradley, 2016; Etherington, 2007). Five of the included studies used questionnaires to establish type, severity and/ or frequency of bullying by others, toward the respondent (Bradley, 2016; Cook et al., 2019; Liu et al., 2018; Segura. 2012; Sreckovic et al., 2017). The strength of such approaches is that they attempt to directly measure the bullying of autistic children, and therefore may be used to establish whether interventions have a real-term impact. Three studies used questionnaires that have previously been validated in neurotypical populations (Liu et al., 2018; Segura, 2012; Sreckovic et al., 2017). Two studies (Bradley, 2016; Cook et al., 2019) used measures whose validity and reliability have not yet been established. As far as I can determine, none of the measures have been validated for use with autistic children. Validation of measures may be particularly important in autistic groups as common difficulties, e.g. with emotion recognition, rigidity of thinking and social cognition may lead to differences in the interpretation of questionnaire items (Santosh et al., 2016).

There was a paucity in the measurement of outcomes among the other targets of intervention identified by Humphrey and Hebron (2015), i.e. neurotypical peers; staff and school culture. Although the central tenet of a number of the included interventions was to promote contact between autistic children and neurotypical peers, studies did not generally establish whether this impacted the attitudes or bullying perpetration of neurotypical participants. There were two exceptions to this. Etherington (2007) used non-standardised methods to collect verbal reports from neurotypical children, asking about attitudes toward their autistic peer. Cook et al. (2019) had the most comprehensive approach to outcome measurement among neurotypical participants. This study used both a standardised (though non-validated) questionnaire which had a bullying perpetration scale, and measured neurotypical participants' attitudes and behavioural intentions toward an autistic character in a vignette. Staff and school culture were respectively targeted by interventions in two of the included studies, however, outcome measures were not used to establish whether there were discernible post-intervention changes.

Alongside bullying-related outcomes, studies reported data relating to a number of other variables. Most commonly this involved measurement of the perceived effectiveness or acceptability of interventions, which was a potential strength within the literature. Indeed, Balen et al. (2006) highlighted the ethical and empirical importance of treating child participants as 'active beings' whose evaluative feedback can shape the adaptation of interventions and the conduct of future research. There were also studies that measured the social skills of participants, which was particularly relevant where broad-based social skills programmes had incorporated components on responding to bullying. While social skills are therefore a valid target for outcome measurement, it may also be of value to evaluate the wider impact of interventions by incorporating mental health and social wellbeing outcomes. For example, Bradley (2016) evaluated loneliness, social satisfaction and self-esteem.

## **Recommendations for Future Work**

The interventions evaluated by the included studies incorporated a maximum of two of the four key areas identified by Humphrey and Hebron (2015). Broadly, interventions focused either upon the understanding and skills of autistic children, or creating additional opportunities for connection between autistic children and neurotypical peers. There is, therefore, still the need for researchers to develop and evaluate multicomponent interventions, targeting each of the four areas for intervention, i.e. the knowledge and skills of autistic children; the attitudes and behaviours of neurotypical peers; staff approach, and; school culture. It may possible to evaluate school-based anti-bullying interventions established as effective for neurotypical populations (e.g. see Gaffney et al., 2019), but with specific adaptations to meet the needs of autistic children. Alongside school-based interventions it may be important for researchers to develop and evaluate programmes, which aim to reduce bullying in the sibling relationships of autistic children. Indeed, sibling bullying is emerging as another area in which autistic children may have increased difficulties, compared with neurotypical peers (Toseeb et al., 2018; Toseeb et al., 2019). This is a relatively new focus for autism research, and one task will be to establish whether sibling bullying would necessitate different strategies for intervention, compared with school bullying. Certainly, Wolke et al. (2015) suggest that sibling bullying interventions should focus upon the home environment.

To date studies evaluating interventions aimed at reducing the bullying of autistic children have been relatively small-scale, indeed half of the included papers used single-case design. It may be possible to further develop the evidence base by moving up the hierarchy of research design (Murad et al., 2016). One way to do so would be to conduct larger scale, more rigorously controlled intervention studies. For example, researchers could more consistently use designs in which participants are randomised into groups, and implement extended follow-up periods to establish the longer-term impact of interventions. Use of active control groups would also be of value, e.g. to compare the effectiveness of different anti-bullying skills interventions for autistic children (ideally within the context of wider multi-component approaches). Comparing the approaches evaluated by the included studies may be viable, i.e. contrasting a social skills intervention that has anti-bullying components, with a programme that solely targets the bullying-related knowledge and skills of autistic children. The majority of the included studies used quantitative approaches and, with the exception of Bradley (2016), those that collected verbal feedback from participants did not use formal methods of qualitative analysis to process this. Therefore, there is also a gap in the literature for qualitative research, which uses evidence-based methods of analysing the feedback of autistic children who have participated in anti-bullying interventions.

Comprehensive measurement of outcomes will also be an important consideration for future research. It may be possible to implement combinations of the evaluative methods used in the included studies, e.g. behavioural observation of participants and (validated) child- and parent-reported questionnaires of bullying experiences. Adams et al. (2014) validated the Modified Schwartz Peer Victimisation Scale with a sample of male autistic adolescents. However, further work to validate standardised questionnaires that measure bullying victimisation in autistic samples would be a useful avenue for research. Questionnaires that measure bullying-related distress, alongside bullying frequency could be of particular value. Where researchers are evaluating multi-component interventions, use of outcome measures with each of the targeted groups will be important. This may allow for identification of the 'active components' of programmes, i.e. those elements of interventions which are responsible for effecting change (Craig et al., 2008). Routine use of secondary outcome measures, e.g. those relating to mental health and wellbeing may allow researchers to determine the wider impact of interventions, and to conduct analyses to establish which factors mediate and moderate intervention effects.

## Strengths and Limitations of the Review

A key strength was the adherence to guidelines for the completion of scoping reviews, specifically the recommendations made by Arksey and O'Malley (2005) and Peters et al. (2015). The publication of a protocol prior to review commencement (Hastings, 2019), and the a priori definition of the research questions and methodological decision making may have reduced the risk of bias. Moreover, the review used a comprehensive and wide-ranging search strategy and date restrictions were not imposed, so as to increase the likelihood that all relevant studies would be identified. Additional strengths of the search strategy were the use of reference list reviewing and the inclusion of unpublished studies (i.e. grey literature).

While unpublished studies were identified and included in the present review, a limitation of the search strategy was that specific searches were not undertaken of grey

literature databases, e.g. Open Grey, EThOS, and ProQuest (Dissertations & Theses). In this way, an opportunity to reduce publication bias was missed. The search strategy may also have been strengthened further by the inclusion of non-English language studies, the contacting of experts in the field and, given recent findings relating to sibling bullying among autistic children (Toseeb et al., 2018; Toseeb et al., 2019), the use of 'sibling' as a search term.

Another potential area for improvement in the review would have been to employ an independent rater to review citations, in order to reduce the risk of systematic bias. The recommendations of Humphrey and Hebron (2015) were a useful framework for characterising interventions evaluated by the included studies. This framework should inform but not limit the future development of interventions aimed at reducing the bullying of autistic children. In particular parents and family are not included as one of the four key areas within the framework, however, research with neurotypical children has indicated that their involvement in interventions can be of significant value (Gaffney et al., 2019).

## **Clinical Implications**

The interventions evaluated by the studies included in the review focused either upon the skills and understanding of autistic children, or promotion of contact between this group and their neurotypical peers. Professionals who are seeking to implement evidence-based interventions aimed at reducing the bullying of autistic children may consider replicating one such programme. However, this review did not set out to establish the (comparative) effectiveness of interventions or rate the quality of the available evidence, therefore recommendations cannot be made as to which specific programme professionals should favour. Moreover, there remains a need for the development and evaluation of multi-component interventions. There is a need to continue building the evidence base, therefore where professionals implement interventions locally, reporting and publishing the results (i.e. generating practice-based evidence) would be of value. There are no 'gold standard' ways of assessing bullying outcomes among autistic children, and work to continue validating standardised questionnaires that measure bullying victimisation in autistic groups would constitute a significant advancement for this area of research.

## Conclusion

The scoping review highlights that research evaluating interventions aimed at reducing the bullying of autistic children is in its infancy. There was a split between interventions focussing on the skills and understanding of autistic children, and those which facilitated contact with neurotypical peers. Future research should aim to develop and evaluate multi-component interventions. There was substantial heterogeneity in the research designs used and the outcomes evaluated. While the studies included in the review were not formally assessed for quality, it was possible to reflect on strengths and areas for improvement that may be addressed in future research.

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## Appendix

## Appendix A. Data extraction fields used within the charting table.

- 1. Authors
- 2. Year
- 3. Country of origin
- 4. Journal
- 5. Aims of study
- 6. Population receiving intervention
- 7. Sample size (bold= only this group completed outcome measures)
- 8. Age range (mean)
- 9. Setting
- 10. Methodology and follow-up period
- 11. Anti-bullying intervention
- 12. Duration of intervention
- 13. Comparator/ control
- 14. Outcomes measured (bold= bullying measure)
- 15. Key findings on bullying outcomes

## Section 2: Empirical Study

# Feasibility Issues Relating to the Investigation of Bullying Victimisation and

Psychosis-Like Experiences in Autistic Children.

#### Abstract

**Background:** Bullying of autistic children by their peers is prevalent. This is a concern given the established relationship between childhood bullying victimisation and adverse mental health outcomes in neurotypical populations. In autistic children a relationship has been established between bullying victimisation and internalising mental health difficulties. However, no studies have examined the relationship between bullying victimisation and psychosis-like experiences (PLEs). This study aimed to investigate the feasibility of examining these phenomena in autistic children, and to test a preliminary hypothesis of association.

Design: A quantitative, cross-sectional design was used.

**Methods:** Data was collected from parents of autistic children (N=53), who were first recruited via a child autism diagnostic service and then online. Participants completed a demographics questionnaire, the Modified Schwartz Peer Victimisation Scale, and the Child Behaviour Checklist. Hierarchical multiple regression was used to test the relationship between bullying victimisation and PLEs, while controlling for: age, sex, family history of psychosis and internalising difficulties.

**Results:** It was found that there is a lack of suitable tools for measuring PLEs in autistic children, and that recruiting a large sample via a clinical service may not be feasible. Preliminary hypothesis testing failed to establish a statistically significant relationship between the variables of interest.

**Conclusions:** There are a number of feasibility issues that should be addressed in future research, which examines the relationship between bullying victimisation and psychosis-like experiences (PLEs) in autistic children. The development of sensitive and reliable questionnaires for measuring PLEs in autistic children would be a valuable next step.

## **Practitioner Points**

- Providers of mental health services for autistic children should consider asking about bullying victimisation.
- In assessing the potential mental health impact of bullying in autistic children, practitioners may consider asking about a range of phenomena, including PLEs.
- While there are established limitations, parent-reports of bullying and PLEs may be useful as a supplement to child-reports, or where there are barriers to engaging autistic children in assessment.

## Introduction

## Autism in Childhood

Autism Spectrum Disorder (ASD) is characterised by enduring difficulties across two broad areas: (a) social communication and interaction, and (b) restricted and/ or repetitive behaviours or interests (American Psychiatric Association (APA), 2013). To warrant a diagnosis of ASD difficulties must have been observed in the early developmental period, and must cause clinically significant challenges in daily functioning. While these criteria are drawn from the Diagnostic and Statistical Manual of Mental Disorders (APA, 2013), they are closely aligned with those detailed in the International Classification of Diseases (World Health Organisation, 2018). The language used to discuss autism requires careful consideration, and there is no consensus as to the most appropriate terminology. This study will use the term 'autistic' to describe individuals with an ASD diagnosis, following findings by Kenny et al. (2016) that this is a preferred term among parents of autistic children and adults.

Estimates of the prevalence of ASD among children in the UK vary, with figures falling between 0.3-1.6% of the population (Baron-Cohen et al., 2009; Mackay et al., 2016; Scott et al., 2002; Taylor et al., 2013). Research with eight-year-old children in

the United States established a prevalence figure of 1.9%, in addition to highlighting that ASD diagnosis is four times more common among boys than girls (Maenner et al., 2020). Globally, prevalence of ASD among children and adults has been estimated at 0.62% (Elsabbagh et al., 2012).

The importance of early interventions for psychological wellbeing cannot be understated, and there is a need to study childhood risk factors that impact the development of mental health difficulties (Membride, 2016). The experiences of autistic children can differ from those of their neurotypical peers (Rowley et al., 2012), hence the decision to focus specifically upon this group. Autistic children have reported particular difficulties with adverse experiences in school, including feelings of isolation and incidents of bullying by peers (Goodall, 2018). The bullying of autistic children will therefore be the focus of the present study.

## **Autism and Bullying**

Bullying has traditionally been defined as aggressive behaviour repeatedly directed toward another, with the intent of causing harm (Olweus, 2013). Within this definition three concepts are crucial: (a) that there is an imbalance of power between those involved, (b) that there is intentionality behind bullying behaviours, and (c) that there is repetition. However, there has been a shift in thinking toward acknowledging that single incidents or low frequency behaviours can cause significant harm, thereby deemphasising the importance repetition (Olweus, 2013; Volk et al., 2014). Volk et al. (2014) subsequently developed a theoretically derived 'redefinition' of bullying as "aggressive goal-directed behaviour that harms another individual within the context of a power imbalance" (p.328).

It has been repeatedly found that autistic children are more commonly subjected to bullying than neurotypical peers, and that this is an issue across educational settings (Campbell et al., 2017; Humphrey & Symes, 2010; Hwang et al., 2018; Schroeder et al., 2014). Maïano et al. (2016) conducted a meta-analysis, synthesising the findings of 15 studies which examined bullying among autistic youth. Comparison of autistic children with their neurotypical peers revealed that both groups were equally likely to perpetrate bullying, however, the risk of being bullied by others was three times greater for autistic youth. The overall pooled prevalence of bullying victimisation among autistic participants was 44%. Emerging evidence also indicates that bullying of autistic children by their siblings is more prevalent compared with neurotypical groups (Toseeb et al., 2018).

## **Bullying and Mental Health**

Being bullied during childhood has been linked with increased risk of adverse mental health outcomes in neurotypical populations. Moore et al. (2017) conducted a meta-analysis of 165 studies examining outcomes following childhood bullying victimisation. It was concluded that there is substantial evidence that bullying victimisation has a causal role in the development of mental health difficulties, with particularly strong associations established for depression, anxiety and suicidality. It has been hypothesised that the relationship between bullying victimisation and mental health difficulties is bidirectionally causal (Cappadocia et al., 2012). In line with this, one longitudinal study found that mental health difficulties in children aged 11-16 years at timepoint one, were associated with an increased risk of reporting bullying victimisation at timepoint two (six-month follow-up), particularly for females (Le et al., 2019). Bullying victimisation at timepoint one was a significant predictor of mental health difficulties (depressive symptoms and suicidal ideation) at timepoint two (sixmonth follow-up). Mental health difficulties may therefore heighten the risk of being bullied, in addition to being a potential consequence of victimisation. Research examining the relationship between bullying victimisation and mental health difficulties in autistic groups has produced similar results. Saggers et al. (2017) conducted interviews with 10 autistic adolescents who reflected upon the ways that being bullied impacted their emotional wellbeing, self-confidence and trust in others. Bullying victimisation among autistic children has been extensively associated with internalising mental health difficulties, particularly anxiety and depression (Adams et al., 2014; Cappadocia et al., 2012; Chou et al., 2020; Toseeb et al., 2019; Zablotsky et al., 2013).

## **Bullying, Psychosis Experiences and Autism**

Outside of the autism literature, a clear link has been made between bullying and 'positive symptoms' of psychosis, in addition to 'positive' psychosis-like experiences (PLEs). PLEs are phenomena that fall on the psychosis continuum (e.g. unusual perceptual experiences; persecutory ideas) but do not meet clinical thresholds for diagnosis of a schizophrenia spectrum disorder (SSD) (Yung et al., 2009). For individuals experiencing first episode psychosis, the chance of them reporting premorbid bullying was two times greater than for control participants without psychosis (Trotta et al., 2013). Within the control group individuals who had experienced bullying were twice as likely to report PLEs. Bullying victimisation in childhood has been extensively linked with development of PLEs (Fisher et al., 2013; van Dam et al., 2012). Cunningham et al. (2016) conducted a meta-analysis of ten prospective studies, concluding that bullying victimisation predicts PLEs, and has a causal role in the aetiology of psychosis. Current evidence suggests that PLEs can emerge in neurotypical children as young as 12, following bullying earlier in childhood (Arseneault et al., 2011; Campbell & Morrison, 2007; Lataster et al., 2006).

The Traumagenic Neurodevelopmental model of psychosis has been proposed to explain the link between childhood adversity (including bullying) and psychosis (Read et al., 2005; Read & Bentall, 2012). The model purports that trauma in early life can lead to a heightened sensitivity to stress. This may increase the risk that PLEs (presumed to be universal human phenomena) will be appraised as catastrophic or threatening, leading to intense distress and increasing the likelihood of an SSD diagnosis. In addition to this broad understanding, the model has been used to account for specific associations, e.g. between bullying victimisation and persecutory ideas.

There is evidence that SSDs are more prevalent among autistic than neurotypical groups, which may be because autistic individuals experience greater exposure to known risk factors for psychosis, including bullying (Selten et al., 2015). Chisholm et al. (2015) summarised the findings of nine studies examining the rate of SSDs among the autistic population, highlighting how rates of co-occurrence ranged from 0-34.8% (mean 13.8%). A more recent meta-analysis of 10 studies calculated the pooled prevalence of SSDs in autistic adults to be 6.4%, compared with a population prevalence of 1.1% (Marín et al., 2018).

Fewer studies have looked at the prevalence of PLEs in autistic groups. Autistic traits have been associated with an increased risk of reporting PLEs (Jones et al., 2012; Sullivan et al., 2013), although Taylor et al. (2015) failed to replicate this finding. Studies with autistic children suggest that PLEs are prevalent in this group. Barneveld et al. (2011) compared a group of autistic children with a group of neurotypical children matched for age and sex. Participants completed the Schizotypal Personality Questionnaire (Raine, 1991) to assess PLEs. Autistic children scored significantly higher than neurotypical peers across all PLE domains with moderate to large effects. Eussen et al. (2014) conducted a study with 91 autistic children aged 12-19 years, using the Prodromal Questionnaire (Loewy et al., 2005). It was found that 22 participants

(24.2%) scored  $\geq$ 14 on the positive symptoms scale; 14 was used as a cut-off as this predicts 'ultra-high risk' status for later emergence of SSDs.

There is a dearth of research investigating the psychosocial factors associated with PLEs in autistic children. Gadow and DeVincent (2012) established a link between PLEs and internalising mental health difficulties (depression; anxiety, and; obsessions and compulsions) in autistic children. Additionally, there was evidence for sex differences, with parent-reports indicating that autistic girls were more likely than boys to be classed as having 'schizophrenia spectrum traits' i.e. PLEs. Kyriakopoulos et al. (2015) also found that PLEs in autistic children were associated with other mental health phenomena, including phobias. Aside from this I am unaware of any studies investigating the potential psychosocial determinants of PLEs in autistic children. This includes an absence of literature examining the relationship between bullying victimisation and ('positive') PLEs, which is the focus of the present study.

## **Current Study**

In neurotypical groups, both cross-sectional and prospective research designs have been used to study the relationship between childhood bullying victimisation and PLEs. Cross-sectional studies (n=8) included in a meta-analysis by van Dam et al. (2012) used similar methodological approaches. Typically, researchers identified validated methods of assessing bullying victimisation and PLEs (questionnaires and/ or clinical interviews), administered these to participants, and used statistical procedures to test the relationship between the variables of interest, while controlling for potential confounds. Clinical and non-clinical populations have been recruited, and sample sizes are typically large. Indeed, the eight cross-sectional studies reported by van Dam et al. (2012) had a mean sample size of 2,821 (range 64-8,580).

Preliminary work to establish the feasibility of conducting such research with autistic children would be a useful precursor to large-scale cross-sectional investigations. Indeed, there are a number of issues which are of particular relevance to autistic groups and should be thoroughly considered prior to large-scale studies. It has been highlighted, for example, that measurement tools tend not to be validated for use with autistic children (Hanratty et al., 2015). This is a particular issue as interpretation of questionnaire items can be impacted by traits commonly observed in autism, e.g. rigidity of thinking, and difficulties with emotion recognition. Furthermore, the lack of previous work investigating the relationship between bullying victimisation and PLEs in autistic children presents a challenge for identifying a predicted effect size, in order to inform a power calculation. In neurotypical children the magnitude of the relationship is highly variable across studies, though generally falls in the small-medium range (Campbell and Morrison, 2007; Catone et al., 2017; Cunningham et al., 2016; Fisher et al., 2013; Lataster et al., 2006; van Dam et al., 2012). It is not known whether this would be similar in autistic children. Indeed, the research summarised above, highlighting that both bullying victimisation and PLEs are more common in autistic children, may be an indicator that the relationship between these variables, and the magnitude of any effect is different, in comparison to neurotypical children.

Feasibility studies are used to establish whether, and how, a piece of research can be done (Eldridge et al., 2016). Key parameters which may be investigated include: identifying and characterising suitable measurement tools, establishing possible avenues of recruitment, and testing participant response rates (Arain et al., 2010). More recently, Lancaster and Thabane (2019) discussed the importance of feasibility studies in testing "preliminary hypotheses of association" (p. 3). Establishing the magnitude of the relationship between the variables of interest can inform power calculations in future work.

## Aims and Hypothesis

The primary aim of the current study will be to establish the feasibility of investigating the relationship between bullying victimisation and PLEs in autistic children. The cross-sectional methodology used in previous studies with neurotypical children, and summarised by van Dam et al. (2012) will inform the design. Focus will be on the following aspects of feasibility:

**Measurement Issues.** How can information regarding bullying victimisation and PLEs be collected from autistic children and their parents? What issues specific to ASD become relevant in measuring these phenomena?

**Recruitment Issues.** Is it possible to recruit a substantial sample via a clinical service? What effect size will be detected between the variables of interest, and what are the implications of this for achieving adequate power in a full-scale cross-sectional study?

The secondary aim of the study is to test the preliminary hypothesis of association between bullying victimisation and PLEs in autistic children. Within this it is necessary to control for confounding variables, specifically: age and socioeconomic status (Adams et al., 2014); sex and internalising mental health difficulties (Gadow & DeVincent, 2012), and; ethnicity, and family history of psychosis (Karcher et al., 2018). Therefore, the current feasibility study will investigate the preliminary hypothesis that there is a positive association between bullying victimisation and PLEs in autistic children, after controlling for: age, sex, ethnicity, socioeconomic status, family history of psychosis, and internalising difficulties.

#### Method

#### Design

#### Feasibility Issues

The study was designed in consultation with clinical psychology staff who specialise in working with autistic children and their families. Additionally, feedback about the study was sought from parents attending the Aspergers Youth Club Doncaster, an organisation registered on the National Health Service (NHS) public involvement searchable database. As in a study involving neurotypical children, conducted by Karcher et al. (2018), child- and parent-reported data was originally going to be gathered.

Searches were undertaken to identify appropriate questionnaire-based measures which could be used to gather data on PLEs and bullying victimisation. A number of PLE questionnaires were identified, which have been validated for use with neurotypical children, e.g. the Specific Psychotic Experiences Questionnaire (Ronald et al., 2014), the Adolescent Psychotic-Like Symptom Screener (Kelleher et al., 2011), and the Prodromal Questionnaire- Brief Child Version (PQ-BC) (Karcher et al., 2018). The measures identified were typically child self-report, rather than parent-reported tools. To the best of my knowledge there are no PLE measures which have been validated for use with autistic children and/ or their parents. There is a tendency for studies of bullying victimisation among autistic children to use bespoke questionnaires, or specific items from validated measures (Maïano et al., 2016). However, there are measures of bullying victimisation available that have been validated for use with autistic children and their parents, including the Modified Schwartz Peer Victimization Scale (MSPVS) (Adams et al., 2014).

This study was poised to use the PQ-BC and the MSPVS, however, feedback from parents at patient and public involvement (PPI) groups led to a reconsideration of study design. A number of concerns were raised about the feasibility of collecting data directly from children. There were particular worries about the extent to which children would engage with an unfamiliar researcher, and their ability to concentrate for extended periods. Parents also raised concerns about the ethical implications of asking children about potentially distressing topics. This feedback informed the decision to collect data solely from parents, which in turn limited the range of instruments available for measuring PLEs. While the parent-report version of the MSPVS was used, it was necessary to identify an alternative, validated parent-report measure of PLEs. The Child Behaviour Checklist (CBCL) (Achenbach & Rescorla, 2001) was used, as the CBCL thought problems scale was previously established as a valid tool for screening psychosis symptoms in neurotypical children (Salcedo et al., 2018; Simeonova et al., 2014). Questionnaires were hosted on Qualtrics to promote ease of access by parents, who recruited using opportunity sampling.

There were two recruitment streams. Initially, participants were recruited solely via an NHS autism assessment pathway, based at Doncaster Royal Infirmary. A clinical sample was targeted in the first instance, as a way of ensuring that all participants had an ASD diagnosis. The clinical service had a large database of children who had received diagnoses historically, and a high throughput of new cases (58 children aged over 5 years received an ASD diagnosis in March-May 2018). It was therefore anticipated that it would be possible to recruit a substantial sample. However, due to low rates of participation, the recruitment strategy was broadened and parents were approached using online methods. Consent rates (clinical recruitment) and dropout rates (both recruitment streams) were calculated and are reported in the results section.

#### Autism Assessment Pathway Recruitment

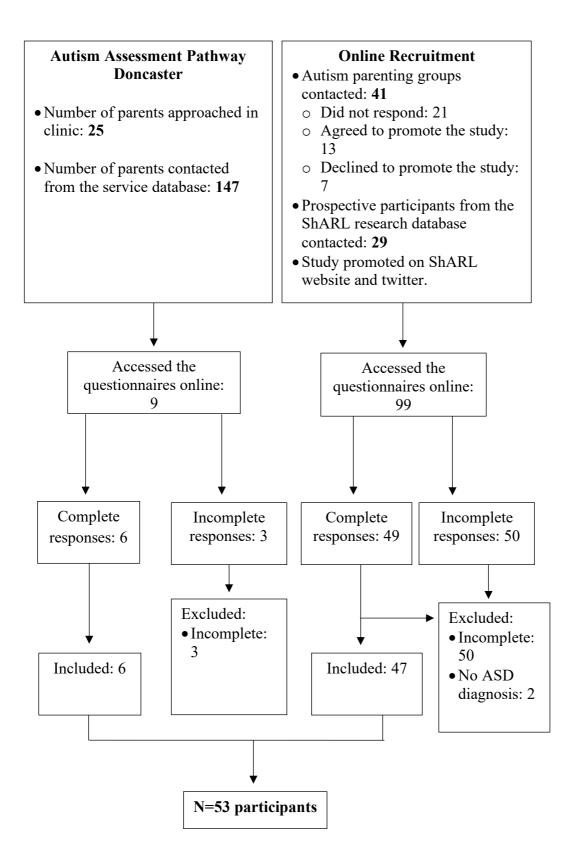
The Autism Assessment Pathway maintain a database of children who have received an ASD diagnosis from the service. Assistant psychologists working within the service posted recruitment packs to prospective participants in groups of ~50, starting with children diagnosed most recently. Participant recruitment packs included an invitation letter (Appendix A) and information sheet (Appendix B). The study was accessed via a hyperlink which took participants to the consent form (Appendix C), and questionnaires hosted on Qualtrics. When online recruitment commenced the information sheet was updated (Appendix D) and hosted on Qualtrics. Thereafter the service approached prospective participants with an updated invitation letter (Appendix E). Clinicians in the service also mentioned the study to families at diagnostic feedback appointments, where this was clinically appropriate. Recruitment via the autism assessment pathway ran between October 2019 and April 2020.

#### **Online Recruitment**

Due to low rates of participation a backup recruitment strategy was implemented, wherein prospective participants were approached online, with the aid of a recruitment poster (Appendix F). Autism parenting groups were contacted via Facebook, and the study was promoted via the Sheffield Autism Research Lab (ShARL) webpage and Twitter account. ShARL also keep a database of individuals who have consented to be contacted about research. Parents of children who would have been eligible for inclusion in the study were contacted by email. Online recruitment ran from January-April 2020. The overall recruitment process is summarised in Figure 1.

# Figure 1

# Participant Recruitment Flowchart.



## Ethical Considerations

Ethical approval for the study was granted by an NHS Research Ethics Committee (Appendix G), and the Research and Development department of the participating NHS trust (Appendix H). Both also approved an ethical amendment to permit online recruitment (Appendices I & J). The topics of the questionnaires may have triggered concerns for participants (e.g. in relation to their child's mental health, or experiences of being bullied), therefore details of relevant charities were provided upon completion of the study. Informed consent was sought from participants, and it was made clear that individuals could withdraw from the study at any time.

#### Measures

**Demographics.** A questionnaire (Appendix K) was developed to gather information from participants about child age, sex, ethnicity, postcode (as an indicator of socioeconomic status), ASD diagnosis, additional diagnoses, and family history of psychosis. The item regarding family history of psychosis was developed based on the approach of Karcher et al. (2018), who adapted question five of the Family History Assessment Module Screener (Rice et al., 1995).

**Bullying.** The MSPVS (Appendix L; Adams et al., 2014) is a 12-item parent-report questionnaire, which was adapted from a measure originally developed by Schwartz et al. (2002). Items are rated on a 1-7 scale capturing frequency of bullying, where 1 is '[removed due to copyright restrictions]' and 7 is '[removed due to copyright restrictions]'. The MSPVS produces four subscales ('verbal', 'relational', 'physical' and 'social' victimisation) which can be combined into a total score. Adams et al. (2014) reported Cronbach's alpha coefficients for the subscales ranging between .78 and .95.

Mental Health. The CBCL specific problem measure (Appendix M; Achenbach & Rescorla, 2001) is a 118-item parent-report questionnaire designed for caregivers of

children aged 6-18 years. Items are rated on a 0-2 scale with reference to the past 6 months, where 0 is '[removed due to copyright restrictions]', 1 is '[removed due to copyright restrictions]'. Thought problems scale t-scores were used as a measure of PLEs. The CBCL also produces an internalising scale (with associated t-scores), which was used in the present study. The CBCL specific problem measure has been validated for use with autistic children. Pandolfi et al. (2012) established scale reliability using confirmatory factor analysis, producing a median value of .85 and a range of .69 to .94. Criterion validity was established across the scales, with moderate to large effects.

#### Procedure

Upon accessing the study via Qualtrics, participants were presented with the information sheet, after which they were asked to complete the consent form. The demographics questionnaire was completed first, followed by the MSPVS and CBCL. To finish participants were presented with a thank you message and the contact details of relevant charities, should they want to access support (Appendix N).

## **Preliminary Hypothesis Testing**

## Sample

Hooper (n.d.) highlights how power calculations are not typically undertaken in feasibility studies, however, proposed sample size should be justified in relation to the aims of the research. A key aim of this study was to establish the sample size requirements for a larger-scale cross-sectional investigation. To achieve such an aim in the context of feasibility studies samples sizes between 30 and 50 have been recommended (Browne, 1995; Lancaster et al., 2004; Sim & Lewis, 2012). This study

therefore aimed to recruit as many participants as practicable, with 30 as the minimum permissible number.

Participants were parents of autistic children. To be included in the study their children had to have a diagnosed ASD, and be aged 6-18 years. Participants would have been excluded if they reported that their child had a diagnosed condition linked with sensory deprivation (e.g. blindness). Following application of exclusion criteria, the final sample size was N= 53 autistic children. Given the potential mental health impact of the UK Coronavirus lockdown implemented on March 23rd 2020, it may be important to note that nine responses (17%) were received during lockdown. Sample demographics are described in Table 1. The majority of the children comprising the sample were male (66%), white (92.5%), and did not have a family history of psychosis (81.1%). The mean age of participants was 10.55 years, while mean age at diagnosis of ASD was 7.51 years. Where postcode data was provided by participants (n=46) this was converted into Index of Multiple Deprivation decile scores, which rank postcodes on a 1-10 scale from most to least deprived (Ministry of Housing, 2019). Index of Multiple Deprivation deciles were taken as an indicator of socioeconomic status. The majority of participants had one or more additional diagnoses (54.7%), which are described in Table 2.

# Table 1

# Sample Demographics

	N	0/
	Ν	%
Gender		
Male	35	66.1
Female	18	33.9
Ethnicity		
White	49	92.5
Mixed- White & Asian	2	3.8
Asian	1	1.9
Arab	1	1.9
Additional diagnoses		
None	24	45.3
One comorbid condition	14	26.4
Multiple comorbid conditions	15	28.3
Family history of Psychosis		
No	43	81.1
Yes:		
First-degree relative	5	9.4
Second-degree relative	4	7.5
Not reported	1	1.9
Total	10	18.9
	Mean (Range)	Standard Deviation
Age	10.6 (6-18)	3.2
Age ASD diagnosis received (n=49)	7.5 (2-17)	3.5
Socioeconomic status (n=46)	4.6 (1-10)	3.0

Note. The sample size for all of the variables was N=53, unless otherwise stated.

## Table 2

Additional Diagnoses

Diagnostic Category	Specific Condition	Ν	% of Overall Sample
Neurodevelopmental	ADHD	8	15.1
	DCD	4	7.6
	Dyslexia	3	5.7
	Learning	4	7.6
	Sensory	6	11.3
	Tourette's	3	5.7
Mental Health	Anxiety	9	17.0
Wiental Health	Depression	2	3.8
	OCD	1	1.9
D1	A.1	1	1.0
Physical Health	Adenomatous Polyposis Asthma	1 2	1.9
	1 10 111110	2 1	3.8 1.9
	Cerebral Palsy Eczema	1	1.9
	Epilepsy	1	1.9
	Hyper mobility	5	9.4
	Hyperthyroidism	1	1.9
	Neurofibromatosis	1	1.9
	Obesity	1	1.9

*Abbreviations*: ADHD= Attention Deficit Hyperactivity Disorder, DCD= Developmental Coordination Disorder, OCD= Obsessive Compulsive Disorder *Notes.* (a) With the exception of ADHD and OCD, diagnoses which participants described solely with abbreviations were not included as it was uncertain what conditions they referred to; two participants reported additional diagnoses in this way. (b) Children who have more than one additional diagnosis are represented multiple times across the data.

## Statistical Analysis

Data were analysed using version 26 of the Statistical Package for Social Sciences (SPSS). Hierarchical multiple regression was used to test the preliminary

hypothesis, with CBCL thought problems t-scores as the dependent variable in the

primary analysis.

Detailed inspection of the thought problems scale highlighted that a number of the items may have measured behaviours typically observed among autistic children. Descriptive comments from participants indicated that many were responding to an item (84) about '[removed due to copyright restrictions]' with reference to behaviours typically associated with the core symptoms of ASD, rather than PLEs. Example responses included, "repeats words she hears, with no understanding what they mean" and "mentally rigid about clothes and weather". Therefore, a new PLE scale was created for the purposes of the study and a second hierarchical multiple regression was run using this scale as the dependent variable. By necessity the PLE scale was composed of raw scores. The non-validated PLE scale was constructed with reference to the PQ-BC (Karcher et al., 2018) and the NHS definition of psychosis as having three key 'positive' features: hallucinations, delusions and confused thoughts (NHS, 2019). The items included in the PLE scale were therefore informed by theoretical and clinical judgement, as to which were most likely to be measuring the construct. Additionally, items were combined and assessed for internal reliability using the Cronbach's alpha statistic. The final combination of items were those with the highest level of internal reliability. The following CBCL items were included in the PLE scale: '[removed due to copyright restrictions]' (item 13), '[removed due to copyright restrictions]' (item 34), '[removed due to copyright restrictions]' (item 40), '[removed due to copyright restrictions]' (item 70), '[removed due to copyright restrictions]' (item 85), and '[removed due to copyright restrictions]' (item 89).

The independent variables inputted into both hierarchical multiple regression analyses were: age (years), sex (male or female), family history of psychosis (yes or no), internalising difficulties (CBCL t-scores), and total bullying frequency (MSPVS total scores). Ethnicity was excluded as a covariate due to sample homogeneity, while socioeconomic status was excluded due to missing data. In both regression analyses age, sex and family history of psychosis were entered into the model, followed by internalising difficulties. The independent variable of interest, total bullying frequency, was entered last to establish whether it predicted PLEs (thought problems t-scores, or non-validated PLE scale raw scores) over and above previously investigated variables.

#### **Results**

#### **Feasibility Issues**

#### **Consent Rate**

The consent rate of parents recruited via the clinical service was calculated as the number of individuals who consented to participate and completed all of the measures, as a proportion of those who were given information about the study. The consent rate achieved for clinical recruitment was 3.5%. As it was not possible to accurately estimate how many parents accessed information about the study following its promotion online, consent rates could not be calculated for this recruitment stream.

#### **Dropout Rate**

Dropout rates were calculated as the number of individuals who failed to complete all of the measures, as a proportion of the overall number who accessed the study via Qualtrics. The dropout rate for clinical recruitment was 33.3%, while the dropout rate for online recruitment was 50.5%. The combined dropout rate for both recruitment streams was 49.1%.

## Scale Reliability

Cronbach's alpha was calculated for the thought problems and internalising scales of the CBCL, in addition to the newly conceived CBCL PLE scale, and the MSPVS total score. Alpha statistics are reported in Table 3.

# Table 3

Questionnaire	Scale	Cronbach's Alpha	Internal Consistency
CBCL	Thought Problems	α = .64	Questionable
CBCL	Internalising	$\alpha = .90$	Excellent
CBCL	PLEs	$\alpha = .62$	Questionable
MSPVS	Total bullying frequence	$\alpha = .95$	Excellent

Cronbach's Alpha Statistics

## **Preliminary Hypothesis Testing**

### **Descriptive Statistics**

Means and standard deviations were calculated for internalising difficulties, total bullying frequency, thought problems, and the non-validated PLE scale. Descriptive statistics are summarised in Table 4. CBCL t-scores of  $\geq$ 70 are classified in the clinical range, while t-scores between 65 and 69 are borderline clinical (Achenbach & Rescorla, 2001). For the internalising scale 69.8% of the sample scored in the clinical range and 13.2% scored in the borderline clinical range. For the thought problems scale 83.0% scored in the clinical range, while 7.5% of the sample scored in the borderline clinical range. Sample mean scores for both the internalising difficulties and thought problems scales fell within the clinical range.

# Table 4

# Descriptive Statistics

	Mean (Range)	Standard Deviation
Internalising difficulties CBCL scale	72.9 (48-90)	10.2
Total bullying frequency (MSPVS)	39.0 (12-84)	18.0
Thought Problems CBCL scale	74.5 (50-87)	7.2
PLE (non-validated CBCL scale)	3.3 (0-11)	2.5

# **Correlation Analysis**

Spearman's Rho correlation coefficients were calculated to assess the relationship between the continuous variables (Table 5). Bullying frequency (MPSVS total scores) correlated only with the CBCL thought problems scale, with a moderate effect size. Scatterplots illustrating the relationships between MSPVS scores and the CBCL scales are depicted in Figure 2.

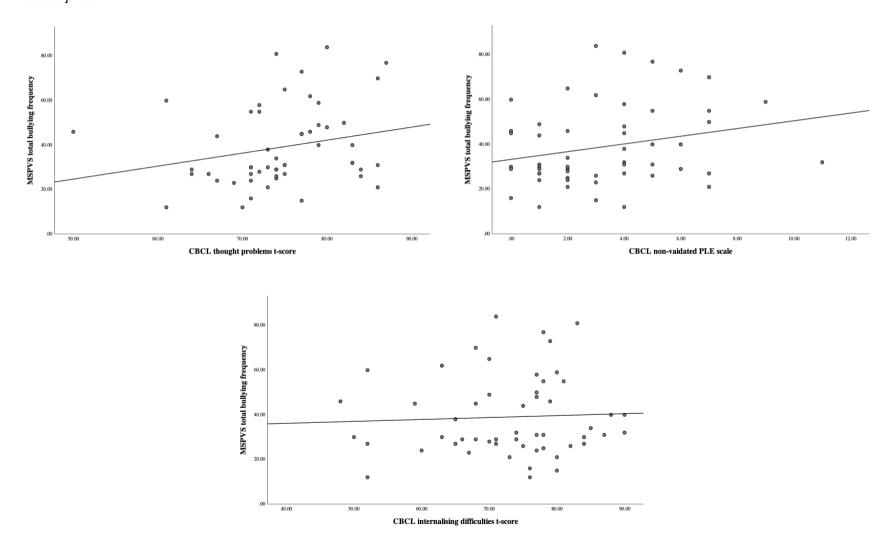
# Table 5

Spearman	'S	Rho	Coefficients
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	Age	MSPVS total	CBCL Internalising	CBCL thought problems
Age	-			
MSPVS total	16	-		
CBCL internalising	.35*	.08	-	
CBCL thought problems	.001	.34*	.42*	-
CBCL PLE Note. N= 53. * p < .05, **	.36* <sup>c</sup> p < .001	.25	.56**	.64**



Scatterplots



Note. Outliers were checked for errors and deemed genuine, therefore they were retained in subsequent analyses.

#### Hierarchical Multiple Regression

A hierarchical multiple regression was run to establish if the addition of total bullying frequency scores improved the prediction of PLEs (as measured via the thought problems scale) over and above age, sex, family history of psychosis and internalising difficulties alone<sup>1</sup>. Data were examined to establish whether they met the assumptions for multiple regression analysis (Laerd Statistics, 2020; Tabachnick & Fidell, 2013). Linearity was established via visual inspection of partial regression plots, and a plot of studentized residuals against predicted values. Visual inspection of the latter plot also revealed no evidence of homoscedasticity. The Durbin-Watson statistic (2.26) fell between 1.5 and 2.5 indicating that there was independence of residuals. Tolerance values were greater than 0.1 and correlation coefficients were < .7, therefore there was no evidence of multicollinearity. There were no studentized deleted residuals greater than  $\pm 3$  standard deviations and no values for Cook's distance above 1. Data were also checked for high leverage values; < 0.2 was considered safe, 0.2-0.5 was risky and > 0.5 was dangerous. There were two leverage values greater than 0.2, however, visual inspection of the data indicated that scores were unlikely to be errors. Additionally, leverage values were only marginally over 0.2 (.24 and .22), which meant that they were risky rather than dangerous. The related cases were therefore retained in the analysis. The assumption of normality of residuals was met, as assessed with a Q-Q plot.

Table 6 gives full details of the regression models tested in the primary analysis. The full model of age, sex, family history of psychosis, internalising difficulties and

<sup>&</sup>lt;sup>1</sup> The results of the secondary analysis (using the non-validated PLE scale as the dependent variable) were comparable to those of the primary analysis; details are therefore reported in Appendix O as supplementary information.

total bullying frequency to predict PLEs (as measured with the thought problems scale) was statistically significant,  $R^2 = .43$ , F(5, 47) = 6.95, p < .001, adjusted  $R^2 = .36$ . The addition of internalising difficulties to the prediction of PLEs led to an increase in  $R^2$  of .36, which reached statistical significance F(1, 48) = 29.08, p < .001. The addition of total bullying frequency to the prediction of PLEs led to an increase in  $R^2$  of .03, which was not statistically significant F(1, 47) = 2.12, p = .152.

# Table 6

		Thoug	ht Problems S	Scale		
	Model 1		Model 2		Model 3	
Variable	В	ß	В	ß	В	ß
Constant	71.99**		52.48**		48.31**	
Age	.21	.09	42	19	32	14
Sex	-1.82	12	-4.45*	30	-4.01*	27
Family History of Psychosis	1.54	.08	-1.45	08	54	03
Internalising difficulties			.48**	.68	.46**	.65
Total Bullying Frequency					.068	.170
$R^2$	.04		.40		.43	
F	.60		7.98**		6.95**	
$\Delta R^2$	.04		.36		.03	
$\Delta F$	.60		29.08**		2.12	

Hierarchical Multiple Regression 1; Thought Problems Scale

*Note.* N= 53. \* p < .05, \*\* p < .001.

## **Post-hoc Power Analysis**

G Power was used to compute post-hoc power for the overall model, and the independent variable of interest (total bullying frequency) within the primary regression analysis ( see Table 7).

#### Table 7

*Post-Hoc Power Analyses* 

Model	Power	
Total bullying frequency	0.30	
Overall model	0.99	

#### Discussion

The present study aimed to establish the feasibility of investigating the relationship between bullying victimisation and PLEs in autistic children, and to test the preliminary hypothesis of association between these variables.

#### **Measurement Issues**

During PPI groups parents identified a number of issues that must be accounted for, in order to gather information about bullying victimisation and PLEs directly from autistic children, in a valid and ethical manner. Specifically, parents suggested that researchers must account for differences in social skills, which may impact the ability of autistic children to engage with unfamiliar professionals. This issue may be particularly pertinent when asking autistic children to participate in research about potentially distressing topics, i.e. bullying and PLEs. Additionally, there is a need to account for the variations in cognitive ability observed among autistic children. Parents highlighted how difficulties with concentration may impact the completion of large questionnaire batteries. This issue may be compounded by high rates of co-occurrence between ASD and ADHD, a condition known to impact attention and concentration (Antshel & Russo, 2019; Leitner, 2014). It is essential to recognise heterogeneity of ability among autistic children, and to include this population in research (Hollin & Pearce, 2019). The complexities raised by parents at the PPI groups should not preclude the inclusion of autistic children as participants. However, it was not possible, in the available timeframe, for this study to address the practical and ethical issues raised by parents, and still collect data from a minimum of 30 children. Thus, the decision was made to collect parent-reported data only. These issues should, however, be addressed in future research, such that autistic children can be included as participants alongside their parents.

Choice of measures was limited by the established issue that tools tend not to be validated for use with (parents of) autistic children (Hanratty et al., 2015). The MSPVS was validated for use with autistic children and their parents by Adams et al. (2014), however, participants in their study were male adolescents, and the findings may not generalise to female or younger autistic children. Despite this potential issue, the internal consistency of the MSPVS total bullying frequency scale was excellent within the present study. A child self-report measure, the PQ-BC, was the original questionnaire of choice for measuring PLEs, but a parent-report alternative had to be identified, following changes to study design. The CBCL has been found to have robust measurement properties in autistic children (Hanratty et al., 2015). Moreover, the thought problems scale of the CBCL has been established as a valid tool for screening psychosis symptoms in neurotypical children (Salcedo et al., 2018; Simeonova et al., 2014). In the present sample, however, the thought problems scale of the CBCL, and the non-validated PLE scale lacked internal reliability. Indeed, although efforts were made to identify the combination of relevant items with the highest Cronbach's alpha, when

constructing the non-validated PLE scale, it was only possible to achieve 'questionable' internal consistency.

The poor internal reliability of the CBCL scales used to measure PLEs may have been a product of using parent-reported data. Achenbach and Rescorla (2001) reported a Cronbach's alpha of .78 for use of the thought problems scale in neurotypical children, indicating acceptable internal consistency. While this is better than the internal reliability achieved in the present sample, both findings may point to the limitations of asking parents about the subjective internal experiences of their children (see Kline et al. 2013). Accurate reports by parents rely largely upon disclosures by children about their experiences. A variety of factors may impede such disclosures, e.g. children may not appraise PLEs as unusual or threatening, and may therefore not feel it necessary to talk to parents about their experiences. Autistic children in particular may have a different understanding of the social norms that can lead to PLEs being appraised as unusual.

A final measurement issue detected within the present feasibility study was the impact of the conceptual crossover between ASD and psychosis, upon assessment of PLEs in autistic children. An item about '[removed due to copyright restrictions]' was excluded from the non-validated PLE scale as parents scored this with reference to behaviours that are typically observed in autistic children. It is possible that some of the 'positive' symptoms of psychosis overlap with features of ASD. For instance, sensory difficulties are common in autistic people (Mannion et al., 2014), and it is conceivable that some such experiences are comparable with hallucinations. Researchers should therefore exercise caution in their choice of measurement tools, and ensure that questionnaire items adequately delineate ASD and PLEs. It may be that current tools are not sufficiently able to do this. Future work to validate existing measures (e.g. the PQ-BC), or develop new tools, which are specifically designed to assess PLEs in autistic

children, would be of value. Interviewing autistic children about how they experience, describe and understand PLEs may inform the wording of questionnaire items in a measure developed specifically for this population. This approach would also be in line with calls for ASD research, which facilitates meaningful participation at all stages of the research process (Fletcher-Watson et al., 2019; Pellicano et al., 2014).

#### **Recruitment Issues**

The consent rate of parents approached via the clinical service was extremely low (3.5%). This is a strong indicator that recruiting a clinical sample, in order to examine the relationship between bullying victimisation and PLEs in autistic children, may not be feasible in the context of larger-scale research. There was also a high rate of dropout (non-completion of questionnaires), with three of the nine people recruited via the clinical service failing to complete all of the measures. The overall dropout rate for both recruitment streams was 49.1%. Various factors may have created barriers to parents participating in the study.

A potential issue was that the study was perceived to be lacking in direct impact for autistic children, as highlighted by one of the autism parenting groups which declined to promote the study. It was explained that "we do sometimes publish requests for research participants, but the research needs to have a significant impact on the lives of children and young people...this doesn't quite sound like the direct impact we are looking for" (anonymous, personal communication, February 5, 2020). The literature examining participation of autistic people in research highlights that similar concerns may have been held by prospective participants. Pellicano et al. (2014) highlighted how autistic people and individuals from the wider autism community may be sceptical about researcher intentions, and concerned that topics are pursued based on intellectual curiosity, rather concern for practical applicability of findings. Other parents may have been deterred by the fact that autistic children were not recruited as participants in the study. Indeed, one parent contacted the lead researcher and stated, "I feel the age range of your study is the perfect age for the autistic person to answer for themselves" (anonymous, personal communication, February 17, 2020). In a follow-up communication the parent explained, "unfortunately I don't feel comfortable answering on behalf of my child and don't feel comfortable asking others to so the same so I won't be advertising this study for you" (anonymous, personal communication, February 19, 2020). Again, concerns of this type have previously been highlighted in the research literature. Fletcher-Watson et al. (2019) suggested that including the parents of autistic children in research is important, but should not happen to the exclusion of autistic individuals. This strengthens the argument that follow-up studies should endeavour to include both autistic children and their parents as participants.

A more general issue is that parents may not have found the time to participate due to the demands of caring for their child(ren), which can be heightened when children have additional needs (Pellicano et al., 2014). This issue may have been compounded for parents approached via the clinical service, who may also have needed to prioritise adjusting to their child's ASD diagnosis (Da Paz et al., 2018). For parents who progressed to the questionnaires, the battery was large (the CBCL alone was 118 items), which may go some way in explaining dropout rates. The above barriers should be considered in future research examining the relationship between bullying victimisation and PLEs in autistic children, particularly as preliminary hypothesis testing indicates that large samples may be needed to investigate these phenomena.

## **Preliminary Hypothesis Testing**

Together the variables of age, sex, family history of psychosis, internalising difficulties and total bullying frequency accounted for 43% of the variance in PLEs, as

measured with the CBCL thought problems scale. Internalising difficulties alone accounted for 36% of the variance. This is consistent with the findings of Gadow and DeVincent (2012), who established that autistic children who experienced PLEs had higher rates of internalising mental health difficulties than peers who did not. The final addition of total bullying frequency into the regression analysis increased the amount of variance accounted for in the overall model by 3%. The association between bullying victimisation and PLEs was a positive one whereby, as total bullying frequency scores increased, so did scores on the thought problems scale. The observed effect size for bullying victimisation as a predictor of PLEs in this sample was very small ( $R^2 = .03$ ). These results were replicated in the supplementary analysis, using non-validated PLE scale scores as the dependent variable.

It is possible that the magnitude of the relationship between bullying victimisation and PLEs in autistic children was underestimated. In a study involving neurotypical children, Arseneault et al. (2011) established that the likelihood of reporting PLEs following bullying by peers almost doubled when looking at child self-reports (relative risk= 4.36), compared with parent-reports (relative risk= 2.47). In this way, had the present study collected child-reported data, the detected effect may have been larger, and bullying victimisation may have accounted for more variance in PLEs.

The detected relationship detected between bullying victimisation and PLEs did not reach statistical significance in either analysis. Findings cannot, therefore, be taken as evidence in favour of the preliminary hypothesis that there is a positive association between bullying victimisation and PLEs in autistic children, after controlling for confounding variables. Nonetheless, caution should be taken regarding interpretation of null findings at this stage. Indeed, Arain et al. (2010) warned against over-emphasis on hypothesis-testing and the drawing of definitive conclusions in the context of feasibility studies. This is particularly important in the present study, given that post-hoc power calculations indicated that the regression analyses were underpowered for testing bullying victimisation as a predictor of PLEs. Additionally, as discussed above, the use of parent-reports only may have meant that the magnitude of the relationship between bullying victimisation and PLEs was underestimated.

## Limitations

Parents of autistic children attending the PPI group provided valuable insights into the feasibility of collecting data on bullying victimisation and PLEs from autistic children. While it was a strength of the present study that the design was adapted in response to this feedback, it may have been possible to involve parents further at this stage. O'Cathain et al. (2015) suggested that there is an important role for qualitative approaches in the context of feasibility studies. Conducting a series of focus groups with parents at the PPI forum, and using formal methods of qualitative analysis may have provided richer insights, as to how best to investigate the relationship between bullying victimisation and PLEs in autistic children. Similarly, gathering qualitative feedback from parents who participated in the study regarding their experiences of being recruited, and completing the questionnaires may have given an indication as to the acceptability of the design.

Another limitation of the present study was that, where participants were recruited online, there was no objective way of confirming that children had a diagnosed ASD. Screening items were included in the demographics questionnaire, asking parents to confirm that their child had an ASD diagnosis, and to state when this was received. Participants who said that their child was undiagnosed were excluded from the study. Nonetheless, the design may have been strengthened by the inclusion of an ASD screening tool, e.g. the Childhood Autism Spectrum Test (Williams et al., 2008). When online recruitment commenced it was decided not to include an additional measure, due to the length of the existing battery and concerns about participant burden. However, an ASD screening tool would have provided a more objective way of confirming that children were autistic. Additionally, it may have been possible to include severity of ASD traits as a predictor of PLEs in the regression analyses.

## **Future Research**

The present feasibility study highlighted the complexities that may arise in investigating the relationship between bullying victimisation and PLEs in autistic children. While this study did not find a statistically significant association between bullying victimisation and PLEs, and the magnitude of the detected relationship was small, this should not preclude future research in this area. However, it will be important to address various feasibility issues identified herein, prior to conducting a large-scale cross-sectional investigation of these phenomena. Limitations regarding the measurement of PLEs, e.g. poor internal validity of the validated and non-validated CBCL scales, highlights a key area for future research. The field would benefit from the development of more sensitive and reliable methods of assessing PLEs in autistic children. Investigating multiple ways of asking about the same phenomena may be one way of managing the potential for misinterpretation of items due to the conceptual crossover between ASD and PLEs. Parents highlighted the potential challenges of engaging autistic children in research investigating bullying victimisation and PLEs, while the results of this study have confirmed that there are significant limitations associated with using parent-reports in isolation. A combined approach may be the way forward, and researchers could then formally establish inter-rater agreement, as exemplified by Kline et al. (2013).

Given the issues that arose with engaging a clinical sample, future research may benefit from recruiting a community sample, and incorporating an ASD screening tool into the battery of questionnaires to strengthen study design. It may also be of value to further investigate internalising difficulties as a predictor PLEs, particularly as they accounted for such a large proportion of the variance in PLE scores in the present study. There is uncertainty regarding whether bullying victimisation and internalising difficulties are independent predictors of PLEs, or whether they are inter-related. Indeed, in neurotypical children Fisher et al. (2013) found that the relationship between bullying victimisation and PLEs may be mediated by internalising difficulties. An additional consideration for future research is whether to examine PLEs as a cluster of related phenomena, as in the present study, or whether to take the approach of Catone et al. (2017) who focussed upon particular PLEs (e.g. suspicious thoughts) and looked at their relationship with specific forms of bullying. Certainly, in the psychosis literature it is increasingly common to examine the causal network surrounding specific phenomena, e.g. paranoid thoughts (Bentall, 2014; Bentall and Fernyhough, 2008).

#### **Clinical Implications**

At this stage, practitioners should exercise caution in drawing conclusions about the relationship between bullying victimisation and PLEs in autistic children. However, given that both bullying victimisation and PLEs occur at an elevated rate in this group, mental health providers for autistic children may consider routinely incorporating questions about these phenomena into assessments.

There are currently no validated tools for assessing PLEs in autistic children, though there are a limited number of validated tools for assessing bullying victimisation. Although this study highlights the limitations of using parent-report measures, they may have some clinical utility. This may particularly be the case where there are barriers to engaging children in assessment, e.g. if children struggle to concentrate or discuss distressing experiences with an unfamiliar professional. Parentreports may also be a useful source of supplementary information to use alongside child-reports.

## Conclusion

This study aimed to establish the feasibility of investigating the relationship between bullying victimisation and PLEs in autistic children, and to test the preliminary hypothesis of association between these variables. A number of feasibility issues became relevant, specifically in relation to the measurement of these phenomena in autistic children, and the recruitment of a clinical sample. Preliminary analyses failed to establish a relationship between bullying victimisation and PLEs in autistic children. However, this finding should be interpreted with caution and should not preclude future research in this area.

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## Appendices

### **Appendix A. Invitation Letter**

UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 6 01.11.2019. IRAS ID: 257859

Doncaster and Bassetlaw Hospitals

Dear Parent/ Guardian,

We are writing to invite you to participate in a study looking at unusual thoughts, feelings and sensations experienced by autistic children.

People of all backgrounds report unusual experiences e.g. seeing or hearing things that other people cannot or feeling suspicious of others. These experiences can occur in healthy individuals but have also been linked with various mental health difficulties.

Previous research with neurotypical children has found that various factors influence unusual experiences in childhood. While we know that autistic children have unusual experiences, research has not yet determined whether the same factors are associated with these. We would like to find out more about the factors associated with unusual experiences in autistic children.

Please find further details about the study on the enclosed information sheet. The study would involve you completing a series of online questionnaires about your child's experiences. The questionnaires would take 30-60 minutes to complete.

Please read the enclosed information sheet carefully; if you have any questions about the study please contact Kimberley Hastings, using the contact details below. If you are happy to take part in the study, after reading the information sheet please access the questionnaires via the following web link:

## https://tinyurl.com/yyezmscm

If you would prefer to complete the questionnaires on paper, please contact the research team, who can post these to you with a prepaid return envelope.

Thank you very much for taking the time to read this letter.

Yours faithfully,

Kimberley Hastings

Trainee Clinical Psychologist

Under the supervision of Professor Elizabeth Milne

UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 6 01.11.2019. IRAS ID: 257859

## **Contact Details**

## Address:

Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

## Email:

khastings1@sheffield.ac.uk

## Telephone:

Please leave a message with research officer Amrit Sinah on 0114 2226650 and a researcher will return your call.

## Appendix B. Information Sheet [Example items on p.3 of the information sheet

redacted due to copyright restrictions]

UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 6 01.11.2019. IRAS ID: 257859 Doncaster and Bassetlaw Hospitals

### Participant Information Sheet

### What factors are linked with unusual experiences in autistic children?

You are being invited to take part in a research project on behalf of your child. Before you decide whether or not to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information; our contact details are below.

### What is the purpose of the study?

It is common for people to have unusual experiences e.g. seeing, hearing or feeling things that other people cannot, or feeling suspicious of others. These experiences are reported by people of all ages and backgrounds and are sometimes linked with mental health difficulties.

Research has found that that unusual experiences in neurotypical children are linked with various factors. We would like to see if the same factors are associated with unusual experiences in autistic children.

### Why am I being asked to take part?

We would like you to complete a number of online questionnaires about your child. You would be asked about many aspects of your child's mental health (e.g. symptoms of anxiety and depression) and their unusual experiences. You would also be asked about their age, sex, ethnicity, experiences of being bullied, socioeconomic background and family history of psychosis. We would like to look at all of these factors as part of our analysis.

### Do I have to take part?

Taking part in this research is entirely voluntary. If you do not wish to take part, there will be no negative consequences. You may also discontinue your participation at any time, without giving a reason why.

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UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN, VERSION 6 01 11 2019, IRAS ID:
257859
                                       Doncaster and Bassetlaw Hospitals NHS
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108

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form, before you complete the questionnaires.

# What will happen if I take part? What will I have to do?

You can access the questionnaires using one of the methods below:

Type the following link into your web browser:

# https://tinyurl.com/yyezmscm

# OR:

2. If you have a QR reader on your phone, you can access the questionnaires by scanning the following QR code. Open your camera app and hold the camera toward the image below. This should bring up a message that you can click to get to the questionnaires.



OR:

3. You may also contact the lead researcher (Kimberley Hastings) and a link can be emailed directly to you. If you would prefer to complete paper questionnaires, these can be posted out with a prepaid return envelope. Researcher contact details can be found below.

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UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 6 01.11.2019. IRAS ID:
257859 Doncaster and Bassetlaw Hospitals
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NHS Foundation Trust

You will be asked to rate of statements about your child's unusual experiences and other aspects of mental health. You will be asked how true the statements are. Example statements include:



Your will also be asked about how often your child has experienced different types of bullying. Example questions include:



We are also collecting additional information from you including postcode of the family home, family history of psychosis and details regarding your child's age, sex and ethnicity. We will be looking at how all of these factors relate unusual experiences.

# What are the possible disadvantages and risks of taking part?

The questionnaires ask about topics that may be upsetting. If any of the questions cause you distress, you can contact a member of the research team using the details below.

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UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 6 01.11.2019. IRAS ID:
257859 Doncaster and Bassetlaw Hospitals
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If taking part in the study raises any concerns about your child being bullied or worries about their mental health (including unusual experiences), the research team can provide information on services that can offer advice and support.

# What are the possible benefits of taking part?

Whilst there are no immediate benefits for people participating in the project, it is hoped that this work will help us to better understand the experiences of autistic children. We hope that where autistic children (or their families) are curious or worried about unusual experiences, our research will help them to understand what may cause them.

# Will my taking part in this project be kept confidential?

All the information that you provide will be kept strictly confidential and will only be accessible to members of the research team. The only exception for this would be if information arose which caused the research team concern for the safety of you, your child or any other individuals. In these circumstances we would have a duty of care to pass the information on.

You and your child will not be able to be identified in any reports or publications unless you have given your explicit consent for this. If you agree to us sharing the information you provide with other researchers (e.g. by making it available in a data archive) then your personal details will not be included unless you explicitly request this.

# What is the legal basis for processing my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your child's personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)).

As we will be collecting some data that is defined in the legislation as more sensitive (i.e. information about your child's ethnic origin and health), we also need to let you know that we are applying the following condition in law: that the use of your child's data is 'necessary for scientific or historical research purposes'.

# NHS Foundation Trust

# What will happen to the data collected, and the results of the research project?

Your child's data will be stored securely at the University of Sheffield, accessible only to members of the research team. Data will be anonymised as your child will be assigned a participant number.

Your child's data will be stored on a password protected computer at the University of Sheffield. Postcode data will be used to calculate a statistic (the 'index of multiple deprivation') before being erased.

You may withdraw your child's data without giving a reason why up until December 2019, which is when we will begin analysing the data. To do so you can contact the lead researcher (details below). Up until commencement of data analysis your child's name will be stored securely with their participant number, so we can withdraw their data if you wish. However, after data analysis commences your child's name will be erased and you will no longer be able to withdraw their data from the study.

The results of this study will form part of a Clinical Psychology Doctoral thesis. We also aim to publish the results in an academic journal. As stated above neither you nor your child will be personally identified in any reports or publications.

Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions. We will ask for your explicit consent for your data to be shared in this way.

# Who is organising and funding the research?

This study is being conducted by Kimberley Hastings (Clinical Psychologist in Training), as part of the qualification towards becoming a Doctor of Clinical Psychology at the University of Sheffield. Kimberley is being supervised by Professor Elizabeth Milne, who is also based at the University of Sheffield. The research is being carried out in collaboration with the NHS, specifically the Autism Assessment Pathway based at Doncaster Royal Infirmary.

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UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 6 01.11.2019. IRAS ID:
257859 Doncaster and Bassetlaw Hospitals
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The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

# Who has ethically reviewed the project?

This project has been approved by the NHS ethical review board. This means that it has been agreed that the project is safe to be conducted in NHS settings and in the community.

# What if something goes wrong and I wish to complain about the research?

If you would like to make a complaint about this project, in the first instance you should contact the lead researcher or their supervisor. If you do not feel satisfied that your complaint has been dealt with appropriately you can contact the Head of the Psychology Department, Professor Glenn Waller. He can be contacted at the following address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT.

If your complaint relates to how your child's personal data has been handled, additional information about how to raise a complaint can be found in the University's Privacy Notice:

https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 6 01.11.2019. IRAS ID: 257859 Doncaster and Bassetlaw Hospitals

NHS Foundation Trust

## Contact Details

Lead researcher

Name: Kimberley Hastings Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT Email: khastings1@sheffield.ac.uk Telephone: Please leave a message with research officer Amrit Sinah on 0114 2226650 and Kimberley will return your call.

## Supervisor

Name: Professor Elizabeth Milne Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT Email: e.milne@sheffield.ac.uk

## Thank you very much for taking time to read about the project.

# **Appendix C. Consent Form**

UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 7 02.12.2019. IRAS ID: 257859

Doncaster and Bassetlaw Hospitals

## What factors are linked with unusual experiences in autistic children?

### Consent Form

Please tick the appropriate boxes	Yes	No
Taking Part in the Project		
I have read and understood the project information sheet (version 7) dated 02/12/2019 or the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)		
I have been given the opportunity to ask questions about the project.		
I agree to take part in the project. I understand that taking part in the project will involve me completing online questionnaires about my child.		
I understand that my participation is voluntary and that I can withdraw from the study at any time. I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw from the project.		
How my information will be used during and after the project		
I understand that my own and my child's personal details such as name, postcode and diagnoses etc will not be revealed to people outside the project.		
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that neither me or my child will be named in these outputs.		
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.		
I understand and agree that other authorised researchers may use my child's data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.		
I give permission for the questionnaire data that I provides to be stored in White Rose depository, so it can be used for future research and learning.		
So that the information you provide can be used legally by the researchers		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.		

Name of participant

Signature

Date

The template of this consent form has been approved by the University of Sheffield Research Ethics Committee and is available to view here: https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/further-guidance/homepage

### Project contact details for further information

Lead Researcher: Kimberley Hastings (khastings1@sheffield.ac.uk)

Supervisor: Professor Elizabeth Milne (e.milne@sheffield.ac.uk)

In the event of a complaint, please contact Head of Department: Professor Glenn Waller (g.waller@sheffield.ac.uk)

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Department of Psychology,

University of Sheffield,

Cathedral Court,

1 Vicar Lane,

#### Telephone

In the event that you want to contact any of the abovenamed people by telephone, please call:

Research Support Officer Amrit Sinah on: 0114 2226650

A message will be passed onto the staff member, who will return your call.

Sheffield, S1 2LT

The template of this consent form has been approved by the University of Sheffield Research Ethics Committee and is available to view here: <a href="https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/further-guidance/homepage">https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/further-guidance/homepage</a>

## Appendix D. Information Sheet (updated for online recruitment) [Example items

## on p.2 of the information sheet redacted due to copyright restrictions]

UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 7 02.12.2019. IRAS ID: 257859 Doncaster and Bassetlaw Hospitals NHS

## Participant Information Sheet

## What factors are linked with unusual experiences in autistic children?

You are being invited to take part in a research project on behalf of your child. Before you decide whether or not to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information; our contact details are below.

## What is the purpose of the study?

It is common for people to have unusual experiences e.g. seeing, hearing or feeling things that other people cannot, or feeling suspicious of others. These experiences are reported by people of all ages and backgrounds and are sometimes linked with mental health difficulties.

Research has found that that unusual experiences in neurotypical children are linked with various factors. We would like to see if the same factors are associated with unusual experiences in autistic children.

### Why am I being asked to take part?

We would like you to complete a number of online questionnaires about your child. You would be asked about many aspects of your child's mental health (e.g. symptoms of anxiety and depression) and their unusual experiences. You would also be asked about their age, sex, ethnicity, experiences of being bullied, socioeconomic background and family history of psychosis. We would like to look at all of these factors as part of our analysis.

### Do I have to take part?

Taking part in this research is entirely voluntary. If you do not wish to take part, there will be no negative consequences. You may also discontinue your participation at any time, without giving a reason why.

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UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 7 02.12.2019. IRAS ID:
257859 Doncaster and Bassetlaw Hospitals NHS
NHS Foundation Trust
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It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form, before you complete the questionnaires.

## What will happen if I take part? What will I have to do?

You will be asked to rate statements about your child's unusual experiences and other aspects of mental health. You will be asked how true the statements are. **Example statements include:** 



You will also be asked about how often your child has experienced different types of bullying. **Example questions include:** 



We are also collecting additional information from you including postcode of the family home, family history of psychosis and details regarding your child's age, sex and ethnicity. We will be looking at how all of these factors relate unusual experiences.

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UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 7 02.12.2019. IRAS ID:
257859 Doncaster and Bassetlaw Hospitals MHS
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## What are the possible disadvantages and risks of taking part?

The questionnaires ask about topics that may be upsetting. If any of the questions cause you distress, you can contact a member of the research team using the details below.

If taking part in the study raises any concerns about your child being bullied or worries about their mental health (including unusual experiences), the research team can provide information on services that can offer advice and support.

## What are the possible benefits of taking part?

Whilst there are no immediate benefits for people participating in the project, it is hoped that this work will help us to better understand the experiences of autistic children. We hope that where autistic children (or their families) are curious or worried about unusual experiences, our research will help them to understand what may cause them.

## Will my taking part in this project be kept confidential?

All the information that you provide will be kept strictly confidential and will only be accessible to members of the research team. The only exception for this would be if information arose which caused the research team concern for the safety of you, your child or any other individuals. In these circumstances we would have a duty of care to pass the information on.

You and your child will not be able to be identified in any reports or publications unless you have given your explicit consent for this. If you agree to us sharing the information you provide with other researchers (e.g. by making it available in a data archive) then your personal details will not be included unless you explicitly request this.

### What is the legal basis for processing my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your child's personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). As we will be collecting some data that is defined in the legislation as more sensitive (i.e. information about your child's ethnic origin and health), we also need to let you know that we are applying the following condition in law: that the use of your child's data is 'necessary for scientific or historical research purposes'.

# What will happen to the data collected, and the results of the research project?

Your child's data will be stored securely at the University of Sheffield, accessible only to members of the research team. Data will be anonymised as your child will be assigned a participant number.

Your child's data will be stored on a password protected computer at the University of Sheffield. Postcode data will be used to calculate a statistic (the 'index of multiple deprivation') before being erased.

You may withdraw your child's data without giving a reason why up until March 2020, which is when we will begin analysing the data. To do so you can contact the lead researcher (details below). Up until commencement of data analysis your name will be stored securely with data about your child, so we can withdraw their data if you wish. However, after data analysis commences your name will be erased and you will no longer be able to withdraw your child's data from the study.

The results of this study will form part of a Clinical Psychology Doctoral thesis. We also aim to publish the results in an academic journal. As stated above neither you nor your child will be personally identified in any reports or publications.

Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions. We will ask for your explicit consent for your data to be shared in this way.

# Who is organising and funding the research?

This study is being conducted by Kimberley Hastings (Clinical Psychologist in Training), as part of the qualification towards becoming a Doctor of Clinical Psychology at the University of Sheffield. Kimberley is being

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UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 7 02.12.2019. IRAS ID:
257859 Doncaster and Bassetlaw Hospitals
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supervised by Professor Elizabeth Milne, who is also based at the University of Sheffield. The research is being carried out in collaboration with the NHS, specifically the Autism Assessment Pathway based at Doncaster Royal Infirmary.

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

# Who has ethically reviewed the project?

This project has been approved by the NHS ethical review board. This means that it has been agreed that the project is safe to be conducted in NHS settings and in the community.

# What if something goes wrong and I wish to complain about the research?

If you would like to make a complaint about this project, in the first instance you should contact the lead researcher or their supervisor. If you do not feel satisfied that your complaint has been dealt with appropriately you can contact the Head of the Psychology Department, Professor Glenn Waller. He can be contacted at the following address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT.

If your complaint relates to how your child's personal data has been handled, additional information about how to raise a complaint can be found in the University's Privacy Notice:

https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 7 02.12.2019. IRAS ID: 257859

Doncaster and Bassetlaw Hospitals MHS NHS Foundation Trust

# Contact Details

Lead researcher

Name: Kimberley Hastings Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT Email: khastings1@sheffield.ac.uk Telephone: Please leave a message with research officer Amrit Sinah on 0114 2226650 and Kimberley will return your call.

### Supervisor

Name: Professor Elizabeth Milne Address: Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT Email: e.milne@sheffield.ac.uk

### Thank you very much for taking time to read about the project.

## Appendix E. Invitation Letter (updated for online recruitment)

UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 7 02.12.2019. IRAS ID: 257859

Doncaster and Bassetlaw Hospitals

Dear Parent/ Guardian,

We are writing to invite you to participate in a study looking at unusual thoughts, feelings and sensations experienced by children on the autism spectrum.

People of all backgrounds report unusual experiences e.g. seeing or hearing things that other people cannot or feeling suspicious of others. These experiences can occur in everyone, but have also been linked with various mental health difficulties.

Previous research with neurotypical children has found that various factors influence unusual experiences in childhood. While we know that children on the autism spectrum have unusual experiences, research has not yet determined whether the same factors are associated with these experiences. We would like to find out more about the factors associated with unusual experiences in children on the autism spectrum.

Taking part in the study would involve you reading some additional information about the project, then filling in 3 questionnaires about your child. The online questionnaires would take up to 30 minutes to complete. If you have any questions about the study please contact Kimberley Hastings, using the contact details below.

You can access the questionnaires using one of the methods on the following page.

UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 7 02.12.2019. IRAS ID: 257859

Doncaster and Bassetlaw Hospitals MHS NHS Foundation Trust

1. Type the following link into your web browser:

### https://tinyurl.com/yyezmscm

OR:

If you have a QR reader on your phone, you can access the questionnaires by scanning the following QR code. Open your camera app and hold the camera toward the image below. This should bring up a message that you can click to get to the questionnaires.



OR:

 You may also contact the lead researcher (Kimberley Hastings) and a link can be emailed directly to you. If you would prefer to complete paper questionnaires, these can be posted out with a prepaid return envelope. Researcher contact details can be found below.

Thank you very much for taking the time to read this letter.

Yours faithfully,

Kimberley Hastings Trainee Clinical Psychologist Under the supervision of Professor Elizabeth Milne UNUSUAL EXPERIENCES IN AUTISTIC CHILDREN. VERSION 7 02.12.2019. IRAS ID: 257859

Doncaster and Bassetlaw Hospitals

### Contact Details

## Address:

Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

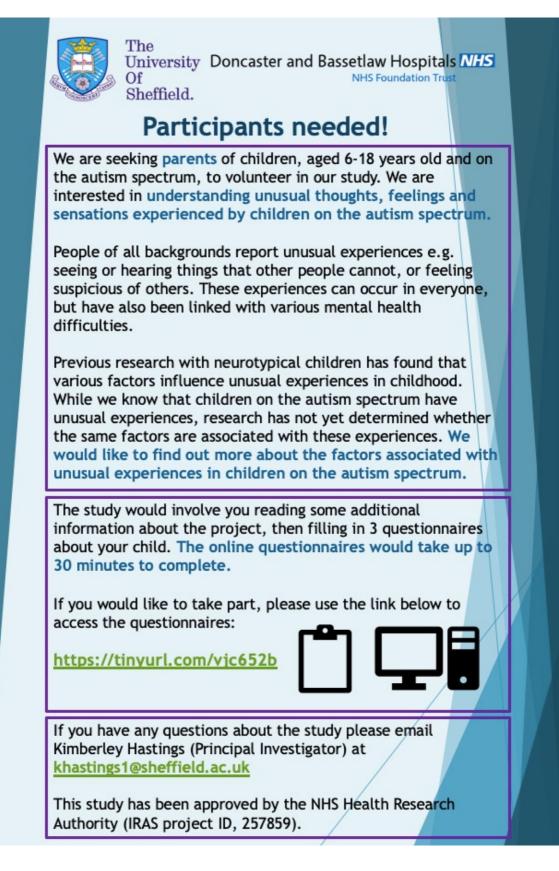
### Email:

khastings1@sheffield.ac.uk

### Telephone:

Please leave a message with research officer Amrit Sinah on 0114 2226650 and a researcher will return your call.

# **Appendix F. Recruitment Poster**



### **Appendix G. Research Ethics Committee Approval**



North East - Newcastle & North Tyneside 1 Research Ethics Committee

NHSBT Newcastle Blood & Transplant Centre Holland Drive Newcastle upon Tyne NE2 4NQ

Telephone: 0207 1048084

<u>Please note</u>: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

16 May 2019

Miss Kimberley Hastings Trainee Clinical Psychologist Sheffield Health and Social Care NHS Foundation Trust University of Sheffield Clinical Psychology Department Cathedral Court, Vicar Lane S1 2LT

Dear Miss Hastings

 
 Study title:
 Is there an association between being subjected to bullying and the presence of psychosis-like experiences in autistic children?

 REC reference:
 19/NE/0147

 Protocol number:
 N/A

 IRAS project ID:
 257859

The Proportionate Review Sub-committee of the North East - Newcastle & North Tyneside 1 Research Ethics Committee reviewed the above application in correspondence.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact <u>hra.studyregistration@nhs.net</u> outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

### Ethical opinion

On behalf of the Committee, the sub-committee gave a Favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

A Research Ethics Committee established by the Health Research Authority

#### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, <u>www.hra.nhs.uk</u> or at <u>http://www.rdforum.nhs.uk</u>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact <u>hra.studyregistration@nhs.net</u>. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non-registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion").

### Approved documents

The documents reviewed and approved were:

A Research Ethics Committee established by the Health Research Authority

Document	Version	Date
IRAS Application Form [IRAS_Form_16042019]		16 April 2019
Letters of invitation to participant [Invitation letter V4 13.03.2019]	4	13 March 2019
Non-validated questionnaire [Demographics Questionnaire V2 28.03.2019]	2	28 March 2019
Other [Email re chief investigator ]		29 April 2019
Participant consent form [Consent Form V4 10.05.2019]	4	10 May 2019
Participant information sheet (PIS) [Information Sheet V4 13.03.2019]	4	13 March 2019
Referee's report or other scientific critique report [Scientific Approval]	1	28 January 2019
Referee's report or other scientific critique report [Scientific Approval]	2	26 March 2019
Research protocol or project proposal [Research Protocol V5 28.03.2019]	5	28 March 2019
Summary CV for Chief Investigator (CI) [CV_KH V1 19.03.2019]	1	19 March 2019
Summary CV for supervisor (student research) [CV_EM V1 20.03.2019]	1	20 March 2019
Validated questionnaire [Sample Child Behavior Checklist]	1	13 March 2019
Validated questionnaire [Modified Schwartz Peer Victimization Scale]	1	20 August 2018

### Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

### Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study.

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <u>http://www.hra.nhs.uk/about-thehra/governance/guality-assurance/</u>

A Research Ethics Committee established by the Health Research Authority

### **HRA** Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities— see details at: <u>https://www.hra.nhs.uk/planning-and-improving-</u> research/learning/

With the Committee's best wishes for the success of this project.

19/NE/0147 Please quote this number on all correspondence

Yours sincerely

Mayer

Mr Paddy Stevenson Chair

Enclosures:	List of names and professions of members who took part in the review
	'After ethical review – guidance for researchers' SL-AR2
Copy to:	Dr Andrew Thompson - Research Dept, University of Sheffield
	Professor Elizabeth Milne – University of Sheffield
	Lead Nation - England

### North East - Newcastle & North Tyneside 1 Research Ethics Committee

### Attendance at PRS Sub-Committee of the REC meeting on 8 May 2019

### Committee Members:

Name	Profession	Present	Notes
Dr Maria Bokhari	Clinical Trials Officer/Co- ordinator	Yes	
Mr Andrew Brenikov	Historian	Yes	
Mr Paddy Stevenson (Chair)	Research Operations Manager/Registered Nurse	Yes	

### Also in attendance:

Name	Position (or reason for attending)
Gillian Mayer	Approvals Officer

Ymchwil lechyd a Gofal Cymru Health and Care Research Wales



Miss Kimberley Hastings Trainee Clinical Psychologist Sheffield Health and Social Care NHS Foundation Trust University of Sheffield Clinical Psychology Department Cathedral Court, Vicar Lane S1 2LT

Email: hra.approval@nhs.net HCRW.approvals@wales.nhs.uk

09 July 2019

Dear Miss Hastings

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	Is there an association between being subjected to
	bullying and the presence of psychosis-like
	experiences in autistic children?
IRAS project ID:	257859
Protocol number:	N/A
REC reference:	19/NE/0147
Sponsor	Organization not set

I am pleased to confirm that <u>HRA and Health and Care Research Wales (HCRW) Approval</u> has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, <u>in</u> line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

# How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see <u>IRAS Help</u> for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

### How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

### What are my notification responsibilities during the study?

The document "After Ethical Review – guidance for sponsors and investigators", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The <u>HRA website</u> also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

### Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is 257859. Please quote this on all correspondence.

Yours sincerely, Catherine Adams

Approvals Manager

Email: hra.approval@nhs.net

Copy to: Dr Andrew Thompson

## List of Documents

# The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	Version	Date
Evidence of Sponsor Insurance or Indemnity (non NHS Sponsors only) [Insurance part 1 V1 24.05.2019]	1	22 May 2019
HRA Schedule of Events	1	29 April 2019
IRAS Application Form [IRAS_Form_16042019]		16 April 2019
IRAS Application Form XML file [IRAS_Form_16042019]		16 April 2019
Letters of invitation to participant [Invitation letter V4 13.03.2019]	4	13 March 2019
Non-validated questionnaire [Demographics Questionnaire V2 28.03.2019]	2	28 March 2019
Other [Email re chief investigator ]		29 April 2019
Other [Statement of Activities]	2	09 July 2019
Participant consent form [Consent Form V4 10.05.2019]	4	10 May 2019
Participant Information sheet (PIS) [Information Sheet V4 13.03.2019]	4	13 March 2019
Referee's report or other scientific critique report [Scientific Approval]	1	28 January 2019
Referee's report or other scientific critique report [Scientific Approval]	2	26 March 2019
Research protocol or project proposal [Research Protocol V5 28.03.2019]	5	28 March 2019
Summary CV for Chief Investigator (CI) [CV_KH V1 19.03.2019]	1	19 March 2019
Summary CV for supervisor (student research) [CV_EM V1 20.03.2019]	1	20 March 2019
Validated questionnaire [Sample Child Behavior Checklist]	1	13 March 2019
Validated questionnaire [Modified Schwartz Peer Victimization Scale]	1	20 August 2018

IRAS project ID 267869

### Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There is only one participating NHS organisation therefore there is only one site type.	Organisations will not be required to formally confirm capacity and capability, and research procedures may begin 35 days after provision of the local information pack, provided the following conditions are met. • You have contacted participating NHS organisations (see below for details) HRA and HCRW Approval has	A statement of activities has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used. Please note that from 5 June, the Statement of Activities used in England and Wales for non- commercial studies and the Site Specific Information form, used in Northern Ireland and Scotland is being replaced with a UK wide Organisational Information document. See <u>https://www.hra.nhs.uk/about- us/news-updates/launch-uk-</u> <u>local-information-pack-</u>	The project will be funded by the University of Sheffield. This will cover the cost of all the resources for the project (questionnaires, postage etc).	The Chief Investigator will be responsible for all research activities performed at study sites.	The sponsor has confirmed that local staff in participating organisations in England who have a contractual relationship with the organisation will undertake the expected activities. Therefore, no honorary research contracts or letters of access are expected for this study.

been issued.			1
	supporting-set-nhshsc-		
The NHS	research-uk/		
organisation			
has not			
provided a			
reason as to			
why they			
cannot			
participate			
The NHS			
organisation			
has not			
requested			
additional time			
to confirm.			
<ul> <li>You may start</li> </ul>			
the research			
prior to the			
above deadline			
if HRA and			
HCRW			
Approval has			
been issued			
and the site			
positively			
confirms that			
the research			
may proceed.			
may proceed.			

You should now		
provide the local		
information pack for		
your study to your		
participating NHS		
organisations. A		
current list of R&D		
contacts is accessible		
at the NHS RD Forum		
website and these		
contacts MUST be		
used for this purpose.		
The password to		
access the R&D		
contact list is		
Redhouse1.		

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up. Time will be needed for clinical staff to identify potential participants from the service database and post participant information packs. Time

will be needed in feedback sessions, for staff to mention the study to caregivers and pass them a participant information pack

## **Appendix H. DBTH Ethical Approval**

# NHS

Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust

> Doncaster Royal Infirmary Armthorpe Road, Doncaster South Yorkshire

> > Tel: 01302 366666 Fax: 01302 320098

Minicom: 01302 553140 (only for people who are deaf)

Doncaster Clinical Research Joint Research Office with NHS Doncaster and NHS Bassetlaw Tel: 01302 644069 Fax No.: 01302 642925

Email: dbth.clinicalresearch@nhs.net

19 August 2019

#### CONFIDENTIAL

Miss Kimberley Hastings University of Sheffield Cathedral Court, Floor F 1 Vicar Lane Sheffield S12LT

#### Dear Miss Hastings.

Study Title:

Chief Investigator: Sponsor: DBH Reference: REC Reference: IRAS ID: Is there an association between being subjected to bullying and the presence of psychosis-like experiences in autistic children? Miss Kimberley Hastings University of Sheffield 1004/2019/NCT 19/NE/0147 257859

The Research & Development Department at Doncaster & Bassetlaw Teaching Hospitals NHS Foundation Trust has completed a capacity and capability review for the above study and can confirm authorisation for the study to be undertaken within the Trust. For your information, the project reference is 1004/2019/NCT I would be grateful if you could quote this number in any further correspondence with this department.

#### Documentation

Your authorisation has been granted based on submission of the following documentation:

- Research Protocol (Version 5, dated 28 March 2019)
- HRA approval (dated 09 July 2019)
- REC approval (dated 16 May 2019)
- IRAS Application Form (Submission code: 257859/1321039/37/59)

Trust authorisation for this research study is on the understanding and provision that you will adhere to the conditions detailed below.

#### Contracts

It is your responsibility to ensure you have sufficient indemnity to undertake this project. In addition, it is also your responsibility to ensure that letters of access / honorary contracts are in place where necessary. For information relating to letters of access / honorary contracts, please contact the R&D team.



Become a Trust member and make a difference to the care our hospitals provide. Email foundation.office@dbh.nhs.uk or visit www.dbh.nhs.uk for more information about membership.

Jan 2017

### Good Clinical Practice training

In accordance with ICH GCP guidelines and the UK Statutory Instruments, all key personnel involved in a Clinical Trial as part of the research team, must have completed GCP training within the last three years. It is your responsibility to ensure the research team have received this training. For information regarding upcoming GCP training courses, please contact the R&D team.

#### Auditing

I would strongly urge you to maintain an accurate and up to date site file for your documentation, as the Trust randomly audits projects to assess compliance with the relevant legal frameworks and legislation. If your study is selected, you will be notified in writing not less than two weeks prior to the required submission date of documentation. In addition, where monitoring and auditing procedures are carried out by the Sponsor, you will be required to cooperate, where appropriate.

### Monitoring

In order to ensure adequate monitoring of ongoing studies, the R&D department will send through periodic monitoring forms which require completion by the Principal Investigator or delegated individual. These forms need to be completed and sent through to the Research Governance department as a condition of the approval of this study.

I would like to take this opportunity to wish you well with your project. If you have any questions, or if I can be of any further assistance to you, please do not hesitate to contact me.

Yours sincerely

Rodling

Emma Adams Research & Development Manager

- CC Professor Elizabeth Milne Department of Psychology Email: e.milne@sheffield.ac.uk
- cc Dr Andrew Thompson Department of Psychology Email: a.r.thompson@sheffield.ac.uk

# Appendix I. Research Ethics Committee Approval to Recruit Online

nrescommittee.northeast-newcastleandnorthtyneside1@nhs.net <noreply@harp.org.uk> to me, a.r.thompson 👻

Dear Miss Hastings,

IRAS Project ID:	257859 Unusual experiences in autistic children. Version 1. <b>3, 02.12.2019</b>			
Short Study Title:				
Amendment No./Sponsor Ref:				
Amendment Date:	02 December 2019			
Amendment Type:	Substantial Non-CTIMP			

I am pleased to confirm HRA and HCRW Approval for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the conditions outlined in your categorisation email.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <a href="http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/">http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/</a>.

Please contact <u>hra.amendments@nhs.net</u> for any queries relating to the assessment of this amendment.

Kind regards,

Miss Yasmin King Approval Administrator Health Research Authority Ground Floor | Skipton House | 80 London Road | London | SE1 6LH E.hra.amendments@nhs.net W. www.hra.nhs.uk

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📼 Tue, 7 Jan, 11:33 🔺 🔦 🗄

# Appendix J. DBTH Ethical Approval to Recruit Online

# Doncaster and Bassetlaw Teaching Hospitals

NHS Foundation Trust

Doncaster Clinical Research Joint Research Office with NHS Doncaster and NHS Bassetlaw Tel: 01302 644069 Fax: 01302 642925 Email: dbfh.clinicalresearch@nhs.net

05 February 2020

### CONFIDENTIAL

Miss Kimberley Hastings University of Sheffield Cathedral Court, Floor F 1 Vicar Lane Sheffield S1 2LT Doncaster Royal Infirmary Armthorpe Road, Doncaster South Yorkshire DN2 SLT

> Tel: 01302 366666 Fax: 01302 320098

Minicom: 01302 553140 (only for people who are deaf)

Dear Miss Hastings,

Study Title:

Chief Investigator: Sponsor: DBH Reference: REC Reference: IRAS ID: Amendment: Is there an association between being subjected to bullying and the presence of psychosis-like experiences in autistic children? Miss Kimberley Hastings University of Sheffield 1004/2019/NCT 19/NE/0147 257859 SA3, dated 02 December 2019

The Research & Development Department at Doncaster & Bassetlaw Teaching Hospitals NHS Foundation Trust has completed a capacity and capability review for the above study amendment and can confirm continued authorisation for the study within the Trust. For your information, the project reference remains 1004/2019/NCT. I would be grateful if you could quote this number in any further correspondence with this department.

#### Documentation

Your authorisation has been granted based on submission of the following documentation outlining the substantial amendment approved by North East - Newcastle & North Tyneside 1 Research Ethics Committee (07 January 2020) and the HRA (07 January 2010).

### Amended documentation approved by the HRA is listed in Appendix A

#### Contracts

It is your responsibility to ensure you have sufficient indemnity to undertake this project and that letters of authority / honorary contracts are in place where necessary.

### Auditing

I would strongly urge you to maintain an accurate and up to date site file for your documentation, as the Trust randomly audits projects to assess compliance with the relevant legal frameworks and legislation. If your study is selected, you will be notified in writing not less than two weeks prior to the required submission date of documentation.



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Jan 2017

I would like to take this opportunity to wish you well with your project. If you have any questions or I can be of any further assistance to you, please do not hesitate to contact me.

Yours sincerely

Realing

Emma Adams Research Management & Governance Manager

Attachment:

P

Appendix A - REC letter dated 07 January 2020 (3 pages)

# Appendix K. Demographics Questionnaire

UNUSUAL EXPERIENCES IN AUT CHILDREN. VERSION 3 02.12.2019 257859		Doncaster and Bassetlaw Hospitals MHS NHS Foundation Trust							
Child Demographics Questionnaire									
1. What is your home postcode?									
2. How old is your child?									
3. What is your child's sex (please	tick)?								
Male Female									
4. What is your child's ethnicity (p	lease tick)?								
White									
English / Welsh / Scottish / Northern I	rish / British 🔲	Irish 🛄							
Gypsy or Irish Traveller 🔲									
Any other White background, please s	pecify 🔲								
Mixed / Multiple ethnic groups									
White and Black Caribbean	W	hite and Black African							
White and Asian									
Any other Mixed / Multiple ethnic bac	kground, please	specify 🔲							
Asian / Asian British									
Indian 🔲 🛛 I	Pakistani 🔲								
Bangladeshi 🔲 🛛	Chinese 🔲								

Doncaster and Bassetlaw Hospitals
Any other Asian background, please specify
Black / African / Caribbean / Black British
African Caribbean
Any other Black / African / Caribbean background, please specify 🔲
Other ethnic group
Arab
Any other ethnic group, please specify
5. Does your child have a diagnosis of an Autism Spectrum Disorder (please tick)?
Yes No
6. How old was your child when they were diagnosed with an Autism Spectrum Disorder?
<ol> <li>Has your child got a diagnosis of any conditions, other than an Autism Spectrum Disorder? If yes, please specify,</li> </ol>

143

8. Have any of your child's relatives (including yourself) ever had a period, lasting six months or more, when they saw visions, heard voices or thought people were spying on them or plotting against them?



If yes, please specify how they are related to your child (e.g. parent, sibling, grandparent).

Relation:	Relation:
Relation:	Relation:

3

# Appendix L. MSPVS

[Removed due to copyright restrictions].

# Appendix M. CBCL

[Removed due to copyright restrictions].

# Thank you very much for taking the time to complete these questionnaires.

If you have any comments, questions or concerns please contact the research team, using the contact details below.

Lead Researcher: Kimberley Hastings (khastings1@sheffield.ac.uk) Supervisor: Professor Elizabeth Milne (e.milne@sheffield.ac.uk) In the event of a complaint, please contact Head of Department: Professor Glenn Waller (g.waller@sheffield.ac.uk)

## Address

Department of Psychology, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield, S1 2LT

## Telephone

In the event that you want to contact any of the abovenamed people by telephone, please call: Research Support Officer Amrit Sinah on: **0114 2226650** A message will be passed onto the staff member, who will return your call.

# **Relevant Charities**

### Kidscape

This is an anti-bullying charity for children and families. Website: https://www.kidscape.org.uk Email: info@kidscape.org.uk Telephone (parent advice line): 02078235430

### YoungMinds

This is a charity advocating for children and young people's mental health. Website: https://youngminds.org.uk Telephone (parents advice line): 0808 802 5544

Mind

The Mind Infoline provides information on mental health difficulties and where to access support. Website: https://www.mind.org.uk/information-support/helplines/ Email: info@mind.org.uk Telephone: 0300 123 3393 Text: 86463 Mind also provides links to other helpful organisations: https://www.mind.org.uk/information-support/information-for-children-and-young-people-az/information-for-parents/useful-contacts/#.XStgKy-ZNQI Appendix O. Results of the Secondary Regression Analysis

A second hierarchical multiple regression was run using the non-validated PLE scale as the dependent variable. Visual inspection of a plot of studentized residuals against unstandardized predicted values indicated that the assumption of homoscedasticity was violated. This was corrected with a square root transformation of the dependent variable (the non-validated PLE scale). The remaining assumption checks were in line with those reported for the primary analysis. Details of the regression models tested in the secondary analysis can be found in Table A1. The full model of age, sex, family history of psychosis, internalising difficulties and total bullying frequency to predict PLEs (as measured with the non-validated scale) was statistically significant,  $R^2 = .45$ , F(5, 47) = 7.67, p < .001, adjusted  $R^2 = .39$ . The addition of internalising difficulties to the prediction of PLEs led to an increase in  $R^2$  of .26, which reached statistical significance F(1, 48) = 21.39, p < .001. The addition of total bullying frequency to the prediction of PLEs led to an increase in  $R^2$  of .26, which reached statistical significance F(1, 47) = 3.01, p = .089.

# Table A1

		Non-Va	alidated PLE	Scale		
	Model 1		Model 2		Model 3	
Variable	В	ß	В	ß	В	ß
Constant	.55		-1.33		-1.88*	
Age	.10*	.38	.04	.15	.05	.20
Sex	.09	.05	16	10	11	06
Family History of Psychosis	04	02	33	16	21	10
Internalising difficulties			.05**	.58	.04**	.54
Total Bullying Frequency					.01	.20
$R^2$	.15		.41		.45	
F	2.95*		8.48**		7.67**	
$\Delta R^2$	.15		.26		.04	
$\Delta F$	2.95*		21.39**		3.01	

Hierarchical Multiple Regression 2; Non-Validated CBCL Scale

*Note*. N= 53. \* p < .05, \*\* p < .001.