Blood, Laura (2022) *Receiving an autism diagnosis and the efficacy of psychological interventions for OCD in children and young people.* D Clin Psy thesis.

https://theses.gla.ac.uk/83364/

Receiving an Autism Diagnosis and the Efficacy of Psychological Interventions for OCD in Children and Young People

Laura Blood

BSc (Hons), PGCert

Submitted in partial fulfilment of the requirements for the degree of

Doctorate in Clinical Psychology

School of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

University of Glasgow

December 2022

Table of Contents

List of Tables

List of Figures

Acknowledgements

Firstly, I would like to thank my supervisors Dr Breda Cullen, Dr Ruchika Gajwani and Dr Jason Lang for all your expertise and support throughout the research process. It had been an invaluable experience and a great pleasure to learn from you. Also, thank you to Jessica Whyte for your contributions to this project.

Secondly, I would like to thank Dr Michelle Bryans along with Sarah and Beth for your persistence with recruitment. Thank you also, to Sophie Little, not just for your contribution to my systematic review but for being my study buddy and continued encouragement right to the end, we did it.

Most importantly I would like to thank all those who participated in the study. I am extremely grateful for your commitment and I feel honoured to have heard your experiences.

To all my friends who I have shared this doctoral experience with, thank you. Thank you for being there in times of happiness, sadness, stressfulness and all of the times in between I truly value all of you.

Matthew, thank you for always telling me this was possible even when I did not believe it myself, and for your ever lasting patience and proof-reading abilities.

Finally, I am leaving this chapter of my life with a greater confidence in myself and my abilities, which I once may have considered disabilities. Thank you to all those who have allowed me to grow and to see myself in a better light.

Chapter 1: Systematic Review

A Systematic Review of Psychological Interventions for Obsessive-Compulsive Disorder in Children and Young People with Autism Spectrum Disorder

Prepared in accordance with the author requirements for the
Journal: Frontiers in Psychology

https://www.frontiersin.org/guidelines/author-guidelines

Abstract

The aim of this systematic review is to evaluate the current literature on the efficacy of psychological interventions for the treatment of obsessive-compulsive disorder (OCD) among children and young people (CYP) with autism spectrum disorders (ASD). There is a high comorbidity with ASD and OCD and, at present, no specific guidance for the treatment of OCD in CYP with ASD. This indicates an urgent need to identify evidence-based interventions which address this complex presentation. Based on a-priori review criteria, 10 studies were included. The design of the studies included two quasi-experimental design, one single case experiment design, one case-controlled study, one case series and five case studies. These studies offer promising, tentative results on the effectiveness of modified psychological interventions for the treatment of OCD in this population. Due to the paucity of high-quality research in this area, studies were not excluded based on poor methodology. Therefore, any conclusions drawn should be interpreted with caution. Also, the wide variety of interventions and modifications within the included studies made analysis and comparison of the interventions difficult. Robust research focussing on modifications in interventions for the treatment of OCD in CYP with ASD is required.

1. Introduction

1.1 Autism spectrum disorder and prevalence of comorbid OCD

Autism spectrum disorder (ASD) is a pervasive, neurodevelopmental condition that is characterised by impairments in social interaction and communication as well as restrictive, repetitive or stereotyped behaviours (Rangasamy, D'Mello & Narayanan, 2013). Restrictive, repetitive behaviours (RRBs) within ASD can be reliably grouped in to three categories: repetitive sensory motor behaviours, insistence on sameness behaviours and restricted interests (Bishop et al., 2013).

Those with ASD are more likely to present with co-occurring conditions than CYP without experiences of ASD, with research indicating 72%-98% of CYP with ASD also meet criteria for at least one co-occurring neurodevelopmental or mental health condition (Joshi et al., 2010; Matson & Nebel-Schwalm, 2007). It is estimated that 17-37% of CYP with ASD also meet the criteria for obsessive compulsive disorder (OCD) (Leyfer et al., 2006; Van Steensel et al., 2011). The reported global prevalence of OCD in CYP in general ranges from 0.25% - 3% (Ruscio, 2010; Kalra & Swedo, 2009) indicating that OCD is more prevalent amongst those with ASD than the general population.

1.2 Obsessive compulsive disorder

OCD is characterised by the presence of obsessions leading to time consuming compulsive behaviours that cause functional impairment (Jiujias, Kelly & Hall, 2017). Obsessions are described as persistent, negative thoughts that are unpleasant, irrational and ego-dystonic in that they are distressing and unacceptable. Common examples include fear of contamination and fear for loved one's survival. Compulsions are behaviours that are used to relieve the anxiety caused by the obsessive thoughts. They are performed excessively and can contribute to functional impairment. Some common examples include washing hands and checking behaviours (APA, 2013). OCD was previously classified as one of the nine major anxiety disorders, however, in the DSM-5 it has been classified separately under Obsessive-Compulsive related disorders. The ICD-10 classifies OCD under Neurotic, stress-related and somatoform disorders, along with other anxiety disorders (WHO, 1993). However, the ICD-11 proposes that this classification is updated as "Anxiety and Fear Related Disorders" which will still encompass OCD (Simpson & Reddy, 2014).

1.3 ASD and comorbid[1] OCD

The phenomenology of some behaviours in OCD and ASD overlap. This includes compulsive like behaviours, restricted and repetitive behaviours, ritualised patterns of behaviour and resistance to change across different contexts (APA, 2013). This overlap can make differential diagnosis and subsequent treatment of OCD symptoms in CYP with ASD difficult (Jiujias, Kelly & Hall, 2017). Perez (2013) highlights that the compulsions in OCD have a functional relationship with the obsessive thoughts in that they aim to supress and neutralise anxiety caused by the obsessive thoughts. The compulsions in OCD are usually preceded by an obsession and associated with the momentary relief of anxiety and ego-dystonia (Krebs & Heyman, 2015). Such obsessions and compulsions can cause debilitating anxiety and are often resistant to change (Krebs & Heyman, 2015). However, RRBs within ASD are thought to be ego-syntonic in that they represent a pleasurable, affective experience that are not resisted and do not cause symptoms of anxiety (Kose, Fox, & Storch, 2018). They are behaviours that the child or young person is intrinsically motivated to perform (Perez, 2013). RRBs, although described in the DSM as “restrictive”, can include interests which contribute to a sense of happiness, pride and validation (Mercier, Mottron & Belleville, 2000).

Severe, chronic anxiety is a feature in OCD and is also a common co-occurring condition in ASD (APA, 2013). Severe and enduring anxiety is a criterion in the diagnosis of OCD and is often expressed as the primary precursor to compulsions (Starcevic, 2011). It also plays a dual role in that obsessions cause the individual to experience anxiety and the function of compulsions is to alleviate anxiety caused by them. Whilst this distinction is important it is often difficult to establish (Meier, et al. 2015). Those with ASD who exhibit clinical levels of anxiety report higher instances and increased severity of RRBs on the Repetitive Behaviour Questionnaire (Rodgers et al., 2012). However, it is important to distinguish the function of these RRBs. Perez (2014) indicated that the function of RRBs for those with ASD is primarily that of pleasure and enjoyment as well as soothing. The behaviour is used to help cope with emotionally negative stimuli and as distractors from distress.

Meier and colleagues (2015) conducted a longitudinal study looking at the co-occurrence of OCD and ASD along with familial risk in a large cohort. Their results

---

[1] Throughout this paper ASD and OCD are described as comorbid in that they are distinct conditions that occur together (Tyrer, 2017) however, it is unclear which features of OCD and ASD co-exist.

suggested that OCD is far more common in individuals with ASD than would be expected by chance. A diagnosis of ASD increased the risk of a later OCD diagnosis and vice versa. They also conducted parental analysis which showed considerable family links between the two disorders. The high co-morbidity was partially suggestive of shared genetic liability as one of the ways ASD and OCD may be linked. In addition, etiological factors including neuro-chemical systems and environmental risk factors such as parent-child interaction, divorce and adverse life events were proposed as reasons for the heightened co-morbidity (Mataix-Cols et al., 2013; Lichtenstein et al., 2010; Grisham, Anderson, & Sachdev, 2008). In spite of the growing evidence for increased comorbidity of ASD and OCD the DSM-5 does not list OCD under comorbid diagnosis with ASD or vice versa (APA, 2013).

The current evidence base suggests that there is a higher-than-expected chance of comorbidity between ASD and OCD. It also shows that they are both conditions that are phenotypically similar yet diagnostically distinct and should be carefully assessed and treated as such. RRBs and obsessions and compulsions may look phenomenologically similar but they have been shown to differ in a number of clinically important ways which are important to the assessment and subsequent treatment of OCD in CYP with ASD.

1.4 Treatment of OCD in children and young people with ASD

Cognitive Behavioural Therapy (CBT) with Exposure Response Prevention (ERP) and generic family involvement is the current evidence-based psychological treatment for typically developing CYP with OCD (National Institute for Health and Care Excellence [NICE], 2005).

There is a recognition in the guidance of the elevated prevalence of OCD in individuals with ASD (Joshi et al., 2010) however, apart from general CBT adaptations for CYP with ASD (NICE, 2021) there are no additional recommendations for treatment of OCD in CYP with ASD (NICE, 2021). Walters and colleagues (2016) reviewed effective modifications to CBT for young people with ASD. They found that modified CBT reduced anxiety, symptoms of OCD and depression. However, gold standard research using RCTs was only conducted on CBT for anxiety. They noted that often there was a greater number of modifications employed in the studies than recommended by NICE guidelines indicating that more research on disorder specific modifications is warranted. In their review (Walter et al., 2016), only two studies employed all the NICE recommended modifications whilst all studies used visual aids and emotion recognition skills building. The majority of studies also involved parents. With this promising research base for modified treatment for comorbid conditions within ASD, a more, well established, evidence-based practice for an OCD and ASD comorbid presentation would be a valuable addition to clinical guidance.

There have been three recent reviews which included treatment of OCD in CYP with ASD (Neil & Sturmey, 2014; Kose et al. 2018 & Bedford, Hunsche & Kerns, 2020). Neil & Sturmey (2014) conducted a systematic review on the prevalence and features of OCD in individuals with ASD as well as assessment and treatment of obsessions and compulsions in individuals with ASD. They included psychological and pharmacological interventions in their review. They used an operationalised criteria proposed by Chambless and Hollon (1998) to evaluate whether treatments were empirically supported. They did not, however, use a quality assessment tool to assess the quality of the studies being reviewed which limits the reliability of the review. Also, the included treatments studies were not limited to participants with a diagnosis of ASD and OCD.

Kose, Fox and Storch (2017) reviewed studies that utilized CBT in the treatment of OCD for individuals with comorbid diagnosis of ASD and OCD. Whilst all participants had a diagnosis of ASD, only 65% of them had a diagnosis of OCD. Bedford and colleagues (2020) completed a narrative review to provide an update on the body of research between 2015-2020 in relation to the co-occurrence, assessment and treatment of OCD in children and adults with ASD. Whilst this was a not a systematic review it was a useful resource to aid in the understanding of the current state of the literature and future directions.

To our knowledge there are no previous systematic reviews with a focus on the effectiveness of psychological treatments for diagnosed OCD in children and a young people with ASD. There is a growing body of literature highlighting the prevalence of co-occurring ASD and OCD and differences in the effectiveness of psychological treatments for those with and without ASD. Therefore, the present study aims to review current research on the effectiveness of psychological therapies for the treatment of OCD in CYP with ASD, make recommendations for future research and highlight any implications for practice.

1.5 Aims

In line with the above rationale, the aim was to systematically review the quantitative evidence on the effectiveness of psychological therapies in treating OCD in CYP with ASD. The review aimed to narratively synthesise the results and report findings in line with PRISMA guidelines (Page et al., 2021).

1.6 Review questions

The review aimed to answer the following questions

a. What is the evidence for the efficacy of psychological treatments for symptoms of OCD in young people with ASD?

b. What modifications are made to psychological interventions in relation to the treatment of OCD for CYP with ASD?

2. Methods

A protocol for this systematic review was registered with the Open Science Framework (OSF) on 9th June 2022 (Registration DOI: 10.17605/OSF.IO/REAQD).

2.1 Search strategy

All searches were completed between 2nd and 9th June 2022 using the following terms:

1. Autis* OR "Autism Spectrum Disorder" OR ASD OR Asperger* OR "autistic disorder" OR "intellectual disability*" OR "pervasive developmental disorder" OR PDDNOS

2. Obsess* OR “Compulsive behavio*” OR OCD OR "Obsessive Compulsive Disorder" OR "Restrictive behavio*

3. Intervention OR therap* OR behavio* OR cognitive OR treatment* OR Psycholog* OR ERP OR CBT OR "Exposure Response Prevention" OR "Cognitive Behavio* Therapy

4. 1 AND 2 AND 3

Limits including only studies published in English, studies from 2013 until 2022 and involving human participants were placed on the above search. The limit of publication date was included to allow for a review of recent publications that included the as then new, DSM-5 criteria for ASD. MEDLINE; PsycINFO; Cochrane Library and EMBASE were searched. Due to time constraints no manual searches of key journals or reference lists were conducted.

The PICO framework (population, intervention, comparator, outcome) (Blaine, 2022) was used to develop review questions as it is considered best practice when looking to develop a research question based on interventions, as described here:

P: Children and young people with ASD and a diagnosis of OCD
I: Psychological therapy to treat OCD
C: No comparator
O: Efficacy of psychological therapy

2.3 Inclusion and exclusion criteria

Inclusion criteria were as follows:

- children and young people under the age of 18;
- Studies published in English;
- Studies published from 2013 onwards;
- Studies published in a peer-reviewed journal;
- Participants had a diagnosis of ASD either pre-participation or diagnosis was confirmed as part of the studies inclusion criteria;
- Participants had a diagnosis of OCD either pre-participation or diagnosis was confirmed as part of the studies inclusion criteria;
- Studies reported pre and post outcome measures relating to the intervention for the treatment of OCD symptoms.

Exclusion criteria were:

- Qualitative designs and grey literature (book chapters, conference papers, dissertations or theses).

2.4 Study selection

Endnote for Windows was used to manage the results of the database searches (n= 2253). De-duplication was conducted on Endnote, removing 604 papers. The remaining papers were then imported to Rayann where a further 55 duplicate papers were removed. A total of 1594 papers were screened by title or title and abstract according to the inclusion/exclusion criteria whereby 1549 were removed. A second-rater blind rated 10% (n=160) of the papers which resulted in no conflicts. The remaining 45 papers were reviewed in full. A second-rater blind rated 50% (n=23) of the full text papers and no conflicts were reported. From this a further 35 papers were excluded based on the exclusion criteria. Further eligibility examination indicated that 14 of the papers were not focussed on treatment of OCD, five of the papers did not indicate ASD diagnosis, 14 papers did not report efficacy of treatment as an outcome and there were no results available for two of the papers screened. A final ten papers were included in the review for methodological quality evaluation and narrative synthesis.

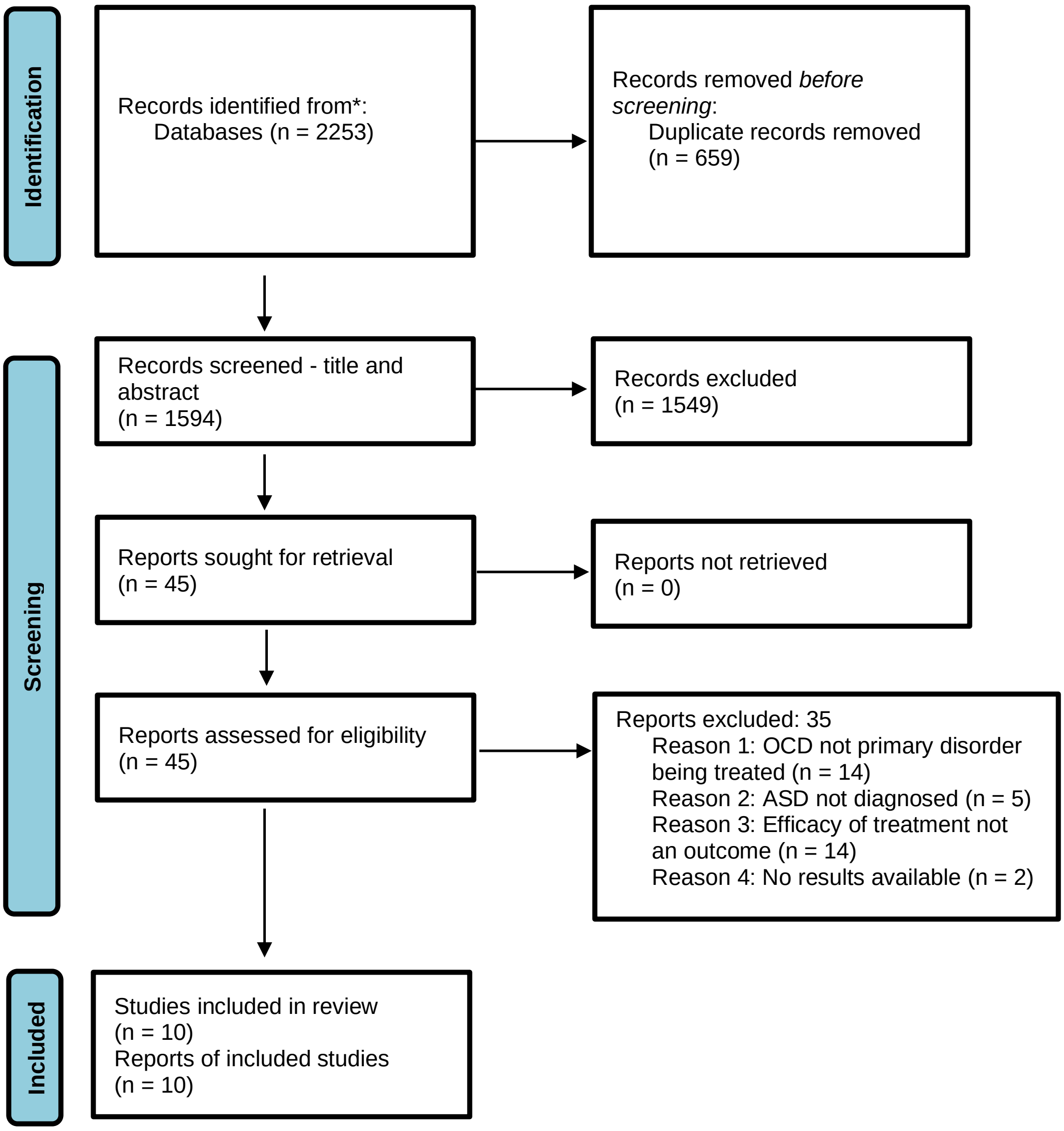


Figure 1.1. PRISMA Flow chart of search strategy and results (Page et al., 2021)

2.5 Data Extraction and Synthesis

Data extraction was completed using a form designed for this review with the following categories: Author, date and country, Method, Sample (n, core and co-morbid diagnosis), Psychological intervention, Pre and Post measures, Results, Modifications and Quality rating. Papers were ordered based on their quality appraisal scores.

To account for methodological diversity and sample variability, narrative synthesis was employed, using a textual approach, providing a descriptive summary of the studies to enable investigation of similarities and differences and assessment of the strength of the evidence. A preliminary synthesis was conducted which involved presenting key information from the papers in a tabular form (Table 1). The results were then discussed in relation to the two aims of this review with attention being paid to the quality of the included papers.

2.6 Assessment of Quality

For this review The Crowe Critical Appraisal Tool version 1.4 (CCAT) (Crowe, 2013) (Appendix 1.2) was employed as the quality assessment tool due to its ability to evaluate a variety of study designs included in this review. The CCAT was developed based on exiting tools, research methods and reporting guidelines. It has 22 items, divided in to 8 categories. Each category has item descriptors which make it easier to appraise and score. The categories include preliminaries, introduction, design, sampling, data collection, ethics, results, and discussion. They are scored 0-5 with a maximum overall score of 40 and minimum of 0. The raw scores are converted into a corresponding percentage which is provided with the tool. A higher percentage indicates that the paper is of higher methodological quality. This tool scores papers based on their quality in relation to their design. It does not compare methodologies or designs, so a case study may score seemingly high on the CCAT even though a case study is not considered a robust methodology. A limitation of this tool is that it is dependent on the appraisers scoring. It also offers an overall score which can overlook performance in individual categories which may mask poorer areas of a paper's performance (Crowe, 2013).

A second-rater was employed to rate the quality of 50% (n=5) of the papers. There was not more than a one-point difference across all categories, across all papers and only up to a 2% difference in final percentage ratings. These differences were discussed and resolved which resulted in a 100% percentage agreement. See Table 1.1 for individual category scores alongside corresponding percentage score. For this review, based on the CCAT categorisations, a percentage score of 76% - 85% denotes a good quality paper, a score of 70-75% indicates medium quality and a score of 69% or below indicates low quality. These quality ratings have been categorised for this systematic review and are indicative of the methodologies and design in relation to gold standard research such as RCTs when measuring the efficacy of interventions.

Table 1.1 CCAT scores and converted percentage score

Study	**Preliminaries**	**Introduction**	**Design**	**Sampling**	**Data collection**	**Ethical**	**Results**	**Discussion**	**Total**	**Percentage**
Murray et al., 2015	4	5	4	4	4	3	5	5	35	85%
Wickberg et al., 2022	5	4	3	4	4	5	4	5	34	85%
Jassi et al., 2021	4	5	4	3	4	2	4	5	31	78%
Ordaz et al., 2018	4	5	4	3	4	2	4	4	33	75%
Iniesta-Sepúlveda et al., 2018	3	5	4	3	4	2	4	5	30	75%
Nadeau et al., 2014	5	4	3	4	4	2	4	3	29	73%
Vause et al., 2014	4	5	3	2	4	3	4	4	28	70%
Merricks et al., 2017	3	5	4	3	4	2	3	3	27	68%
Krebs et al., 2016	2	5	4	3	4	1	4	3	26	65%
Jones and Jassi., 2020	3	4	3	4	3	2	4	3	26	65%

Table 1.2. Overview of Included Studies

Study Details	**Participant selection**	**Psychological intervention**	**Pre and Post measures**	**Results**
Murray et al., 2015 UK Retrospective Case-controlled study 44 children mean age 15 22 ASD and OCD 22 Typically developing with OCD	ASD verified with ADOS and or ADI-R (N=15) ICD-10 diagnosis included Asperger's, (N=15) high functioning autism (N=2) and PDD-NOS (N=5) OCD Met ICD-10 Criteria + CY-BOCS	Individual CBT with ERP 1) Psychoeducation about OCD and anxiety and OCD hierarchy formation 2) Graded ERP 3) Relapse prevention Homework each week Typical: 14, 1-hour sessions over 17 weeks Booster sessions offered if clinical need identified Parents involved where clinically appropriate. All present during psychoeducation and relapse prevention	CY-BOCS	OCD+ASD group responding less well to treatment (Responders CY-BOCS score reduction of >35%) Lower remission (post treatment CY-BOCS of <12) rates observed in OCD+ ASD group Standard CBT protocols not as effective for those with ASD vs typically developing young people
Wickberg et al., 2022 Sweden Quasi-experiment (feasibility study) 76 7-17-year-olds	ASD pre-study DSM-5 criteria OCD DSM-5 criteria and >16 on CY-BOCS	Internet-based CBT (ICBT) adapted from previously developed digital programme for non-ASD population. 14 modules to complete Benchmark group for comparison to measure feasibility of ICBT intervention In person CBT intervention (March & Mulle 1994) modified OCD CBT protocol for ASD with OCD group sessions 1 hour + 3 hour session per week for 6 weeks then 1 hour session per week for 4 weeks (total 24 hours of treatment)	CY-BOCS	ICBT: 52% of participants classed as treatment responders at end of treatment (>35% CY-BOCS) 43% in remission at end of treatment (<12 CY-BOCS) Benchmark: 78% of participants classed as treatment responders at end of treatment 54% in remission at end of treatment

				Post treatment gains maintained over 3 month follow up
Jassi et al., 2021 UK Quasi-experiment 34 11-17-year-olds	ASD 67.65% ADOS and/or ADI-R 32.35% diagnosed via clinician assessment OCD pre-study	Individually modified CBT with ERP as its main component Adaption of standard Turner C, Volz C, Krebs G (2019) CBT protocol for OCD 20 sessions (adapted from 14 sessions)	CY-BOCS CGI-S CGI-I CGAS ChOCI FAS-PR RBQ-2 WSAS-Y WSAS-P Treatment satisfaction survey	Mixed-effects regression analysis for repeated measures CY-BOCS scores collected at baseline; session 7; session 14; end of treatment; 3-month post 51.51% classed as treatment responders (>35% CY-BOCS)
Ordaz et al., 2018 USA Case Study 12-year-old male	ASD Pre-study ADOS in study CARS-2 OCD PARS DSM-V interview schedule ADIS-IV	Behavioural interventions for anxiety in children with autism BIACA (Wood, Drahota, Sze, Har, et al., 2009) 16 sessions, 90 minutes, weekly	Parent rated YTPs CGI-S ADIS-IV PARS	Reduction in measures ADIS-IV clinical severity rating 5 > 3 (sub threshold) PARS 19 > 11
Iniesta-Sepúlveda et al., 2018 USA Case Series 9 11-17-year-olds	ASD DSM-IV-TR criteria and review from two psychologists OCD DSM-IV-TR criteria and >16 on CY-BOCS	Archival record review of Intensive CBT with ERP Either outpatient (3hours a day 5 days a week) or partial hospitalisation (6.5 hours a day 5 days a week) for 24-80 days between 75 and 520 hours of treatment	CY-BOCS CIC-C/P PQ-LES-Q SCARED PROMIS CGI-S	Wilcoxon signed rank test z=2.67 p=0.008 (for the CY-BOCS) 78% responder (>35% reduction in CY-BOCS score) 33% remission (<12 on CY-BOCS)
Nadeau et al., 2014 USA Case Study 9-year- old male	ASD Clinical interview and ADI-R	Behavioural Interventions for Anxiety in Children with Autism (BIACA) (Wood, Drahota, Sze, Har, Chiu, & Langer, 2009)	CY-BOCS ADIS	CY-BOCS reduction in scores from 27 – 0

	OCD Self report, parental measures and CY-BOCS + social phobia and specific phobia	16 sessions weekly 35 – 70 mins Affective education; coping skills development; identification and ranking of rewards; OCD hierarchy; ERP in vivo and home		ADIS clinical severity rating Pre 6 post 3 (OCD in remission) and post treatment gains maintained over 4 month follow up
Vause et al., 2014 Canada Single case experimental design (SCED) 2 8-10-year-old children	ASD pre-study qualified clinician assessment and ADIR in study OCD pre-study	Adapted function-based CBT with ERP based on March and Mulle (1998) protocol Psychoeducation/mapping; cognitive training; graded exposure and response prevention; relapse prevention	CY-BOCS ADIS-P QOL CSQ	Multiple baseline design across behaviours and participants (1) baseline; (2) psychoeducation and mapping (PM); and (3) function-based assessment and intervention (FBAI), cognitive training (CT), exposure and response prevention (ERP) plus positive reinforcement Reduction in all pre-post measures and post treatment gains maintained over 4 month follow up
Merricks et al., 2017 USA Case Study 12-year-old male	ASD pre-study OCD pre-study	Partial hospitalisation - Intensive exposure-based CBT; 33 sessions over 12 weeks with a family member (5 days a week 6.5 hours a day) Separate family sessions weekly	CY-BOCS PROMIS Paediatric Depression Scale	Reduction in all pre-post measures
Krebs et al., 2016 UK Case Study 14-year-old male	ASD pre-study OCD Pre-study	ERP-based CBT protocol developed for young people (Turner et al., 2014) Adapted for ASD in study 18 sessions over 4 months	CY-BOCS ChOCI FAS	Reduction in all pre-post measures and post treatment gains maintained over 6 and 12 month follow ups
Jones and Jassi, 2020 UK Case Study 16-year-old male	ASD Pre-study OCD Pre-study with CY-BOCS	CBT for OCD with ERP protocol (Turner et al., 2014). Using adaptions from Jassi et al. (2020)	CY-BOCS ChOCI-R COIS-R	Reduction in all pre-post measures and post treatment gains maintained over 12 month follow up
ADI-R = Autism Diagnostic Interview - Revised; ADIS = Anxiety Disorders Interview Schedule from the DSM-V; ADOS = Autism Diagnostic Observation Schedule; ASD = Autism Spectrum Disorder; CBT = Cognitive Behavioural Therapy; CGAS = Children's Global Assessment Scale;				

CGI-S & CGI-I = Clinical Global Impressions-severity and Improvement; ChOCI = Children’s Obsessive Compulsive Inventory; CIC-C/P = Columbia Impairment Scale – Parent and Child; COIS-R = Child OCD Impact Scale – Revised; CSQ = Customer Satisfaction Questionnaire; CY-BOCS = Children’s Yale-Brown Obsessive Compulsive Scale; DSM-V = Diagnostic and Statistical Manual 5th Version; ERP = Exposure Response Prevention; FAS-PR = Family Accommodation Scale – Parent Report; ICD-10 = International Classification of Disease 10th Version; OCD = Obsessive Compulsive Disorder; PARS = Paediatric Anxiety Rating Scale; PDD-NOS = Pervasive Developmental Disorder-Not Otherwise Specified; PROMIS = Paediatric Item Bank for Depression of the Patient-Reported Outcomes Measurement Information System; PQ-LES-Q = Paediatric Quality of Life Enjoyment and Satisfaction Questionnaire; QOL = Quality of Life; RBQ-2 = Repetitive Behaviour Questionnaire; SCARED = Screen for Childhood Anxiety Disorders; WSAS-Y/P = Work and Social Adjustment Scale – Youth and Parent; YTPs = Youth Top Problems

3. Results

3.1 Participants

This review identified 10 studies (Murray et al., 2015; Wickberg et al., 2022; Merricks et al., 2017; Jassi et al., 2021; Iniesta-Sepúlveda et al., 2018; Ordaz et al., 2018; Nadeau et al., 2014; Vause et al., 2014; Krebs et al., 2016 & Jones & Jassi, 2020) that evaluated the effectiveness of psychological interventions for the treatment of OCD in CYP with ASD. Study designs included case studies (Nadeau et al., 2014; Ordaz et al., 2018; Merricks et al., 2017; Krebs et al., 2016, Jones & Jassi, 2020) case series (Iniesta-Sepúlveda et al., 2018), case control studies (Murray et al., 2015), single case experiment design (SCED) (Vause et al., 2014) and quasi-experimental studies (Wickberg et al., 2022; Jassi et al., 2021). The majority of participants were male (n= 107, 64%) and age ranged from 7 to 17 years old. A total of 170 young people with a primary diagnosis of OCD, including 148 who also had a diagnosis of ASD were recruited to individual and family-based CBT interventions with sample sizes ranging from one to 76.

Table 1.3. Modifications of CBT based Interventions

First Author and number of participants	**Modifications Throughout the Intervention**	**Modifications at the Psychoeducation Stage**	**Modifications at the Intervention Stage**
Nadeau et al., (2014) (N = 1) Alongside modifications already implemented within BIACA	Immediate rewards rather than points-based system; visual reward chart;	Using participants interests to create vignettes as part of affective education to provide education and training to the family in identifying anxiety, obsessions, rituals, physiological symptoms, cognitive errors	Individualised coping plan for anxiety; menu of potential consequences for “what’s the worst that can possibly happen?” based on participants past experiences and general consequences
Wickberg et al. (2022) (N = 76)	ICBT: visual support and time aids; high parental involvement Benchmark: Use of time aids; visual aids	ICBT: Psychoeducation including differentiation between OCD and ASD repetitive behaviours	ICBT: regulating strong feelings; generalization of exposure exercises; reducing mental rigidity during exposures. Benchmark: adjusting appropriate rituals to functional routines; daily activity schedules; schedules for ERP; introduction of new rules in line with treatment goals; participated in an OCD course focusing on parent behaviours and family accommodation
Jassi et al. (2021) (N = 34)	Extended from 14 to 20 sessions	Differentiating OCD and ASD related repetitive behaviour	Visual, mini hierarchies Emphasising similarities between in vivo and home tasks Off site visits to conduct ERP tasks Family lead ERP tasks
Ordaz et al. (2018) (N = 1) Alongside modifications already implemented within BIACA	Fostering independence; Flexibility to maintain motivation; Additional rewarding; Strong family component		

Iniesta-Sepúlveda et al. (2018) (N = 9)	Incorporated age-appropriate self-care activities; incorporated individuals' interests	Increased attention paid to assisting identification of physiological cues for anxiety and environmental triggers;	Concrete therapeutic exercises (in vivo exposure activities); Reduced focus on cognitive techniques (Socratic questioning, thought challenging); Considerable family involvement in to encourage guidance in home-based activities and to be part of the hierarchy development and anxiety rating
Vause et al. (2014) (N = 2)	Increased use of visuals; positive reinforcement; family involved in all sessions with responsibilities to review coping strategies and implement home practice.	Family-focussed treatment; function-based behavioural assessment and intervention (QABF);	Protracted cognitive component
Merricks et al. (2017) (N = 1)	Lower auditory and visual stimulation; Token economy e.g., trading completed treatment sessions for an enjoyable activity; greater parental involvement	Exposures modified to account for sensory defensiveness and theory of mind;	
Krebs et al. (2016) (N = 1)	Greater use of visual materials; short breaks throughout sessions; highly structured sessions with agenda and timings visible; down time at end of sessions to discuss special interests; working with school; weekly family meetings;	Repetition of key psychological concepts; extended psychoeducation around anxiety; use of special interests for anxiety rating scale; Regular home-based sessions; Parents leading ERP tasks in sessions; developing social activities in parallel with CBT	Highly graded ERP; directive approach to ERP
Jones and Jassi (2020) (N = 1)	Workbook with material visually presented; family involvement to increase predictability of treatment; agenda laid out each session to increase predictability parents trained as co-therapists	Extended psychoeducation Included discussion about ASD traits relevant to young person; education on overlap and differences between OCD and ASD	In-vivo ERP in all areas; specific work on family accommodation; Named the OCD to externalise it, a tool from Narrative Therapy to remove blame from child; visual diagram of the body to identify physiological changed due to anxiety; special interests incorporated in developing an idiosyncratic anxiety rating scale

3.2 Intervention Characteristics and Modifications

The interventions were all CBT based and all incorporated an element of ERP, with one study (Vause et al., 2014) also incorporating a function-based assessment in the form of the Questions About Behavioral Function (QABF) questionnaire (Matson & Vollmer, 1995 as cited in Vause et al., 2014). This was used to help identify potential functions of behaviour such as positive social attention or escape from tasks which individuals with developmental disabilities may display (Carr, 1999). They also included a function-based intervention based on Cooper and colleagues (2007), as cited in Vause et al. (2017) applied behaviour analysis manual. The number of sessions ranged from 14 to 33 with duration ranging from 35 minutes to six and a half hours. The setting of the interventions included a clinic or therapist's office, the patient's own home or a hospital setting.

Ordaz and colleagues (2018) and Nadeau and colleagues (2014) assessed the effectiveness of the 'Behavioural Interventions for Anxiety in Children with Autism' (BIACA) (Wood et al., 2020). BIACA is a modular intervention, based on the Building Confidence CBT programme (Wood & McLeod, 2008). It is offered over sixteen, weekly, 90-minute sessions (split between parent and child). Whilst the intervention is modular, it is guided by an algorithm that allows personalisation of the treatment to meet the needs of the child or young person. It utilises CBT strategies such as coping skills and in vivo exposure. It also employs modules to aid in compliance during treatment such as addressing disruptive behaviour with antecedent and incentive-based practice and social engagement skills; special interests are incorporated and behaviours are reinforced with a comprehensive reward system both at home and in school (Wood et al., 2020).

Wickberg et al. (2022) and Vause et al. (2014) used a version of the March and Mulle (1998) protocol for treating OCD in children and adolescents which they adapted for their respective studies. Wickberg also used an adapted version of their own Internet-based CBT programme for non-autistic young people. They included extra modules on regulating strong feelings, generalisation of exposure exercises and reducing mental rigidity during exposures. Jassi et al. (2021) adapted the work of Turner, Volz and Krebs (2019) who co-authored a CBT for OCD manual for therapists treating young people. Their adaptations for use with CYP with ASD included the use of visual aids throughout the psychoeducation and intervention stages, mini hierarchies to break down ERP tasks further, emphasis on similarities between in vivo and home tasks to help with generalisation of ERP tasks, off site visits to conduct ERP tasks and they encouraged the family to lead on ERP tasks at home and in sessions.

Iniesta-Sepúlveda et al. (2018) noted in their study that treatment received by all participants was consistent with standard care CBT with ERP for paediatric OCD but did not provide greater detail. Merricks and colleagues, 2017 stated that intensive exposure-based CBT was employed. They gave detail regarding the intervention but this was not based on a specific model or protocol. Krebs et al. (2016) adapted Turner et al. (2014) CBT protocol in their case study. Finally, Murray et al. (2015) noted that all participants received individualised CBT that included ERP which was guided by three phases: 1) Psychoeducation 2) Graded ERP 3) Relapse prevention. Again, no further information was provided on the validity of this intervention.

With reference to Table 1.3, two studies (Ordaz et al., 2018; Nadeau et al., 2014) used an already adapted intervention for use with CYP with ASD. They further modified the interventions. Nadeau et al (2014) utilised an immediate rather than points-based system and a visual reward chart. They also used the young person’s interests to create vignettes which were used to provide education and training to the family in identifying anxiety, obsessions, rituals, physiological symptoms, and cognitive errors. They created an individualised coping plan for anxiety and a list of potential consequences to the question, “What is the worst that can happen?” which were based on the participants past experiences and general consequences. Ordaz and colleagues (2018) provided additional skills development around independence and social functioning. They maintained flexibility in sessions to maintain motivation and had a strong family component throughout the intervention.

The remaining seven studies (Murray et al., 2015; Wickberg et al., 2022; Jassi et al., 2021; Iniesta-Sepúlveda et al., 2018; Krebs et al., 2016; Merricks et al., 2017 & Jones & Jassi., 2020) incorporated novel modifications in their interventions (Table 1.3). All studies involved parents and families in the intervention, often to provide structure to the home-based ERP tasks as well as during the psychoeducation phase. All studies modified the ERP component of the intervention. Most used techniques to help with the transition from in vivo to home-based ERP tasks including extra guidance on the generalisation of ERP tasks (Wickberg et al., 2022; Jassi et al., 2021), creating scheduled and concrete exposure exercises (Wickberg et al., 2022; Iniesta-Sepúlveda et al., 2018; Krebs et al., 2016) and modifying exposures to account for sensory sensitivities, diming lights and lowering volume for video exposure exercises, and theory of mind differences such as being accompanied by a member of staff during exposure exercises (Merricks et al., 2017).

Three studies (Iniesta-Sepúlveda et al., 2018; Krebs et al., 2016 & Nadeau et al., 2014) explicitly used the young person’s special interests during intervention. Krebs and colleagues (2016) used these to create an anxiety rating scale. Iniesta-Sepúlveda and colleagues (2018) incorporated special interests throughout the treatment process and Nadeau and colleagues (2014) used the young person’s special interests to create vignettes to aid in psychoeducation relating to identifying physiological anxiety symptoms, obsessions, rituals and cognitive errors.

The modifications were not consistent across all studies and they all included novel modifications to varying degrees. Two studies (Ordaz et al., 2018 and Nadeau et al., 2014) used an already modified psychological intervention (BIACA, Wood, Drahota, Sze, Har, et al., 2009) however, they still incorporated further modifications to further personalise the treatment. Murray and colleagues (2015) were able to indicate that a non-adapted OCD intervention for CYP with ASD was not as effective as an adapted intervention.

3.3 Efficacy and Outcome Measures

A variety of outcome measures were used to assess change in OCD symptoms in CYP with a diagnosis of ASD and a comorbid OCD diagnosis. All studies relied on standardised outcome measures that had been validated in a typically developing population. The most commonly used measure was the CY-BOCS which is considered the gold standard measure for assessment of severity of paediatric OCD (Rapp et al., 2016). It is a semi-structured interview made up of 10 items, across five dimensions, rated on a 5-point Likert scale (Rapp et al., 2016). It is administered to the child with or without the parents present, based on clinicians’ judgement. The clinician is able to adjust the ratings based on their observations, clinical judgement and other information (Storch et al., 2004). Ordaz and colleagues (2018) were the only exception and they utilized the Anxiety Disorders Interview Schedule from the DSM-5 (ADIS-IV) and the paediatric anxiety rating scale (PARS). Eight studies also incorporated additional information gathered using self-report, parent report and patient satisfaction questionnaires (Merricks et al., 2017; Jassi et al., 2021; Iniesta-Sepúlveda et al., 2018; Ordaz et al., 2018; Nadeau et al., 2014; Vause et al., 2014; Krebs et al., 2016 & Jones & Jassi, 2020). Most studies reported pre and post outcomes however, three studies

(Murray et al., 2015; Jassi et al., 2021 & Iniesta-Sepúlveda et al., 2018) used further statistical analysis, although due to the low number of participants it is unlikely that this added further robustness to their results.

Individual based change statistics such as the Reliable Change Index can be used to evaluate whether each participant in the study experiences a reliable change in their pre-post scores (Estrada, Ferrer & Pardo, 2019). One way of detecting reliable change is to use standardised pre and post differences such as the suggested cut offs for the CY-BOCS. A 35% reduction in scored indicated that the participant has responded to the treatment offered and a score of twelve or below indicates that the participant is in remission (Skarphedinsson et al., 2017). Four studies (Murray et al., 2015; Wickberg et al., 2022; Jassi et al., 2021; Iniesta-Sepúlveda et al.) included this as a measure of reliable change.

All participants were able to benefit from the interventions in this review as indicated by studies reported promising results in the form of reduced scores on the CY-BOCS and in the case of Ordaz et al. (2018) reductions in the ADIS-IV and PARS. However, it is not possible to determine whether these interventions are efficacious as the interventions were not measured under ideal circumstances, like that of a RCT. Instead, they were measured in real world clinical settings which would pertain more the effectiveness of the intervention.

4. Discussion

This review identified ten studies (Murray et al., 2015; Wickberg et al., 2022; Merricks et al., 2017; Jassi et al., 2021; Iniesta-Sepúlveda et al., 2018; Ordaz et al., 2018; Nadeau et al., 2014; Vause et al., 2014; Krebs et al., 2016 & Jones & Jassi, 2020) that aimed to evaluate the effectiveness of psychological interventions for the treatment of OCD in CYP with ASD. In order to be included, studies had to include participants with a diagnosis of ASD and OCD. They had to be using an intervention for OCD and report pre and post outcome measures. The interventions were all CBT based with elements of ERP. However, they varied in terms of content, modifications, session numbers and duration as well as the setting. Measurements of the outcomes were often multi-model with parent, child and clinician reports included. All bar one study (Ordaz et al., 2018) used the CY-BOCS which is a gold standard measure of the reduction of OCD symptoms. The results of all studies indicated a reduction in the symptoms of OCD for CYP with ASD on the CY-BOCS, and in the case of Orsaz and colleagues (2018) the ADIS-IV and PARS.

It is important to consider the small number and varied quality of the studies as these limits the ability to draw conclusions about the efficacy of the psychological interventions. The varied study designs and lack of RCT's further limits our findings, particularly with the high number of case studies (n=5) (Nadeau et al., 2014; Ordaz et al., 2018; Merricks et al., 2017; Krebs et al., 2016, Jones & Jassi, 2020) that have looked at the effectiveness of OCD treatment within ASD. Case studies are considered to lack scientific rigor and their results are not generalisable to the wider population. They are difficult to replicate and are often time consuming. They also do not provide a control group to ascertain whether improvement would have happened over time regardless of the intervention. Finally, they are prone to researcher bias and selection bias due to the way in which participants are recruited and how researchers are involved in the study. The high number of case studies indicates that this is still an under researched area.

The remaining studies were case series (Iniesta-Sepúlveda et al., 2018), SCED (Vause et al., 2014) and quasi-experimental studies (Murray et al., 2015; Wickberg et al., 2022 & Jassi et al., 2021). They did not include robust randomisation techniques for participant selection or control groups. Two studies did however include comparison groups (Murray et al., 2015 & Wickberg et al., 2022). Whilst they both showed promising indications of efficacy, there is a lack of replicability due to insufficient description of the modifications used in the intervention as well as a lack of a control group to ensure internal validity.

Despite the above stated limitations, all participants were able to benefit from the interventions in this review as indicated by studies reported promising results in the form of reduced scores on the CY-BOCS and in the case of Ordaz et al. (2018) reductions in the ADIS-IV and PARS. The use of self-report pre-post outcome measures and clinician rated measured increases bias in the studies. They are known to have relatively poor reliability and a more robust measure of efficacy or the use of measures to reduce bias would have heightened the quality of research. Only four studies included a measurement of reliable change (Murray et al., 2015; Wickberg et al., 2022; Jassi et al., 2021; Iniesta-Sepúlveda et al.). The remaining studies did not measure whether the pre-post scores equate to reliable change which lessens their robustness and the statistical significance of their results.

The outcomes are largely consistent with the evidence base that suggests modified CBT interventions can be an effective intervention for CYP with ASD and OCD (Kose et al., 2018). Previous reviews similarly indicate that modifications such as increased family and parental involvement had a positive impact on interventions for CYP with ASD (Kose et al., 2018). Murray and colleagues (2015) were the only study to include a typically developing comparison group. Their study indicated that the standard CBT protocol utilised was not as effective for participants with ASD vs typically developing CYP. NICE guidelines (NICE, 2005) do not currently outline specific modifications for the treatment of OCD in individuals with ASD.

The modifications employed were not standard across studies or participants, often involving individualised modifications leading to a lack of replicability and generalisability. The most common modifications were the addition of parental involvement, visual cues throughout the intervention and use of the child or young person's interests with the inclusion of idiosyncratic anxiety rating scales (Jones & Jassi, 2020; Krebs et al., 2016) and breaks and flexibility in sessions to retain motivation (Krebs et al., 2016; Iniesta-Sepúlveda et al., 2018).

Recent research has confirmed high prevalence rates of OCD in CYP with ASD. It is notable that these rates have come from clinical samples and the results are variable, ranging between 17%-37% (Leyfer et al., 2006 & Van Steensel et al., 2011). Interventions modified for a comorbid OCD diagnosis to take in to account the adapted needs of CYP with ASD have promising results, albeit the study designs. Therefore, there is a pressing need for more rigorous research which can contribute to an increased understanding of the modifications within psychological intervention that would meet the individual, age-appropriate needs of those with ASD in treating OCD. This would help eliminate the wide range and variety of modifications currently employed in research and clinical practice to allow the development of an evidence base for appropriate modifications and possibly a complex interventions framework for treating OCD. Such as that which exists for general CBT modification for CYP with ASD (NICE, 2021).

5. Limitations

This review has some limitations. Firstly, due to the paucity of high-quality research in this area, studies included in this review were not excluded based on poor methodology. Therefore, any conclusions drawn should be interpreted with caution. A wide variety of interventions and modifications within the included studies made analysis and comparison of the interventions difficult. A meta-analytic approach was not possible for these reasons. Also, whilst studies using pharmacological intervention were not included in this review some participants were taking medication whilst taking part in the studies, which lowers the internal reliability of the studies as observed improvements may not be the result of the psychological intervention alone. This review focussed on the treatment of OCD in individuals with ASD however, some participants also had further co-occurring diagnoses which also impacts in the internal validity of the studies.

6. Further research

There is a need to expand this field of research to begin to define evidence-based practices for interventions in CYP with neurodevelopmental strengths and vulnerabilities, as is the case with ASD. At present, there is a little in the way of high-quality intervention efficacy research, despite the number of studies indicating a high prevalence of individuals with comorbid OCD and ASD (Postorino et al., 2017; Martin et al., 2020). Robust studies researching modifications in psychological interventions for the treatment of OCD in CYP with ASD would be a welcome addition to the field.

7. Conclusion

This is the first review to consider the efficacy of psychological interventions for CYP who have a diagnosis of ASD and a comorbid diagnosis of OCD. The results suggest that participants may have benefited clinically from the interventions offered as indicated by a reduction and sustained reduction of scores on reported pre and post intervention measures. All interventions were modified to meet the individual’s needs in areas such as increased parental involvement and the use of visual aids. As there is a high prevalence of comorbid ASD and OCD in CYP, ongoing and more rigorous research is required to develop an evidence-base for these promising approaches to psychological intervention in this group.

8. References

American Psychiatric Association (2013) Diagnostic and statistical manual of mental disorders: DSM-5. 5th edn. Washington, D.C.: American Psychiatric Publishing

Anthony, L. G., Kenworthy, L., Yerys, B. E., Jankowski, K. F., James, J. D,. Harms, M. B. et al (2013), Interests in high-functioning autism are more intense, interfering, and idiosyncratic than those in neurotypical development. *Dev Psychopathology,* 25, 643–665

Bedford, S. A., Hunsche, M. C., & Kerns, C. M. (2020). Co-occurrence, assessment and treatment of obsessive compulsive disorder in children and adults with autism spectrum disorder. *Current Psychiatry Reports*, *22*(10), 1-11.

Bishop, S.L., Hus, V., Duncan, A., Huerta, M., Gotham, K., Lord, C. (2013) Subcategories of restricted and repetitive behaviors in children with autism spectrum disorders. *J Autism Dev Disord*, 43, 1287–1297.

Carr, E. G. (1999). Positive behavior support for people with developmental disabilities: A research synthesis. Retrieved from: https://files.eric.ed.gov/fulltext/ED439580.pdf

Chambless, D. L., & Hollon, S. D. (1998). Defining empirically supported therapies. *Journal of consulting and clinical psychology*, 66(1), 7.

Crowe, M., Sheppard, L., & Campbell, A. (2011). Comparison of the effects of using the Crowe Critical Appraisal Tool versus informal appraisal in assessing health research: a randomised trial. *International Journal of Evidence‐Based Healthcare*, *9*(4), 444-449.

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., ... & Varley, J. (2010). Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics*, *125*(1), e17-e23.

Estrada, E., Ferrer, E., & Pardo, A. (2019). Statistics for evaluating pre-post change: Relation between change in the distribution center and change in the individual scores. *Frontiers in psychology*, *9*, 2696.

Grisham, J. R., Anderson, T. M., & Sachdev, P. S. (2008). Genetic and environmental influences on obsessive-compulsive disorder. *European archives of psychiatry and clinical neuroscience*, *258*(2), 107-116.

Jiujias, M., Kelley, E., & Hall, L. (2017). Restricted, repetitive behaviors in autism spectrum disorder and obsessive–compulsive disorder: A comparative review. *Child Psychiatry & Human Development*, 48(6), 944-959.

Jones, G., & Jassi, A. (2020). Modified Cognitive Behavior Therapy for Severe, Treatment Resistant Obsessive-Compulsive Disorder in an Adolescent With Autism Spectrum Disorder: The Importance of Parental Involvement. *Journal of Cognitive Psychotherapy*, *34*(4), 319-335.

Joshi, G., Petty, C., Wozniak, J., Henin, A., Fried, R., Galdo, M., ... & Biederman, J. (2010). The heavy burden of psychiatric comorbidity in youth with autism spectrum disorders: A large comparative study of a psychiatrically referred population. *Journal of autism and developmental disorders*, *40*(11), 1361-1370.

Kose, L. K., Fox, L., & Storch, E. A. (2018). Effectiveness of cognitive behavioral therapy for individuals with autism spectrum disorders and comorbid obsessive-compulsive disorder: A review of the research. *Journal of developmental and physical disabilities*, 30(1), 69-87.

Krebs, G., & Heyman, I. (2015). Obsessive-compulsive disorder in children and adolescents. *Archives of disease in childhood*, *100*(5), 495-499.

Leyfer, O. T., Folstein, S. E., Bacalman, S., Davis, N. O., Dinh, E., Morgan, J., ... & Lainhart, J. E. (2006). Comorbid psychiatric disorders in children with autism: Interview development and rates of disorders. *Journal of autism and developmental disorders*, *36*(7), 849-861.

Lichtenstein, P., Carlström, E., Råstam, M., Gillberg, C., & Anckarsäter, H. (2010). The genetics of autism spectrum disorders and related neuropsychiatric disorders in childhood. *American Journal of Psychiatry*, *167*(11), 1357-1363.

March, J. S., & Mulle, K. (1998). *OCD in children and adolescents: A cognitive-behavioral treatment manual*. Guilford Press.

Martin, A. F., Jassi, A., Cullen, A. E., Broadbent, M., Downs, J., & Krebs, G. (2020). Co-occurring obsessive–compulsive disorder and autism spectrum disorder in young people: prevalence, clinical characteristics and outcomes. *European child & adolescent psychiatry*, *29*(11), 1603-1611.

Matson, J. L., & Nebel-Schwalm, M. S. (2007). Comorbid psychopathology with autism spectrum disorder in children: An overview. *Research in developmental disabilities*, *28*(4), 341-352.

Mataix-Cols, D., Boman, M., Monzani, B., Rück, C., Serlachius, E., Långström, N., & Lichtenstein, P. (2013). Population-based, multigenerational family clustering study of obsessive-compulsive disorder. *JAMA psychiatry*, *70*(7), 709-717.

Meier, S. M., Petersen, L., Schendel, D. E., Mattheisen, M., Mortensen, P. B., & Mors, O. (2015). Obsessive-compulsive disorder and autism spectrum disorders: longitudinal and offspring risk. *PloS one*, *10*(11), e0141703.

Mercier, C., Mottron, L., Belleville, S. (2000). A psychosocial study on restricted interests in high-functioning persons with pervasive developmental disorders. *Autism* 4, 406–425

Merricks, K. L., Nadeau, J. M., Ramos, A., & Storch, E. A. (2017). A case report of intensive exposure-based cognitive behavioral therapy for a child with comorbid autism spectrum disorder and obsessive-compulsive disorder. *Journal of Cognitive Psychotherapy*, *31*(2), 118-123.

National Institute for Health and Care Excellence. (2005). Obsessive-compulsive disorder and body dysmorphic disorder: treatment [NICE Guideline No. 31]. https://www.nice.org.uk/guidance/cg31

National Institute for Health and Care Excellence. (2021). Autism spectrum disorder in under 19s: support and management [NICE Guideline No. 170]. https://www.nice.org.uk/guidance/cg170

Neil, N., & Sturmey, P. (2014). Assessment and treatment of obsessions and compulsions in individuals with autism spectrum disorders: A systematic review. *Review Journal of Autism and Developmental Disorders*, 1(1), 62-79.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C.D., … Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *The BMJ*, 372. https://doi.org/10.1136/bmj.n71

Paula-Pérez, I. (2013). Differential diagnosis between obsessive compulsive disorder and restrictive and repetitive behavioural patterns, activities and interests in autism spectrum disorders. *Revista de Psiquiatría y Salud Mental (English Edition)*, *6*(4), 178-186.

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., ... & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme Version*, *1*(1), b92.

Postorino, V., Kerns, C. M., Vivanti, G., Bradshaw, J., Siracusano, M., & Mazzone, L. (2017). Anxiety disorders and obsessive-compulsive disorder in individuals with autism spectrum disorder. *Current psychiatry reports*, *19*(12), 1-8.

Rangasamy, S., D'Mello, S. R., & Narayanan, V. (2013). Epigenetics, autism spectrum, and neurodevelopmental disorders. *Neurotherapeutics*, *10*(4), 742-756.

Rapp, A. M., Bergman, R. L., Piacentini, J., & McGuire, J. F. (2016). Evidence-based assessment of obsessive–compulsive disorder. *Journal of central nervous system disease*, *8*, JCNSD-S38359.

Rodgers, J., Glod, M., Connolly, B., McConachie, H. (2012). The relationship between anxiety and repetitive behaviors in autism spectrum disorder. *J Autism Dev Disord*, 42, 2404–2409

Ruscio, A. M., Stein, D. J., Chiu, W. T., Kessler, R. C. (2010). The epidemiology of obsessive-compulsive disorder in the National Comorbidity Survey Replication. *Mol Psychiatry*, 15(1), 53–63. pmid:18725912

Russell, A. J., Mataix-Cols, D., Anson, M., & Murphy, D. (2005). Obsessions and compulsions in Asperger syndrome and highfunctioning autism. The British *Journal of Psychiatry*, 186, 525–528.

Simpson, H. B., & Reddy, Y. C. (2014). Obsessive-compulsive disorder for ICD-11: proposed changes to the diagnostic guidelines and specifiers. *Brazilian Journal of Psychiatry,* 36, 3-13.

Skarphedinsson, G., De Nadai, A. S., Storch, E. A., Lewin, A. B., & Ivarsson, T. (2017). Defining cognitive-behavior therapy response and remission in pediatric OCD: a signal detection analysis of the Children's Yale-Brown Obsessive Compulsive Scale. *European child & adolescent psychiatry*, *26*(1), 47-55.

Spain, D., & Happé, F. (2020). How to optimise cognitive behaviour therapy (CBT) for people with autism spectrum disorders (ASD): A Delphi study. *Journal of Rational-Emotive & Cognitive-Behavior Therapy*, *38*(2), 184-208.

Spiker, M. A., Lin, C. E., Dyke, M. V., Wood, J. J. (2012). Restricted interests and anxiety in children with autism. *Autism*, 16, 306–320

Starcevic, V., Berle, D., Brakoulias, V., Sammut, P., Moses, K., Milicevic, D., et al. (2011). Functions of compulsions in obsessive-compulsive disorder. *Aust N Z J Psychiatry*, 45, 449–457

Storch, E. A., Murphy, T. K., Geffken, G. R., Soto, O., Sajid, M., Allen, P., ... & Goodman, W. K. (2004). Psychometric evaluation of the Children's Yale–Brown obsessive-compulsive scale. *Psychiatry research*, *129*(1), 91-98.

Turner, C. M., Mataix-Cols, D., Lovell, K., Krebs, G., Lang, K., Byford, S., & Heyman, I. (2014). Telephone cognitive-behavioral therapy for adolescents with obsessive-compulsive disorder: a randomized controlled non-inferiority trial. *Journal of the American Academy of Child & Adolescent Psychiatry*, *53*(12), 1298-1307.

Turner, C., Volz, C., & Krebs, G. (2019). *OCD-tools to help young people fight back!: A CBT manual for therapists*. Jessica Kingsley Publishers.

Tyrer, P. (2017). Comorbidity, consanguinity and co-occurrence. *BJPsych Advances*, *23*(3), 167-168.

Van Steensel, F. J., Bögels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: a meta-analysis. *Clinical child and family psychology review*, *14*(3), 302-317.

Walters, S., Loades, M., & Russell, A. (2016). A systematic review of effective modifications to cognitive behavioural therapy for young people with autism spectrum disorders. *Review Journal of Autism and Developmental Disorders*, *3*(2), 137-153.

Wood, J. J., & McLeod, B. (2008). *Child anxiety disorders: A treatment manual for practitioners*. New York: Norton

Wood, J. J., Kendall, P. C., Wood, K. S., Kerns, C. M., Seltzer, M., Small, B. J., ... & Storch, E. A. (2020). Cognitive behavioural treatments for anxiety in children with autism spectrum disorder: a randomized clinical trial. *Jama Psychiatry*, *77*(5), 474-483.

World Health Organization (WHO). (1993). The ICD-10 classification of mental and behavioural disorders. World Health Organization.

Chapter 2: Major Research Project

An IPA exploration of parents’ experiences of their child receiving a diagnosis of autism using a reframed approach.

Prepared in accordance with the author requirements for the journal

Frontiers in Psychology

https://www.frontiersin.org/guidelines/author-guidelines

Plain Language Summary

Title: An IPA exploration of parents' experiences of their child receiving a diagnosis of autism using a reframed approach.

Background: Autism is a diagnosis characterised by difficulties with social communication, repetitive and restrictive behaviours, narrow interests, and sensory differences such as being overly sensitive to light or sound. It is currently diagnosed using structured tools to gather developmental and family history along with clinical observations. These tools map on to diagnostic criteria in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM 5) and the International Classification of Diseases, Tenth Revision (ICD-10). Autism is currently diagnosed using a deficit approach as it is the presence of a number of impairments in a person's functioning which leads to a diagnosis. Research is beginning to emerge that shows the current diagnostic approach is unhelpful and potentially harmful for young people. This is because such practice may negatively contribute to an individual's sense of self as, along with the word diagnosis, it implies that the condition or "disorder" it is unchangeable and a person's difficulties could continue throughout their lives. It also overlooks the strengths of a person with autism which may lead to the individual not being fully understood by themselves or others. An alternative is to use a reframed approach. This is a novel idea involving 'identifying' rather than 'diagnosing' someone as autistic and taking a holistic view of the person, focusing on their strengths and abilities as well as acknowledging difficulties. This study will focus on a reframed approach to the assessment and diagnosis of autism.

Aims: This study aims to describe the key features of parent/carers' experiences of the process of their child's assessment for possible autism, receiving a diagnosis using a reframed approach, and the post-diagnostic experience.

Methods: Three parents/carers of young people were recruited from The Neurodevelopmental Service for Children and Young People (NHS Lanarkshire) who are utilising a reframed approach in the diagnosis of children who have autism. Participants were informed of the study and asked to give informed consent by signing a consent form after discussing the study with the researcher. They were then invited to participate in an interview lasting approximately 60-90 minutes. The interview was semi-structured, meaning that the researcher had a list of questions to ask but was also flexible to encourage the participant to talk about their experiences. Interviews were recorded and transcribed and analysed using a qualitative approach called Interpretative Phenomenological Analysis to identify themes. This approach helps to achieve an in-depth insight into a person's experiences by providing a detailed examination of them.

Main findings and Conclusions: Five group experiential themes (GETs) were found. The first GET explores the mother’s experiences of their time before meeting The Neurodevelopmental Team clinicians. The following 3 GETs focus on their experience of The Neurodevelopmental Team along with the family wide implications of receiving a diagnosis. The final theme depicts how the participants see their own and their child’s future. The study concluded that the relationship between families, professionals and services should not be underestimated and should be a central part to the assessment and diagnostic process.

Abstract

Background*:* Autism is a neurodevelopmental condition that is characterised by social communication difficulties, sensory differences, and restrictive or repetitive behaviours or interests. Currently diagnosis is achieved using structured tools and clinical observations which map on to the DSM-5 and ICD-10 criteria. This process is based on a deficit approach. Research is emerging that shows this diagnostic approach is likely to be unhelpful and potentially harmful to children, young people and their parents alike. A reframed approach to diagnosing autism is a novel philosophy that extends focus to the child's strengths, involves 'identifying' rather than 'diagnosing' someone as autistic and takes a holistic view of the person. ***Aims****:* To describe the key features of parent/carers' experiences of their child's autism assessment, receiving a diagnosis using a reframed approach, and post-diagnostic experience. ***Methods****:* Three individual parents/carers of CYP who have experienced the reframed approach were recruited using purposive sampling. Semi-structured interviews were used to explore their experiences and analysed using Interpretative Phenomenological Analysis (IPA). ***Main findings and conclusions:*** Five group experiential themes (GETs) were found. The first GET explores the mother's experiences of their time before meeting The Neurodevelopmental Team clinicians. The following three GETs focus on their experience of The Neurodevelopmental team along with the family wide implications of receiving a diagnosis. The final theme depicts how the participants see their own and their child's future. In conclusion, the relationship between families, professionals and services should not be underestimated and should be a central part to the assessment and diagnostic process.

1.Introduction

1.1 Autism Spectrum Conditions

Autism is a neurodevelopmental condition characterised by social communication difficulties, restrictive or repetitive behaviours or interests, and sensory differences (American Psychological Association, 2013; World Health Organisation, 2020). In 2013, the Diagnostic and Statistical Manual of Mental Disorders version 5 (DSM-5) replaced a range of diagnostic terms relating to autism with a broad diagnosis of Autism Spectrum Disorder (ASD) (APA, 2013). The term autism will be used in this study to emphasise the importance of viewing autism as a 'difference' rather than a 'disorder' (Baron-Cohen, 2000).

Autism is currently diagnosed using structured tools and clinical observations. The Scottish Intercollegiate Guidelines Network (SIGN) guidelines (SIGN, 2016) recommend the use of ASD-specific diagnostic instruments such as the Autism Diagnostic Interview-Revised (ADI-R: Lord, Rutter, & Le Couteur, 1994), Diagnostic Interview for Social and Communication Disorders (DISCO: Wing, *et al.* 2002) and the Developmental, Dimensional Diagnostic Interview (3di: Mandy, Charman & Skuse, 2012) for gathering a detailed family and developmental history. The Autism Diagnostic Observation Schedule – Generic (ADOS-G: Gotham, *et al.* 2006) and Childhood Autism Rating Scale (CARS: Schopler, Reichler, & Renner, 1988) are highlighted as recommended structured observation tools to be used by clinicians who have training and a substantial amount of clinical experience in autism assessments (SIGN, 2016).

The diagnostic process uses the observation of behaviour and assessment of 'dysfunction', highlighting the individual's impairments and mapping these onto the DSM-5 or ICD-10 diagnostic criteria (APA, 2013; WHO, 2020). This is a deficit model of diagnosis and may contribute to an individual's sense that the diagnosis is a fixed, non-relational aspect of themself, which they may continue to hold throughout their lives (Abbott et al., 2013). Whilst diagnostic reports may include strengths and difficulties of an individual, they often still exhibit a reductionist view of the individual and do not describe or acknowledge the dynamic conceptions of the individual's life (Hens, 2019).

1.2 Diagnostic experiences of parents

The diagnostic experience for parents has been highlighted as an important part of the process in many studies. Crane et. al. (2015) stated that most parents were dissatisfied with the autism diagnostic process with 84% describing this as “very stressful”. This supported previous research conducted by Howlin and Moore (1997) who surveyed over 1200 families in the UK, with almost half the families dissatisfied with the process of diagnosis, from referral to post-diagnostic support. However, the authors of the study reported that parents whose children received a diagnosis at a younger age were more satisfied with the process and were more satisfied if they received a “clear-cut” autism diagnosis.

Other research has found that the most concerning aspects of the diagnosis for parents included social communication and social development of their child (Siklos and Kerns, 2007). In a systematic review, Abbott, Bernard, and Forge (2013) collated literature regarding parental perceptions of the experience of their child receiving an autism diagnosis. The studies identified showed that parents appreciated clinicians who recognised strengths as well as difficulties and who were holistic and hopeful in their approach to feedback. They also found that a structured and open approach to the assessment process was favoured by most parents, echoing findings from Howlin & Moore (1997) and Braiden et al. (2010).

Research highlights the importance of how families are given the news of their child's diagnosis and how this can have a significant impact on the levels of distress and anxiety that families experience (Sanders and Morgan, 1997). A positive diagnostic experience is associated with greater levels of acceptance, more effective coping strategies and lower stress levels (Woolley et al., 1989). However, the National Institute for Health and Care Excellence (NICE) guidance on communicating a diagnosis (NICE, 2017) does not mention a holistic or hopeful approach or that it is beneficial to share positives. It states that the professional must explain *“how autism is likely to affect the child or young person's development and function…”* which reverts to a deficit model of diagnosis and could be reductionist as it is difficult to infer how autism may impact on an individual.

1.3 Alternative approaches to diagnosis

An alternative way of approaching the diagnosis of autism is to consider a reframed approach (Attwood & Gray, 1999). This approach, first suggested by Tony Attwood and Carol Gray, aims to move from a *diagnosis* of autism to a *discover*y of autism. They proposed identification based on strengths and talents rather than dysfunction of the individual. Diagnostic reframing involves looking at the way in which assessment and diagnosis, particularly the delivery of feedback to young people and families, are undertaken. It offers a holistic and balanced view of the individual and focuses on the person, identifying areas of strength and potential difficulties associated with autism. It uses positive language such as “passions” rather than “restrictive and repetitive interests” and allows the individual to develop a more positive sense of self concerning their differences (Reframing Autism, 2018).

Reframing is something that people with autism often take upon themselves and Bayat (2007) cites positive reframing of symptoms as one of the most poignant resilience processes for families with children who have differences including autism. A reframing approach may be a helpful way for individuals to have a more positive and less harmful experience of autism identification. However, at present, this is not a standard diagnostic approach suggested by either NICE or SIGN guidelines, nor is there a validated tool to discern positive aspects of autism to allow for a standardised reframed approach to diagnosis. Attwood and Gray (1999) attempted to create a framework for identifying autism “Criteria for Aspie” by taking the DSM-IV’s criteria for Asperger’s Syndrome and redefining them in a positive frame e.g. *“A qualitative advantage in social interaction, as manifested by a majority of the following: free of sexist, age-ist, or culture bias with an ability to regard others at face value.”* However, this framework is not widely utilised, meaning it has not been replicated or validated and has not influenced current guidelines for diagnosing autism.

Within the diagnostic process it is also helpful to consider that comorbidity or co-occurrence of neurodevelopmental conditions is the rule rather than the exception. Davis & Kollins (2012) stated that 30 to 50% of children and young people (CYP) with autism also presenting with symptoms consistent with attention deficit hyperactivity disorder (ADHD).

1.4 Aim of the current Study:

Whilst numerous studies have looked at the current diagnostic process and its possible limitations, none have yet focussed on a reframed approach to diagnosing autism. This study will aim to understand parents' experiences of their children being assessed, and autism being discovered, using a reframed, neurodevelopmentally holistic approach. As this is a novel study, it will explore the diagnostic process in full; from when the conversation of an autism assessment was first broached to post-diagnostic support, to allow for a greater exploration of parents' experiences.

1.5 Research Question:

How do parents/carers experience the process of assessment, their child receiving a diagnosis of autism using a reframed approach and life after the diagnosis has been given?

2. Methods

2.1 Theoretical Framework

This study takes an ontologically relativist stance as it is concerned with an individual's experience which shapes their reality. Epistemologically a constructionist stance is observed as the study aims to derive truth and meaning from engagement with participants and their engagement with the experience.

2.2 Interpretative Phenomenological Analysis

In keeping with the research position, an IPA approach was adopted. IPA is viewed as an approach rather than a method as it guides all aspects of research design (Smith et al., 2022). The theories underpinning IPA include "phenomenology", an approach to the study of experience; "hermeneutics", a theory of interpretation and "idiography" which is the study of the particular in detail and depth (Smith et al., 2022). IPA proposes an in-depth exploration of an individual's experience and how they have made sense of that experience. It was considered that IPA was best suited to find out about parent's experiences of their children being diagnosed with autism and to explore how they have made sense of this experience in the context of their lives. It was considered over other forms of qualitative analysis for its ability to allow for exploration into what the experiences mean and the continued impact on the parent’s lives.

2.3 Participants

Recruitment took place between July 2022 and August 2022. Purposive sampling was used to recruit participants. Whilst this method of sampling reduces the generalisability of the results it did create a homogeneous sample which is appropriate for IPA (Smith et al., 2022). It was intended that between three and seven individuals would participate and that recruitment would end at this point.

According to Pietkiewicz and Smith (2014), there is no set rule for the number of participants that should be included in an IPA study. It is highlighted that the number depends on the depth of analysis and the richness of the individual interviews. It also depends on how the researcher wishes to compare cases as well as any pragmatic restrictions they are working under. This consideration allows for enough time to develop a rich story with deep analysis of data. Hefferon and Gil-Rodreguez (2011) noted that given the idiographic nature of IPA “less is more” when referring to sample size explaining that fewer participants analysed in greater depth is preferable to a broader, shallower analysis of a larger sample.

2.4 Inclusion Criteria

Inclusion

- Parents/carers of young people up to the age of 18 who have received a diagnosis of autism using the reframed approach from The Neurodevelopmental Service for Children and Young People (NSCYP), NHS Lanarkshire, since the service began.
- The parents/carers are English speaking and can give informed consent to participate.
- Participants can take part in the interview through the use of secure video conferencing software.
-

Exclusion

- Any active risk identified by the NSCYP, NHS Lanarkshire, e.g., suicidality or significant co-occurring mental health problems.

2.5 Recruitment Procedure

Ethical approval was obtained from the NHS Research Ethics Committee (Appendix 2.4), and management approval was obtained from the NHS Lanarkshire R&D department (Appendix 2.6). Clinicians identified families they had worked with, or were continuing to work with, who met the study criteria. They then posted the potential participants an information sheet that included contact information for the researcher, along with a reply slip and pre-paid return envelope[2].

If the parent/carer was interested in participating they were asked to return the reply slip which gave consent for their contact information to be shared with the researcher. They were then contacted by the researcher to discuss the study, and their potential participation, in more detail. If they indicated they would like to take part, they were posted or emailed (using NHS or University of Glasgow email) a copy of the consent form to review and then booked to attend the interview via a secure online, video conferencing software. Verbal consent to participate was sought from the participant at the beginning of the interview and recorded on a University of Glasgow Dictaphone.

2.6 Sample

Out of the nine families who were approached to take part, three parents from three families were recruited to take part in the study. Table 2.1 outlines the pseudonyms of the parent's and demographic information of their children who underwent assessment with the NSCYP. The NSCYP use a reframed approach to assessment and diagnosis. The approach reframes the deficit model of diagnosis, with the aim of de-pathologizing the language used in autism assessment and diagnosis. The approach used language that is more in life with how individuals experience autism. For example, instead of citing "restrictive, repetitive behaviours" the diagnostic report may say "enjoys moving their body the same way over and over again" and "restrictive interests" may become "passionate about…". The aim of the reframes approach is to highlight a holistic view of the individual and whilst it does not dismiss difficulties it focusses on strengths and abilities (Attwood & Gray, 1999).

---

[2] An amendment to ethics was granted on 22nd August 2022 to allow for clinicians to ask families in person if they wish to participate in the study and for them to be able to sign the reply slip there and then.

Table 2.1 Participant's Pseudonyms and their child's gender and age at time of diagnosis

Participant Number	Pseudonym	Child's gender and age at time of diagnosis
1	Carol	Male, 8
2	Beverly	Male, 6
3	Nichole	Female, 9

2.7 Research Procedure

As suggested in IPA guidelines (Smith et al., 2022) a semi-structured interview was developed as a guide (Appendix 2.3). This facilitated discussions about the parent's/carer's experiences. The interview followed their experiences chronologically from the first-time autism was raised as a concern to their child receiving a diagnosis and what their post-diagnostic experience had been. The interviews followed the parents/carers narrative and remained flexible. Open-ended and spontaneous follow-up questions were utilised to encourage participants to elaborate on their experiences. The interview schedule was informed by existing literature relating to the exploration of the diagnostic process of autism (Howlin & Moore, 1997). It was also developed with input from a network group facilitated by the NSCYP. The schedule was piloted with the first participant. This transcript was included in the final analysis as there were minimal alterations to the interview schedule for the subsequent participants. The interviews lasted on average 79 minutes (Range 78 - 82). Interviews were digitally recorded and transcribed verbatim on a password-protected laptop for analysis. Participants were given a pseudonym and any references to specific locations or other aspects which may compromise their anonymity were removed from interview transcripts.

As the study involved a significant time commitment it was considered that a small thank you for participation would be appropriate. The parents/carers who participated received a £10 voucher with a thank you note to acknowledge their efforts.

2.8 Analysis

The interview transcripts were analysed using IPA's seven-stage methodological approach as outlined by Smith, et al. (2022). This initially involved immersion in the data by in-depth reading of the transcripts, one by one, and relistening to the interviews. The transcripts were then annotated with initial ideas, thoughts, observations, and reflections relating to the narrative, known as exploratory noting. Experiential statements were constructed as an attempt to reduce the volume of data whilst maintaining its complexity (Appendix 2.7). Care was taken to keep the experiential statements directly related to the participant's experience. The experiential statements from each participant were then ordered and connected. Themes from the ordered experiential statements were derived, consolidated, and organised whilst ensuring they remained grounded in the participant's experiences (Appendix 2.7) (Noon, 2018). These steps were repeated for each transcript before bringing all data together to develop group experiential themes across all interviews (Appendix 2.8). The overall themes were compared and contrasted, and convergence and divergence of experiences were identified (Denovan & Macaskill, 2012). A reflective account was kept by the researcher to help identify and acknowledge subjective views. To enable credibility and triangulation, regular collaboration and supervision assisted different stages of analysis.

2.9 Researcher reflexivity

As the researcher has a central role in the IPA approach it is important for them to consider how their own experiences, beliefs and assumptions could influence the analytic process (Smith et al., 2022). The researcher who conducted the interviews was a female, clinical psychology doctoral trainee. She had previous experience completing autism assessments in an adult population and personal experience of living with a family member who had autism. The researcher kept a reflective log which included potential sources of bias and when they experienced a strong emotional response evoked by interview content. This aids in the skill of 'bracketing' which is the process of highlighting and putting to the side perspectives and expectation throughout the research process (Smith et al., 2022). Research supervision was also used to help triangulate and develop coherence of the interpretation. The COREQ reporting guidance was referenced and adhered to during this study Tong, Sainsbury & Craig, 2007).

3. Results

Five group experiential themes (GETs) were constructed from the data. Initially, each individual interview was analysed and personal experiential themes were constructed see appendix 2.7. From there, connections were established to develop the GETs and group level sub themes which are detailed in table 2.2. The first GET explores the participants experiences of their time before meeting the NSCYP. The following 3 GETs focus on their experience of working with The Neurodevelopmental team in the assessment and diagnostic process along with the systemic implications. The final theme depicts how the participants see their own and their child's future.

Quotations from participants have been used to illustrate GETs and group level sub-themes. Some sections of the included quotations have been removed as they were not relevant or may have identified the participant. The excluded sections are marked with the symbol […]. The interpretations of these selected quotations have been discussed following IPA techniques outlines by Smith and colleagues (2022). The group level sub-themes represent both convergent and divergent experiences and are discussed in greater detail.

Table 2.2 Group Experiential Themes and Group Level Sub-Themes

Group Experiential Themes	**Group Level Sub-Theme**
A. Before meeting the neurodevelopmental team, things were worse	Not being listened to, not being heard, being dismissed
	Fighting for support and guidance
	Systemic escalation of difficulties
B. Complex neurodevelopmental and mental health picture	It's not the autism it's everything else on top of it
	Prioritisation of difficulties
C. The importance of the relationship with the neurodevelopmental team	Working with the neurodevelopmental team was a partnership
	The amount of contact to and from the Neurodevelopmental Service for Children and Young People (NSCYP)
D. The importance of information	The sharing and gathering of accurate information
E. Looking to the future	

A. Before meeting the neurodevelopmental team, things were worse.

All participants spoke about their journey before meeting the NSCYP with a sense of frustration, hopelessness and escalating difficulty.

A1. Not being listened to, not being heard, being dismissed

All participants spoke of how, at some point in their journey, they felt dismissed by professionals and that their concerns were not listened to or taken seriously.
Carol noted that she had been turned away by professionals stating that:

> *"The paediatrician had, you know, looked at [child] during and the appointment had sort of made judgments based on how [child] was interacting with him. And he felt that there was no sort of signs of anything there, that was sort of autistic if you like, or anything that needed further support so he just sort of signed [child] off. Meanwhile though we still continued to experience some challenges and differences with [child] very emotional particularly when he started school" (Pg. 2)*

Beverly spoke about how her concerns were dismissed:

> *"Erm... And she told me at the time that he was just a boy and he was lazy and that he would be fine but they would keep them on the register and they would reassess him sort of 4 weeks later or whatever" (Pg 1)*

Her use of “whatever” indicates that she felt dismissed and ignored.

Nichole shared a similar experience in that she was not taken seriously by professionals and only once she had a letter from an authority was she listened to but still begrudgingly.

> *“So we went to the doctor, he wasn't happy putting her on the list {waiting list for the NSCYP}, he thought it was a load of nonsense but he said, fine, the school had given me a letter, he couldn't ignore it.” (Pg 3.)*

A2. Fighting for support and guidance

Carol was very descriptive about her experiences before meeting the NSCYP. She gave a clear picture of the struggle she experienced during this time. She described pushing for support and not receiving clear or helpful guidance and being left alone to deal with everything. She said:

> *"And again, every two weeks I would be pushing, and my husband would be pushing they really need further help because, you know, he wasn't sleeping, the violence was getting worse, it was just, it was horrible watching them through this and not really understanding what was going on. Well, we just wanted to understand more so we can help him." (Pg. 2/3)*

Carol noted that she just wanted to understand more. She was desperate for guidance from professionals as she appears to not feel able to cope with her son's difficulties on her own, even with the support of her husband.
Beverly shared a similar experience of needing to push for support:

> *"So, I explain the whole story to her {student health visitor}. Erm... And she said no I think there's definitely something going on […] I said yeah, I would like that, that's something I've been pushing for, for as long as I can remember" (pg. 2)*

Nichole also experienced needing to push for and fight for her daughter to be seen by professionals. She stated:

> *"I had sort of suggested like, this doesn't seem quite right like, why's she not getting this. Erm... so I said well, could she be dyslexic? And they said well, no because she's not 8 as if it just like descends on you once you're 8. So, they were like no, no, absolutely not." (pg. 2)*

Nichole eventually went on to get a private dyslexia assessment for her daughter *"so we got her assessed privately for dyslexia"* (pg. 3). As she was not able to get the support her daughter needed from school. She was aware that the way in which they were teaching spelling was not working for her.

> *"Basically [child] couldn't do phonics […] they would repeat three letter words constantly […] they just kept repeating and repeating and repeating and [child] was getting quite upset with school erm*

> *because this went on for like the whole year, they just had the same block of phonics and then […] but if she didn't get them, they just simply went back to the start of that block." (pg. 2)*

She goes on to speak about her struggles in communication with the school in terms of the support her daughter needed, saying:

> *"{Head teacher said} If you're not happy with the school, get in touch with the school. And I'm like, I am and we are falling out about everything and they're like, well it's the school's problem. So educational psychology as well, was a total failing, the head teacher was atrocious, the teachers weren't good and they'd said that if she didn't know how to do phonics then they didn't know how to teach her." (pg. 6)*

A3. Systemic escalation of difficulties

All participants spoke of varying, escalating difficulties during the time before they met the NSCYP.

Carol noted that her son's struggle was traumatic and horrific. She used very strong, emotive words to describe this time, indicating that it was an incredibly difficult time for her and her family. She mentions again about the lack of clear guidance and sees this as one of the reasons that things had escalated in this way. She said:

> *"I would say that it was very traumatic, horrific and it was upsetting to see our son struggle with no clear guidance on how to help him and we became, we were a horrible position because we had [sibling] in the house. The house was unsafe. So, then you've got [child] who clearly needed assistance and help and then we've got wee [sibling] who was barricading herself in her room and stuff and we were having to barricade her in her room with again no help to actually help us understand and then in turn, help [child]. So that things could maybe just be eased a bit it was just horrible." (Pg. 6)*

Beverly spoke more about her son's medical difficulties before meeting the NSCYP however, she did indicate that certain behaviours were troubling for the family which she, in hindsight, links to her son's neurodevelopmental diagnoses.

> *“Chaotic, just total chaos… he doesn't have loads of traditional autistic traits right, he does have, he is very repetitive, very, very repetitive. Erm.... He […] loves anything electronic that he can switch on and off and on and off and on and off [….] He doesn't speak he is nonverbal or preverbal […] he didn't start speaking until he was maybe before he was 4 a half or 5. But in the house he was always making noise […] All the time. In different variations and he would get really, really distressed if you didn't copy exactly how he done it. […] So, we would be followed around by this noise like 24/7 because he would be singing because it's the only way he could communicate […] He never sleeps he doesn't sleep ever, still doesn't sleep now. I don't think I've slept a whole night in seven and a half years because he still doesn't sleep.” (pg. 4)*

Beverly described a house that was in chaos. She noted that she has not had a full night sleep since her son was born. Later on in the interview she noted that her mental health was impacted by the situation. She stated that:

> *“because like, in that same year {2018} I went on antidepressants because I was just not coping with the lack of sleeping, just life in general, all those appointments I had to go to.” (pg. 17)*

Nichole spoke about the escalation in her daughter’s mental health difficulties stating that:

> *“[Child] had suicidal erm thoughts. So, she sorta self-harmed. Just minor like, it was like you know taking like nail files across our face and stuff like that. So, she was all like blood and like all red, her skin was all raggy and stuff like that and she was cutting herself and stuff. Erm... so that was pretty bad. And then she said, like, well, I just don't want to be here anymore and, and stuff like that. So it was pretty horrendous” (pg. 4)*

B. Complex neurodevelopmental and mental health picture

An important feature of the mother's experiences was that of complexity. All of their children had multiple diagnoses, including autism and the parents spoke of how this made things more challenging.

B1. It's not the autism it's everything else on top of it

All mothers expressed that autism was not the main thing that was impacting on their child's and the family's functioning. Beverly said:

> *"…the global delay and I think it makes our autism harder because for some people autism is reading books about subjects and being a genius on them or being extremely high functioning and articulate. [child] is extremely low functioning and a lot of that is due to the global delay and it makes it harder you know. So, it seems like we've got the shit end of the stick…" (Pg. 21)*

Beverly focussed on her son's autism but often noted that his other difficulties and diagnosis made his autism harder and that it was the other difficulties that took up time in her life.

> *"…but that year it was just a really bad year for us because, I worked it out, and I tell people all the time, just [child] on his own, not with anybody else just him on his own, had 126 appointments that year at hospital for all of the different things that you have going on. I'll tell you what he's got going on in a minute it was just a lot to have to deal with and then to be told that he has autism as well was just an absolute scunner because [...] You know it's hard enough having all those other appointments and just add something else on, when I was already not in a great place…" (Pg. 4)*

Beverly spoke of autism as almost an additional difficultly that was not fair on her son because of all of his other difficulties.

Carol focussed a lot on her son's obsessive-compulsive disorder. Her repetition of "horrific" and "horrible" emphasised how incredibly difficult she had found it to cope with and to witness the impact it had on her son; she said:

> *“…he got the OCD diagnosis, as well, we realised the full extent of the horrors and the rituals and the harm he was doing to his body and that, and that, would be the OCD.” (Pg. 12)*
>
> *“…because he was involved in so many violent rituals and stuff he was harming, his body. And, you know, he got like a bowel prolapse and stuff with that. Like, it's horrible because the, CAMHS, but what the neuro development team are doing is, they've triaged, if you like, to focus, on [child's] OCD. Because of the horrible place he was in and it has took months to get to a better place with it.” (Pg. 16)*

She also indicated that the autism was not what was making things difficult for her son or their family. When speaking about her experience of receiving the diagnosis for her son she said:

> *“I came away thinking that to be autistic is who [child] is. It is not something that he's developed. It's not something that's wrong with him. That it's not a condition. […] to be autistic is who you are and your mind is a bit different and it's about embracing those differences. It's not about there being difficulties, it's about being different and being born that way and actually just maybe tackling things in slightly different ways to help support that. So it wasn't said in any way as a mental health condition. […] it was a very reassuring diagnosis. That, your son's not done anything wrong. That's not something that you have done wrong. It's who he is, it's part of his being, he's autistic.” (Pg. 16)*

Nichole focussed on her experience of her daughter’s attention deficit hyperactivity disorder (ADHD) and subsequently limited the amount of time she gave to speaking about autism. Nichole said:

> *“…because I wasn't interested in education for autism. You know that's her personality and that's fine…” (pg. 10)*

She does not appear to see autism as something that needs intervention because it was not causing any difficulties or issues for her daughter in their day-to-day functioning, hence the lack of focus on it. Nichole went on to share her personal experience regarding ADHD stating that:

> *“So, I suppose it's been quite a journey of figuring it all out erm... and actually on the back of it, and I'm now getting assessed for ADHD as well…” (pg. 12)*

This indicated that ADHD had become very important for her and the rest of the family. Therefore, It is understandable why the focus was so heavily skewed towards this. Nichole also spoke, on more than one occasion, about how ADHD was the main cause of her daughter’s difficulties. She stated:

> *“But again, looking back, that was her ADHD and that's why that is what it is…” (pg. 5)*
>
> *“[Child] Can't follow any line of instruction, she's completely intelligent enough to understand like, you know, the picture thing in the wall. She's like she doesn't need that, she knows, but then it just disappears into, you know, losing focus something catches her eye then it just completely erase it on you know, her list of things to do. And so, all of that difficulty, that [child] experiences, every day, erm... she said, this actually ADHD. That's not autism.” (pg. 9)*

B2. Prioritisation of difficulties

Carol shared that the NSCYP looked to prioritise supporting her son with his OCD in the first instance as this was causing the most difficulties for her son and herself, something which she agreed with She said:

> *“They were confident that the main one that was troubling him so much was the OCD and that was their target they were going to target that the OCD” (pg. 12)*
>
> *“…the focus, rather than bombard [child] with lots of different information. We he, he knows so much about OCD just now to help reassure him that he can cope with his OCD.” (pg. 16)*

Whilst there is clear prioritisation in supporting her son with his difficulties. Carol also notes that it is still important to her that her son understands who he is in relation to his autism.

> *“However, that's not to say that they also realize the importance of [child] understanding, who he is. So, what they {the NSCYP} have provided us with is some guidance {in relation to autism} for myself and my husband to use in conjunction with [third sector organisation]…” (pg. 16)*

Beverly also spoke of prioritisation in terms of her son’s difficulties, often citing his medical diagnoses as more time intensive. She said:

> *“…I worked it out, and I tell people all the time, just [child] on his own, not with anybody else, just him on his own had 126 appointments that year at hospital for all of the different things that he has going on […] it was just a lot to have to deal with… (pg. 3)*

Nichole was clear in her prioritisation of supporting her daughter with her difficulties in relation to her ADHD but almost because Nichole did not appear to see any difficulties relating to her autism diagnosis so did not believe it warranted any time or thought.

> *“Erm... I suppose once we learned more about ADHD as well, it sort of helped separate the two sides and I realised, that ADHD was more impacting [child] every day and that was something, because I wasn't interested in education for autism, you know, that's her personality and that's fine.” (pg. 11)*

Nichole speaks about autism as being her daughter’s personality which suggests that she sees autism as something that is not changeable or that would not be impacted by intervention. Hence, this is not a priority for her.

C. The importance of the relationship with the neurodevelopmental team

The quality of the relationship between the family and the NSCYP was extremely important to all participants.

C1. Working with the neurodevelopmental team was a partnership

Carol deeply valued the partnership she had with the NSCYP, expressing this repeatedly. What was most important for her was the equitable nature of that partnership. She described feeling valued and respected as the mother of her son but also that the team took responsibility over certain aspects of her son’s care. She said:

> *“It wasn't like they were like, no, no, no we need to take charge of this. Again, it was a partnership and it was letting us take the lead on it and on what would be best for [child].” (Pg. 17)*
>
> *“Like it's amazing what they do, it really is. Like, just an amazing support that they offer. And they'll scale it back when it's needed but again, it would be on our terms. So I wouldn't change anything.” (Pg. 17)*

The fact that she was listened to and was able to take the lead was an important feature of her experience. She noted that the care was on her terms, she felt in control of what was happening which is a definite shift from how she felt before meeting the NSCYP.

C2. The amount of contact to and from the NSCYP

All mothers noted that the relationship as a whole was, a key, positive aspect of the diagnostic experience and that it was a valued aspect of the service.
Carol highlighted the importance of the support that the NSCYP team offer and how they are a reliable presence in Carol’s life.

> *“…we're going through challenging transactions now, you know it feels good to know that we've got a partnership there, it can help us. Even like this week when I was saying about the school being on the phone there. I've got an appointment with [Clinician], just need a phone call, and then again, following [day of week] as well.” (Pg. 19)*

Beverly also focussed on the relationship between her and the NSCYP but had more of a mixed experience. She described her first meeting with the NSCYP:

> *“The assessment said it would be about an hour on paper but I think we were there about an hour and a half. The two ladies that were there were lovely, one spoke to me and one played with [child].” (pg. 9)*

Beverly noted that the assessment was longer than anticipated and shared that the clinicians asked lots of questions indicating that they were interested in finding out all about her son:

> *“The other lady was just asking me loads of questions about sort of his life. And, and then she sort of ask me questions like how does he behave around people, does he engage with people and [...] If you ask him to do certain things what would his response be and how would he behave in that kind of thing.” (pg. 10)*

After her son receiving a diagnosis of autism Beverly spoke about a gap in contact with the NSCYP. She described feeling ignored for a time and that she was kept waiting for longer than expected and was unable to get hold of clinicians during that time. She said:

> *“There must have been about 5 or 6 people chasing the doctor and nothing, no reply. We were ignored, no reply, no email, no nothing. Then I started emailing [clinician] myself because I found her email address on some website. No acknowledgement, no acknowledgement, nothing back at all. I was phoning again twice a week, trying to chase it because [child] was getting harder and harder to cope with in the house.” (Pg. 11)*

Beverly was angry due to the lack of communication from the NSCYP *“I was raging, and I was like, why does it take so long to get anybody to help me”* (pg. 11).
She then went on to speak in more positive light about her experience of being in the room with the clinicians. In this excerpt Beverly is speaking about a diagnostic appointment for ADHD. She said:

> *“She {clinician in the neurodevelopmental team} was lovely about it, so lovely, I really like her. She talked me though all that stuff and she asked me if I was okay and I said I'm cool, I'm totally fine with it. I think it might help him; I think it will really help him.” (Pg. 18)*

Nichole noted that the efficiency of the relationship was important to her. Stating that:

> *“[…] until we first met [clinician] and then she was available every day and night whenever, you know, it was amazing. It was night and day. You know she phoned us back; she had the teams that day. You know, I've tried to phone everybody and she had her in within*

> *two days and everything moves really quickly and stuff because she's absolutely there to help" (Pg. 15)*

She noted that she felt that the team were there to help which was a positive factor for in the relationship as well as the friendly manner in which she was greeted:

> *"Yeah. And, but they were all really friendly, and I think they really understand the backstory up until that point." (pg. 7)*

The relationship between the clinicians and her daughter was also an important aspect and was part of the reason Nichole had a positive relationship with them. She said:

> *"So [child] had always been really receptive to [clinician] and the other lady and she really enjoyed her time there and I think, I think that it's just a smashing service, it really is, once we got there, you know, you can see that they're really good at what they do and all that sort of stuff." (pg. 8)*

D. The importance of information

All participants spoke about the handling of information and the importance of accurate information in the diagnosis and support of their children.

D1. The sharing and gathering of accurate information

Carol often spoke about how information was handled during the interview. She valued information and believed that more information was better. She noted that it would help to get her son the correct diagnosis and subsequently the support he needed. She often went above and beyond to provide information to the NSCYP. She said:

> *"There was so much information […] we were talking about aunties and uncles and things, they wanted to know absolutely everything about family and about [child]. So that was huge because although [clinician] and I had three sessions, which were about two hours each, I still hadn't got anywhere near finishing that. So, myself and my husband did that in our own time because I wanted it done right to make sure that they had as much information on [child] as they could." (Pg. 14)*

Carol wanted to provide as much information as possible to the team and spoke about how the partnership almost relies on all information being shared and valued. She said:

> *"It can't just be with the neuro development team it can't just be them doing all the work. I do think it needs to be a partnership when with the parents, the child and the doctor because that it's not going to work, they can't give answers if you're not willing to provide information." (Pg 14)*

Carol also shared her frustrations with misinformation, stating that it infuriated her. Not having the correct information possibly left Carol feeling not listened to, not taken seriously and not being seen as an individual. She said:

> *"…and when they {paediatrician} sent me their report of our interview there was misinformation in it,[…] . And that wasn't true." (Pg. 5)*

Beverly reflected on the accuracy of information received in her son's assessment letter and how much information the team asked of her. Again, she reflected that she felt listened to and that her son's difficulties were investigated fully.

> *"…and then we got a letter through about three weeks later sort of detailing the entire appointment […] and I agreed with everything, everything they said it was accurate." (Pg. 9)"*
>
> *"[…] we {Beverly and a clinician at the NSCYP} had a real good conversation, a good hour's conversation about how he definitely was autistic and had ADHD. She completely agreed, she could see that. […] Erm... sort of, she went over everything. […] She was lovely, and then she went on to talk about what we could do to help him. She said it's up to you really." (pg. 14)*

Beverly also reflected on the way information was shared. She noted that a sudden change in circumstance with seeming no warning was devastating for her. She explained that it was the lack of information about the reasons for the change and a lack of time to process which were the main issues.

> *"They {the nursery} told me they were putting in a placement request for a special needs nursery and I was just devastated and then I*

> *started to shout at them and I was really angry about it because they could have given me fore warning […] they just rang me up that day and told me that's what they were doing. If they would have just indicated that they thought there was something going on. […] if they would have told me I would have looked into it." (pg. 7)*

Nichole focussed on how often she was updated by the NSCYP and how much explanation they offered throughout the process.

> *"And so, they really looked a lot at [child's] back history. With all the school, home life and stuff like that. And then the play assessments were ongoing and they updated as quite regularly with stuff like that. And had the parents separately in to talk about how she was getting on. […] they would explain things like what they were doing" (Pg. 7)*

Nichole valued being kept up to date with the progress of the assessments and she also went on to discuss how she valued the time spent explaining her daughter's diagnosis.

> *"[…] So [clinician] got us in then before giving us the report so she could verbally explain things first. Erm... so I suppose that we weren't reading the report, not understanding what terms were and what it all meant. […] and then she'd said about actually it's a dual diagnosis, we've been keeping an open mind about ADHD and we've got enough evidence erm... that [child] qualifies for ADHD as well. And we didn't really know a lot about that. So [clinician] sort of explained the different tendencies that come with that. […] [clinician] sort of related to evidence that they gathered {during the assessment process} […] And so, all of that difficulty, that [child] experiences, every day, erm... she said, this actually ADHD. […]. So she was really good at explaining both." (pg. 9)*

All participants spoke about their initial response when hearing their child's diagnosis for the first time with the majority of them initially having a negative response to the receipt of the diagnoses.

Carol described feeling like she'd been punched in the stomach, that the receipt of the diagnosis was a shock. She said:

> *“Myself and my husband were in the room and [Clinician] was on the video call. And, it was very carefully said. It was said in a way that was compassionate, you know, but very reassuring, but it doesn't change feeling like you've been punched in the stomach…” (pg. 15)*

Carol went on to note that the way in which the diagnosis explained was reassuring and having space to absorb the information was useful in helping her come to terms with it:

> *“I would say that it was emotional finding out but it wasn't really a surprise, just really emotional, but it was done, very, very reassuringly. And she was offering sessions with us to fully explain the diagnosis on a future date so that we could then be equipped with certain techniques and stuff. (pg.15)*

Beverly’s experience of hearing the diagnosis was more of a confirming one. She noted that she was expecting to hear that her son was autistic stating that:

> *“I don't think anything changed for me when we were diagnosed. Other than the fact that I could say officially that he has an autism diagnosis.” (pg.16)*

Nichole noted that her experience an illuminating one and through her own discovery she saw autism as part of her daughter’s neurodiversity

> *“I think that's more of a thing to learn about rather than just autism and ADHD is that the neuro diversity, sort of umbrella.” (pg.12)*

Prior to assessment all parents were encountered misinformation from other services regarding ages for when their children were able to be seen or diagnosed. Carol noted that she was told her son had to be eight before he was seen:

> *“[…] we got told that [child] couldn't see an actual psychologist or a psychiatrist until he was at least eight. I don't know why that was.” (pg. 2).*

Beverly was told that her son was required to be at least five years old before they were able to assess him:

> *"I'm 90% sure she said at the time that they don't tend to get assessed until they're five, for autism, or till there close to 5 or something." (pg. 9).*

Nichole was informed that her daughter needed to be at least eight before she was able to be assessed:

> *"…so I said well could she be dyslexic? And they said well, no because she's not 8 as if it just like descends on you once you're 8." (pg. 2).*

E. **Looking to the future**

All participants noted that they had thought about their child's future as well as their own, in relation to their child's. Two of the participants spoke of a feeling of hope for the future whilst one spoke more of concern and worry.

Carol reflected on how her perception of her son's future had changed since meeting the NSCYP. She noted that she now had hope for the future where previously this was not the case.

> *"But I think that overall like I do have really hope now for [child's] future. I think it would have been a very different answer prior to meeting the neuro development team." (pg. 21)*
>
> *"I'll go back to like a few years, thinking and feeling the darkness. And what we sort of learned in the last year, course, [third sector organisation] I've only got the last year as well as made me realize that with the right environment and with the right people who understand [child] will thrive." (pg.21)*

Beverly shared a different experience of thinking about her son's future. She described feeling worried that her son will not be able to succeed independently due to his difficulties.

> *“I worry about his future because I worry about like after school finishes. Will he be able to hold down a job, probably not. Would he be able to volunteer, probably not. Will he be with me forever, probably yes.” (pg. 17)*

She also touched upon the impact of her future in that she believes her son will be with her forever also stating that *“It's not the way my husband and I thought we'd have a future.”* (pg. 17).

She also reflected on the level of support available to her son and some positives regarding the future saying:

> *“He is the perfect little boy, he's so much fun, he's always smiling. So when I think about the future and when I think about life, I think about how hard it's gonna be but I also think about how much fun it will be because he'll be great fun and he's happy.” (pg. 18)*
>
> *“We are really fortunate because we have a great support network […] and everyone adores him. […]. There will always be people there for him. […], in that respect you know, he'll be fine, he'll be absolutely fine. (pg. 18)*

Nichole described her daughter’s more immediate future regarding her transition from primary school to high school and the concerns she has:

> *“I don't think we can look hugely in the future but those next few years and high school and stuff like that is the next, sort of, looming step that we're going on. […] I have hopes but I don't know if they'll pan out. So erm... I just I would like to hope if I could make a wish that high school would be very flexible…” (pg. 16)*

4. Discussion

This study aimed to explore the experiences of parents whose children had been assessed and diagnosed using a reframed approach by the NSCYP. Specifically, it aimed to understand their journey through the assessment and diagnostic experience and beyond. Five main GETs were identified from the participants’ interviews. These themes were focused on the time before the participants worked with the NSCYP, the complexity of their children's profile, the importance of their relationships with the NSCYP, the importance of information and their view of the future. As the NSCYP use a reframed approach to assessment and diagnosis there will be focus on the features of this approach that have impacted the parent's experiences.

The NSCYP uses a novel approach to assessment and diagnosis, different to most other services in the NHS. They utilise the ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations) model which contributes to the assessment process (Gillberg, 2010). This allows for a holistic assessment of neurodevelopmental comorbidity, one to provide detailed assessment of the CYP strengths and areas of difficulty, instead of a reductionist approach often associated with disorder specific procedures and services. This, of course may lead to a diagnosis whilst not overlooking other underlying conditions or problems (Chawarska et al., 2009). On the back of this, a reframed approach to assessment and diagnosis is taken in the service. This aims to de-pathologize diagnosis and the language used in assessment letters and dissemination of diagnosis to CYP and their families.

4.1 Before meeting the neurodevelopmental team, things were worse

Two of the parents were aware of early differences in their child's development and the third parent, whilst not stating particular difficulties noted that her daughter was different to other children. This is consistent with findings from Marcus et al. (1997) (as cited in Midence & O'Neill, 1999) who noted that parents usually notice differences and difficulties in their children early on.

All participants encountered a delay between first contacting a professional and their child receiving an assessment and subsequent diagnosis. For Carol and Nichole, this was compounded by the fact that they waited for a time before contacting professionals about their concerns. A delay in assessment and diagnosis has been related to higher levels of stress and negative impact on families (Howlin and Moore, 1997). This study highlighted this to be the case for all participants with the time before meeting the NSCYP marked as an incredibly difficult one, with escalating concerns in which there was a consensus of a lack of support and guidance.

This delay also increased the parent's frustration and desperation in their desire for support and information. A sense of professionals being dismissive of the parent's concerns was also evident and increased the presence of frustration and helplessness. This was amplified by a lack of knowing where to turn to receive the required support. Webb and colleagues (2014) noted that delays in receiving a diagnosis impact on the implementation of support. Such delays also impact on the parent's level of confidence with services and healthcare professionals (Harrington et al., 2006) which is noted in the current study, particularly voice by Nichole in relation to the education system.

Osborne and Reed (2008) reported that the majority of parents stated that there is a need a for a quicker and easier route to assessment and diagnosis. They emphasised that the lack of coherence regarding the diagnostic pathway was a barrier. This is replicated in the current study, indicated by all parent's having a different path to assessment.

4.2 Complex neurodevelopmental and mental health picture

This theme encapsulates the reality of neurodevelopmental diagnoses with comorbidity being the rule rather than the exception (Gillberg, 2010). All parents had an experience of complexity in their child's presentation. They also spoke of other difficulties as being their main cause of concern rather than the child's autism or, in the case of Beverly that her child's global development delay was *"making his autism harder*" (pg. 21).

As this level of complexity is not uncommon, it tracks that services should be take a holistic approach to assessment and diagnosis. This is something that Howlin and Moore (1997) refer to in their study as improving the process for parents. The NSCYP appear to be taking this approach which is indicated by the participants receiving an all-inclusive assessments and more than a diagnosis of autism. A holistic approach is one of the underpinnings of the reframed approach and this can be seen to have a positive impact on the parent's experiences as they all share that they felt listened to and felt that their child was seen as an individual and supported well.

As part of this picture of complexity the utilisation of an ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations) model can be seen to be contributing to the assessment process. ESSENCE is an acronym coined by Gillberg (2010) to describe the reality of children presenting in clinical settings with impairing symptoms in the fields of (a) general development, (b) communication and

language, (c) social inter-relatedness, (d) motor coordination, (e) attention, (f) activity, (g) behaviour, (h) mood, and/or (i) sleep (Gillberg, 2010).
If a child experiences major difficulties in one or more of these areas, then input from more than one specialist is usually required. It also signifies that the CYP will experience difficulties in other neurodevelopmental domains. An assessment which encompasses all the above domains rather than being disorder specific helps to provide a holistic overview and detailed assessment of the CYP strengths and areas of difficulty. This, of course may lead to a diagnosis whilst not overlooking other underlying conditions or problems (Chawarska et al., 2009). This is another manifestation of the use of a reframed approach to assessment and diagnosis.

4.3 The importance of the relationship with the neurodevelopmental team

With a focus on the NSCYP all parents gave an overall positive account of the relationships with the service. Jones et al. (2014) reported that the clinician's manner was one of the most positive aspects of the diagnostic process which is shared in the current study.

The factors that foster a good therapeutic relationship appear to be reflected in relationship between parents and clinicians from the NSCYP. Horvath (2000) notes the importance of an active, collaborative partnership in which the individual is valued. This is highly reflected in Carol's experience. She expressed that she had a partnership with the team and that her expertise regarding her son was valued and respected. This gave her a sense of control and ownership over the whole process, whilst not feeling alone or overwhelmed as the NSCYP supported her as and when needed. Nichole shared a similar experience of being involved and respected as an expert in her daughter. Beverly had a turbulent beginning with the team due to a lack of communication but overall stated that the experience was valuable and that the clinicians were lovely.

Participants also spoke positively of the relationship between the clinicians and their children which was important for all. They noted that they felt that their children were listened to and that their individual needs were catered for and respected. This focus on individual needs during assessment is another aspect of a reframed approach, which also lead to a positive experience for the parents. All participants spoke highly of how accessible the NSCYP was, once they had been referred. Griffith and colleagues (2012) highlighted the importance of flexible support for adults with autism as their needs fluctuated over time. A similar outcome was noted in the current study. All participants noted that the team were available when needed and appointments were quick and thorough. Ad-hoc appointments were also available for advice or to “vent” which Carol and Nichole found particularly helpful.

4.4 The importance of information

All participants received multiple diagnoses from the NSCYP including autism, and they reflected that at least one of these additional diagnosis came as a shock and caused a negative reaction. Jones and colleagues (2014) found that a number of attributes including handing the diagnosis in a thoughtful manner; clearly explaining the diagnosis; consulting with parents as experts in their child and demonstrating a high degree of knowledge were found to increase satisfaction of the overall diagnostic experience. Through meetings with the NSCYP team all participants felt they were able to come to terms with and understand the diagnoses.

Participants noted that the most helpful thing about the appointments was that they provided a platform to gain an understanding of their children in order to support them more effectively. They all indicated they were offered a detailed explanation of the outcome of the assessments. The diagnoses were given respectfully and with reassurance, taking in to account the child as a whole, which is in line with the reframed approach. Participants reflected that they were given enough time to take in the information and ask questions, often being offered another appointment solely for this purpose.

Information flowed both ways for all participants and there was a consensus that the parent’s wanted to share as much information as they needed to with the NSCYP. In Carol’s case she noted that she went above and beyond to provide information for the assessment process in order to aid in the correct diagnosis being shared. All the participants commented positively on the amount of information asked of them. They appeared to relate information gathered by clinicians being invested in the process and their family.

All parents noted that once they knew what areas their child was struggling in, and in some cases, once they were able to name the difficulties, they were able to understand their child and begin to support them more effectively. This is a similar finding to Midence & O’Neill (1999). Two of the parent’s viewed autism as part of their child's personality with Nichole stating that she did not want any further education on autism, possibly due to her feeling that it is not something that can be or that she wants to change. Carol spoke of autism being a part of who her son is and was very accepting of this. A more positive diagnostic experience often leads to better acceptance of a child's differences (Howlin & Moore, 1997). Beverly had a divergent experience of autism in that she saw it more as a deficit and a difficulty than the other participants. She also had a less positive diagnostic experience, which may have had an influence on this.

The information received during the dissemination of diagnoses was indicative of a reframed approach. It offered a holistic and balanced view of the CYP and focused on identifying areas of strength and potential difficulties associated with autism. This was evident in the parent's shared experiences. Bayat (2007) reported that reframing is something people with autism often take upon themselves and cited the positive reframing of symptoms as one of the most poignant resilience processes for families with children who have differences including autism. An element of positive reframing among the participants was evident and the information provided by the services and from the parent's own research supporting this discovery.

4.5 Looking to the future

When speaking about the future Carol and Nichole spoke of concerns but also of hope. They both indicated that the right environment and support would be key in securing a positive future for their children which is in line with outcomes from Crane et al (2015) who noted that those who were offered support following diagnosis were more satisfied with the process overall and especially if they felt that support was tailored to the specific needs of their child.

The specificity of support was echoed by Carol and Nichole. They both outline particular support they'd received along with helpful signposting to literature, books and services. Beverly spoke less of further support post diagnosis but instead spoke to the support she received from her family and friends. She did note that the NSCYP were available to answer any questions she had and to offer support regarding medication which she found invaluable. Having support in general, appeared to be a predictor of being able look into the future with a sense of hope.

4.6 Implications for services

Consistent with Osborne and Reed (2008) the current study found that the majority of parents identified a need for a quicker and easier route to assessment and diagnosis. They had a shared experience of being dismissed and concerns ignored prior to meeting the NSCYP. They had contact with a variety of professionals during this time including general practitioners, paediatricians, educational psychologists and teachers. This finding indicates a possible need for wider training in the different presentations of autism and neurodevelopmental difficulties, especially where complexity is indicated.

There was a consensus amongst participants that the time between referral and diagnosis was too long, and this led to increasing difficulties within the family system and for the child themselves. This was compounded by a lack of guidance or support during this time.

The current findings also highlight the need for careful consideration regarding the dissemination of diagnoses. All participants shared a positive experience of how the diagnosis was presented to them via the NSCYP. As well as having a verbal conversation before receiving the report they all stated that the diagnosis was reassuring, carefully shared and explained well. They valued the time given to process the information and ask questions, often in the form of a second or third appointment with the team. The resources and signposting material was spoken highly of in that it was tailored to their child’s individual needs and an appropriate amount.

The experience of meeting the child’s individual needs also extended to the support they received directly from the NSCYP. This adaption of support is something that appeared to be key in the parent’s satisfaction of the service and something that should be carefully considers by others. It is, however, worth noting that the level of involvement offered by the NSCYP was high and may not be sustainable for all CAMHS services particularly in relation to Local Delivery Plan (LDP) standards (Scottish Government, 2022). However, the potential tailoring of support dependant on complexity and as well as creating an agreement on transitioning support to more appropriate resources outside of the NHS could help to maintain patient flow and capacity while still providing ongoing support.

5. Limitations

The current study looked at experiences of three mother’s whose children attended the NSCYP for assessment and diagnosis. The homogeneous sample was a product of the sampling methos used. However, whilst purposive sampling reduces the generalisability of the results the homogeneity is appropriate for IPA (Smith et al., 2022). Further research would be required to establish if the themes generated are relevant to other parents/carers who have used the service.

6. Future research

This study highlighted the need for further research into the experience of families receiving a holistic assessment and reframed diagnoses for their CYP. The need to further understand parent’s experiences of the time between when they become aware that their child may require extra support to redirecting that support is paramount as this will influence service provision where and how it is required. More research into the impacts of ADHD on girls was also an unexpected area of discussion.

7. Conclusion

In conclusion this is the first study to explore the lived experiences of mothers whose children underwent assessment, diagnosis and post diagnosis support at the NSCYP. It afforded invaluable insights into their experiences across various points in the process highlighting a number of areas that invoked strong emotional reactions indicating areas for improvement and for praise. It also highlighted the similarity of the participants experiences as well as key differences in their journeys. The potential consequences of these differences require further consideration for clinical practice and research. The relationship between families, professionals and services should not be underestimated and continue to be the focal point during the assessment and diagnostic process.

8. References

Abbott M., Bernard., P & Forge J. (2013). Communicating a Diagnosis of Autism Spectrum Disorder - a qualitative study of parents‟ experiences. *Clinical Child Psychology and Psychiatry*, 18 (3), 370–382. DOI: 10.1177/1359104512455813

American Psychiatric Association (APA). (2013). Diagnostic and statistical manual of mental disorders (5th ed.). DOI: https://doi.org/10.1176/appi.books.9780890425596

Attwood, T., & Gray, M. (1999). The Discovery of “Aspie” Criteria, *The Morning News*, 11(3), 2-8. Available at: https://carolgraysocialstories.com/wp-content/uploads/2015/10/Fall-1999-ISSUE.pdf

Baron-Cohen S. (2000). Is Asperger syndrome/high functioning autism necessarily a disability? *Development and Psychopathology*, 12 (3), 489-500. PMID: 11014749

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51(9), 702-714. DOI: 10.1111/j.1365-2788.2007.00960.x

Bloom, B., Cohen, R. A., & Freeman, G. (2012). Summary health statistics for us Children: national health interview survey, 2011. *Vital and health statistics. Series 10, Data from the National Health Survey*, (254), 1-88.

Braiden, H., Bothwell, J., & Duffy, J. (2010). Parents' Experience of the Diagnostic Process for Autistic Spectrum Disorders. *Child Care in Practice*, *16*(4), 377-389. DOI: https://doi.org/10.1080/13575279.2010.498415

Chawarska, K., Klin, A., Paul, R., Macari, S., & Volkmar, F. (2009). A prospective study of toddlers with ASD: Short-term diagnostic and cognitive outcomes. *Journal of Child Psychology and Psychiatry*, *50*(10), 1235-1245.

Clarke, V. (2010). Review of the book “Interpretative Phenomenological Analysis: Theory, Method and Research”. *Psychology Learning & Teaching*, 9, 57-56. Available at: https://www.researchgate.net/publication/269930318_Review_of_the_book_Interpretative_Phenomenological_Analysis_Theory_Method_and_Research

Craig, R. (2015). “I don't know what’s the Asperger’s and what’s me”: an IPA exploration of young people and mothers’ experiences of receiving and living with an autism spectrum condition diagnosis during adolescence (Doctoral thesis), University of Glasgow, Glasgow, UK. Available at: http://theses.gla.ac.uk/6702/

Crane L., Chester JW., Goddard L., Henry LA., & Hill EL. (2015). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *The International Journal of Research and Practice,* (2), 1-10. DOI: 10.1177/1362361315573636

Davis, N. O., & Kollins, S. H. (2012). Treatment for co-occurring attention deficit/hyperactivity disorder and autism spectrum disorder. *Neurotherapeutics*, *9*(3), 518-530.

Denovan, A., & Macaskill, A. (2012). An interpretative phenomenological analysis of stress and coping in first year undergraduates. *British Educational Research Journal*, 39(6), 1002-1024. DOI: https://doi.org/10.1002/berj.3019

Gillberg, C. (2010). The ESSENCE in child psychiatry: early symptomatic syndromes eliciting neurodevelopmental clinical examinations. *Research in developmental disabilities*, *31*(6), 1543-1551.

Gotham, K., Risi, S., Pickles, A., & Lord, C. (2006). The Autism Diagnostic Observation Schedule (ADOS). *Journal of Autism and Developmental Disorders*, (4), 613-627. DOI: 10.1007/s10803-006-0280-1

Griffith, G. M., Totsika, V., Nash, S., & Hastings, R. P. (2012). ‘I just don’t fit anywhere’: support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism*, *16*(5), 532-546.

Harrington, J. W., Patrick, P. A., Edwards, K. S., & Brand, D. A. (2006). Parental beliefs about autism: Implications for the treating physician. *Autism*, *10*(5), 452-462.

Hefferon, K., & Gil-Rodriguez, E. (2011). Interpretative phenomenological analysis. *The Psychologist*, 24(10), 756-759.

Hens, K. (2019). The many meanings of autism: conceptual and ethical reflections. *Developmental Medicine & Child Neurology*, *61*(9), 1025-1029. DOI: https://doi.org/10.1111/dmcn.14278

Horvath, A. O. (2000). The therapeutic relationship: From transference to alliance. *Journal of clinical psychology*, *56*(2), 163-173.

Howlin, P., & Moore A. (1997). Diagnosis in Autism: A Survey of Over 1200 Patients in the UK. Autism: *The International Journal of Research and Practice*, (1), 135-162. DOI: 10.1177/1362361397012003

Jones, L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2014). Experiences of receiving a diagnosis of autism spectrum disorder: A survey of adults in the United Kingdom. *Journal of autism and developmental disorders*, *44*(12), 3033-3044.

Kalra, S. K., & Swedo, S. E. (2009). Children with obsessive-compulsive disorder: are they just “little adults”?. *The Journal of clinical investigation,* 119(4), 737-746.

Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24(5), 659-685. DOI: 10.1007/BF02172145

Mandy, W. P., Charman, T., & Skuse, D. H. (2012). Testing the construct validity of proposed criteria for DSM-5 autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, *51*(1), 41-50. DOI: 10.1016/j.jaac.2011.10.013

Marcus, L. M., Kunce, L. J., & Schopler, E. (1997). Working with Families.

National Institute for Health and Care Excellence (NICE). (2017). *Autism spectrum disorder in under 19s: recognition, referral and diagnosis,* [NICE Guideline No. cg128]. https://www.nice.org.uk/guidance/cg128

Noon, E. J. (2018). Interpretive phenomenological analysis: An appropriate methodology for educational research. *Journal of Perspectives in Applied Academic Practice*, 6(1), 75-83. DOI: https://doi.org/10.14297/jpaap.v6i1.304

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *Czasopismo Psychologiczne – Psychological Journal*, 20(1), 7-14

Reframing Autism. (2018). *A Plea to Diagnosticians*. [online] Available at: <https://www.reframingautism.com.au/a-plea-to-diagnosticians/> [Accessed 12 October 2020].

Sanders, J.L., & Morgan, S.B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down Syndrome: Implications for intervention. *Child & Family Behavior Therapy,* 19 (4): 15-32. DOI: https://doi.org/10.1300/J019v19n04_02

Schopler, E., Reichler, R. J., & Renner, B. R. (1988). *The childhood autism rating scale (CARS)*. Los Angeles: WPS. https://institutopod.com.br/wp-content/uploads/2019/11/cars-miguel-1-1.pdf

Scottish Government. (2022). *NHS Scotland performance against LDP standards.* [retrieved from] https://www.gov.scot/publications/nhsscotland-performance-against-ldp-standards/

Scottish Intercollegiate Guidelines Network (SIGN). (2016). Assessment, diagnosis and interventions for autism spectrum disorders. Edinburgh: SIGN. (SIGN 145). [cited 04/01/2021]. https://www.sign.ac.uk/assets/sign145.pdf

Siklos, S. and Kerns, K. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities*, 28(1), 9-22. DOI: 10.1016/j.ridd.2005.09.003

Smith, J., Larkin, M. and Flowers, P. (2009). *Interpretative Phenomenological Analysis*. London: SAGE.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care*, *19*(6), 349-357.

Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology*, 18(1), 1-18. DOI: https://doi.org/10.1186/s12874-018-0594-7

Webb, S. J., Jones, E. J., Kelly, J., & Dawson, G. (2014). The motivation for very early intervention for infants at high risk for autism spectrum disorders. *International journal of speech-language pathology*, *16*(1), 36-42.

Wing, L., Leekam, S. R., Libby, S. J., Gould, J., & Larcombe, M. (2002). The diagnostic interview for social and communication disorders: Background, inter-rater reliability and clinical use. *Journal of Child Psychology and Psychiatry*, *43*(3), 307-325. DOI: 10.1111/1469-7610.00023

Woolley, H., Stein, A., Forrest, G. C., & Baum, J. D. (1989). Imparting the diagnosis of life threatening illness in children. *British Medical Journal*, *298*(6688), 1623-1626.

World Health Organization (WHO). (2020). International statistical classification of diseases and related health problems (11th ed.). Available at: https://icd.who.int/

Appendices

Appendix 1.1 - Sample Search Strategy for PsychINFO Database

#	Last Query	Limiters/Expanders	Results
S11	S3 AND S6 AND S9	Limiters - Publication Year: 2013-2022; Publication Type: Peer Reviewed Journal; English; Population Group: Human	305
S10	S3 AND S6 AND S9		1,089
S9	S7 OR S8		2,466,972
S8	TI (intervention OR therap* OR behavio* OR cognitive OR treatment* OR Psycholog* OR ERP OR CBT OR "Exposure Response Prevention" OR "Cognitive Behavio* Therapy") OR AB (intervention OR therap* OR behavio* OR cognitive OR treatment* OR Psycholog* OR ERP OR CBT OR "Exposure Response Prevention" OR "Cognitive Behaviou* Therapy")		2,454,630
S7	DE "Psychotherapy"		73,084
S6	S4 OR S5		30,955
S5	TI (Obsess* OR “Compulsive behavio*” OR OCD OR "Obsessive Compulsive Disorder" OR "Restrictive behavio*") OR AB (Obsess* OR “Compulsive behavio*” OR OCD OR "Obsessive Compulsive Disorder" OR "Restrictive behavio*")		30,470
S4	DE "Obsessive Compulsive Disorder"		15,258
S3	S1 OR S2		71,732
S2	TI (Autis* OR "Autism Spectrum Disorder" OR ASD OR Asperger* OR "autistic disorder" OR "intellectual disability*" OR "pervasive developmental disorder" OR PDDNOS) OR AB (Autis* OR "Autism Spectrum Disorder" OR ASD OR Asperger* OR "autistic disorder" OR "intellectual disability*" OR "pervasive developmental disorder" OR PDDNOS		70,382
S1	DE "Autism Spectrum Disorders"	Expanders - Apply equivalent subjects	50,231

Appendix 1.2 – Crowe Critical Appraisal Tool Scoring Sample

Crowe Critical Appraisal Tool (CCAT) Form (v1.4)

Reference

Reviewer

This form must be used in conjunction with the CCAT User Guide (v1.4); otherwise validity and reliability may be severely compromised.

Citation	
Merricks, K. L., Nadeau, J. M., Ramos, A., & Storch, E. A. (2017). A case report of intensive exposure-based cognitive behavioral therapy for a child with comorbid autism spectrum disorder and obsessive-compulsive disorder. *Journal of Cognitive Psychotherapy*, *31*(2), 118-123.	Year 2017

Research design (add if not listed)

☐ Not research		Article | Editorial | Report | Opinion | Guideline | Pamphlet | …
☐ Historical		…
☐ Qualitative		Narrative | Phenomenology | Ethnography | Grounded theory | Narrative case study | …
☐ Descriptive, Exploratory, Observational		A. Cross-sectional | Longitudinal | Retrospective | Prospective | Correlational | Predictive | …
		B. Cohort | Case-control | Survey | Developmental | Normative | Case study | …
Experimental	☐ True experiment	Pre-test/post-test control group | Solomon four-group | Post-test only control group | Randomised two-factor | Placebo controlled trial | …
	☐ Quasi-experiment	Post-test only | Non-equivalent control group | Counter balanced *(cross-over)* | Multiple time series | Separate sample pre-test post-test [no Control] [Control] | …
	☐ Single system	One-shot experimental *(case study)* | Simple time series | One group pre-test/post-test | Interactive | Multiple baseline | Within subjects *(Equivalent time, repeated measures, multiple treatment)* | …
☐ Mixed Methods		Action research | Sequential | Concurrent | Transformative | …
☐ Synthesis		Systematic review | Critical review | Thematic synthesis | Meta-ethnography | Narrative synthesis | …
☐ Other		…

Variables and analysis

Intervention(s), Treatment(s), Exposure(s)	Outcome(s), Output(s), Predictor(s), Measure(s)	Data analysis method(s)
"multimodal intensive treatment" CBT with ERP + modifications for ASD 33 sessions over 7 weeks 5 days a week 6.5 hours a day with family member + separate family sessions weekly Partial hospitalization during treatment	CY-BOCS PROMIS Screen for childhood anxiety related disorders Social anxiety scale for children and adolescents	Comparison of pre and post scores on questionnaires No statistical analysis was completed

Sampling

Total size	1	Group 1		Group 2		Group 3		Group 4		Control	
Population, sample, setting	12 yr old male										

Data collection (add if not listed)

Audit/Review	a) Primary | Secondary | … b) Authoritative | Partisan | Antagonist | … c) Literature | Systematic | …	Interview	a) Formal | Informal | … b) Structured | Semi-structured | Unstructured | … c) One-on-one | Group | Multiple | Self-administered | …
Observation	a) Participant | Non-participant | … b) Structured | Semi-structured | Unstructured | … c) Covert | Candid | …	Testing	a) Standardised | Norm-ref | Criterion-ref | Ipsative | … b) Objective | Subjective | … c) One-on-one | Group | Self-administered | …

Scores

Preliminaries	3	Design	4	Data Collection	4	Results	3	Total [/40]	27
Introduction	5	Sampling	3	Ethical Matters	2	Discussion	3	Total [%]	68%

General notes

Category Item	**Item descriptors** [Present; Absent; ■Not applicable]	**Description** **[Important information for each item]**	**Score** [0–5]
1. Preliminaries			
Title	1. Includes study aims 🟨and design 🟨		
Abstract (assess last)	1. Key information 🟨 2. Balanced 🟥and informative 🟨	Included comorbidities I the abstract that do not get spoken about in the case study as they are not the primary disorders being treated	
Text (assess last)	1. Sufficient detail others could reproduce 🟥 2. Clear/concise writing 🟨, table(s) 🟥, diagram(s) 🟥, figure(s) 🟥	This case study provided lots on information about the participant and how he moved through the intervention. However, it did not provide sufficient detail of the intervention for replication.	
		Preliminaries [/5]	3
2. Introduction			
Background	1. Summary of current knowledge 🟨 2. Specific problem(s) addressed 🟨and reason(s) for addressing 🟨		
Objective	1. Primary objective(s), hypothesis(es), or aim(s) 🟨 2. Secondary question(s) ❑		
	Is it worth continuing?	**Introduction [/5]**	5
3. Design			
Research design	1. Research design(s) chosen 🟨and why 🟨 2. Suitability of research design(s) 🟨		
Intervention, Treatment, Exposure	1. Intervention(s)/treatment(s)/exposure(s) chosen 🟨and why 🟨 2. Precise details of the intervention(s)/treatment(s)/exposure(s) 🟥for each group ❑ 3. Intervention(s)/treatment(s)/exposure(s) valid 🟨and reliable 🟨		
Outcome, Output, Predictor, Measure	1. Outcome(s)/output(s)/predictor(s)/measure(s) chosen 🟨and why 🟥 2. Clearly define outcome(s)/output(s)/predictor(s)/measure(s) 🟥 3. Outcome(s)/output(s)/predictor(s)/measure(s) valid 🟨and reliable 🟨	No explanation of why the outcome measures were chosen	
Bias, etc	1. Potential bias ❑, confounding variables ❑, effect modifiers ❑, interactions ❑ 2. Sequence generation ❑, group allocation ❑, group balance ❑, and by whom ❑ 3. Equivalent treatment of participants/cases/groups ❑		
	Is it worth continuing?	**Design [/5]**	4
4. Sampling			
Sampling method	1. Sampling method(s) chosen 🟥and why 🟥 2. Suitability of sampling method 🟨	Reason for using this particular case was not given	
Sample size	1. Sample size 🟨, how chosen 🟥, and why 🟥 2. Suitability of sample size 🟨		
Sampling protocol	1. Target/actual/sample population(s): description ❑and suitability ❑ 2. Participants/cases/groups: inclusion ❑and exclusion ❑criteria 3. Recruitment of participants/cases/groups ❑		
	Is it worth continuing?	**Sampling [/5]**	3
5. Data collection			
Collection method	1. Collection method(s) chosen 🟨and why 🟥 2. Suitability of collection method(s) 🟨		
Collection protocol	1. Include date(s) ❑, location(s) 🟨, setting(s) 🟨, personnel 🟨, materials 🟨, processes 🟥 2. Method(s) to ensure/enhance quality of measurement/instrumentation ❑ 3. Manage non-participation ❑, withdrawal ❑, incomplete/lost data ❑		
	Is it worth continuing?	**Data collection [/5]**	4
6. Ethical matters			
Participant ethics	1. Informed consent 🟥, equity ❑ 2. Privacy ❑, confidentiality/anonymity 🟨	The study did not report that informed consent was gained. It did however use a pseudonym	
Researcher ethics	1. Ethical approval 🟥, funding 🟥, conflict(s) of interest 🟥 2. Subjectivities ❑, relationship(s) with participants/cases 🟥		
	Is it worth continuing?	**Ethical matters [/5]**	2
7. Results			
Analysis, Integration, Interpretation method	1. A.I.I. method(s) for primary outcome(s)/output(s)/predictor(s) chosen ❑and why ❑ 2. Additional A.I.I. methods (e.g. subgroup analysis) chosen ❑and why ❑ 3. Suitability of analysis/integration/interpretation method(s) ❑	The results were not statistically analyzed, they were taken on face value as there was just one participant	
Essential analysis	1. Flow of participants/cases/groups through each stage of research 🟨 2. Demographic and other characteristics of participants/cases/groups 🟨 3. Analyse raw data 🟨, response rate ❑, non-participation/withdrawal/incomplete/lost data ❑		
Outcome, Output, Predictor analysis	1. Summary of results 🟨and precision ❑for each outcome/output/predictor/measure 2. Consideration of benefits/harms 🟨, unexpected results ❑, problems/failures 🟨 3. Description of outlying data (e.g. diverse cases, adverse effects, minor themes) ❑		
		Results [/5]	3
8. Discussion			
Interpretation	1. Interpretation of results in the context of current evidence 🟨and objectives 🟨 2. Draw inferences consistent with the strength of the data 🟥 3. Consideration of alternative explanations for observed results 🟨 4. Account for bias ❑, confounding/effect modifiers/interactions/imprecision 🟨		
Generalisation	1. Consideration of overall practical usefulness of the study 🟨 2. Description of generalisability (external validity) of the study 🟥		
Concluding remarks	1. Highlight study's particular strengths 🟨 2. Suggest steps that may improve future results (e.g. limitations) 🟥 3. Suggest further studies 🟨	The concluding statements were fairly general "necessitates further research" and it did highlight the studies strengths but did not state clearly it's limitations "single case example of a successful multimodal intensive treatment"	
		Discussion [/5]	3
9. Total			
Total score	1. Add all scores for categories 1–8		
		Total [/40]	27

Appendix 2.1 – Participant Information Sheet

URL: https://osf.io/c26ku

Appendix 2.2 – Consent Form

URL: https://osf.io/jgv45

Appendix 2.3 – Interview Schedule

An IPA (Interpretative Phenomenological Analysis) exploration of parents' experiences of their child receiving a diagnosis of autism using a reframed approach.

Interview Schedule

Recording

As you know, I need to record this interview to help me analyse the results later. [start the recording]. This interview is now being recorded. Can you please confirm that this is OK with you?

Consent

OK that's the recorder on now. First, I wanted to thank you for agreeing to speak with me today. Can I check if you have had a chance to read over the Consent Form that was sent to you? What I am going to do now is read through this with you and check that you consent to each of the points.

RESEARCHER TO READ THROUGH CONSENT FORM WITH PARTICIPANT AND CHECK THAT PARTICIPANT CONSENTS TO EACH NUMBERED POINT ON THE FORM. IF PARTICIPANT CONSENTS TO TAKE PART IN THE STUDY, TICK THE BOX BELOW. IF NOT, DO NOT PROCEED WITH THE INTERVIEW.

☐ *Consent given by participant.*

Introduction

1. Experience of life before the diagnosis

a. **Tell me about the experiences at the time that lead to you seeking a diagnosis for your child?**

- *Prompts:*
  Who raised this concern?
  How old was your child at the time of initial concerns?
  Could you tell me more about that?

2. Experience of the assessment process and diagnosis

a. **Can you share with me the process that led to your child's first appointment?**

- *Prompts:*
  Who was involved in the process?
  When did this happen?
  Could you tell me more about that?

b. **Can you tell me what happened during the assessment appointments?**

- *Prompts*
  How many appointments?
  What happened in X appointment?
  How did your child find this?

c. **What was your experience of assessment process as a whole?**

d. **Could you describe the appointment in which your child received their diagnosis?**

- *Prompts:*
  How did you find this appointment?
  How did your child find this?

e. **Could you tell me your experience of being told about your child's diagnosis?**

- *Prompts:*
  What did you think about the diagnosis when you were first told?
  What did others think?

f. **Is there anything that would have made the experience of your child receiving a diagnosis better for you?**

3. Experience of living with a diagnosis

a. **What had been your experience since your child has received their diagnosis?**

- *Prompts:*
  How has your life changed?
  Has the diagnosis been helpful/unhelpful?
  What has been your child's experience?

b. **Is there anything that you have found helpful in understanding your child's diagnosis?**

- *Prompts:*
  Was that sort by you or offered by a service?

c. **How do you feel about/see their diagnosis?**

- *Prompts:*
  How do you think X feels about/sees their diagnosis?

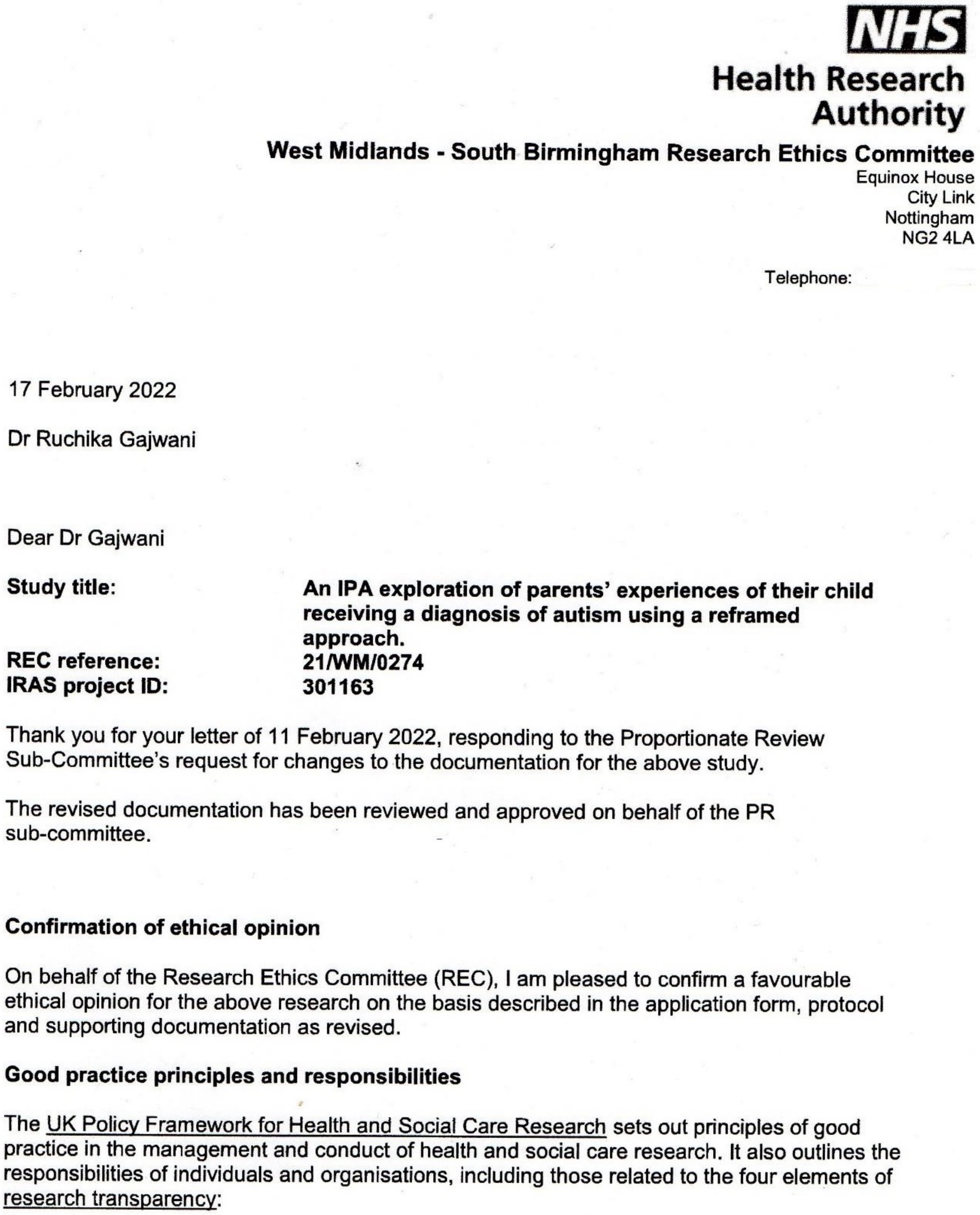
d. **How do you view your child's future since they received their diagnosis?**

- *Prompts:*
  Had this changed from before their diagnosis?

Is there anything else you would like to tell me about this experience that I have not asked about?

End of interview

Appendix 2.4 – REC Approval Letter



NHS
Health Research
Authority
West Midlands - South Birmingham Research Ethics Committee
Equinox House
City Link
Nottingham
NG2 4LA

Telephone:

17 February 2022

Dr Ruchika Gajwani

Dear Dr Gajwani

Study title:	**An IPA exploration of parents' experiences of their child receiving a diagnosis of autism using a reframed approach.**
REC reference:	**21/WM/0274**
IRAS project ID:	**301163**

Thank you for your letter of 11 February 2022, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of the PR sub-committee.

Confirmation of ethical opinion

On behalf of the Research Ethics Committee (REC), I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

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

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) 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.

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 research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:
https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at:
https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

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).

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, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at
https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

The favourable opinion applies to all NHS/HSC 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" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Interview schedules or topic guides for participants [Interview Schedule]	3	22 September 2021
IRAS Application Form [IRAS_Form_05112021]		05 November 2021
Letters of invitation to participant [Reply Slip]	2	15 October 2021
Letters of invitation to participant [Invitation Letter]	3	20 October 2021
Letters of invitation to participant [Interview Confirmation Letter]	3	22 September 2021
Letters of invitation to participant [Video Conferencing access instructions]	1	20 October 2021
Other [Ethics amendments cover letter]	1	16 December 2021
Other [Ethics cover letter]	2	11 February 2022
Participant consent form [Consent form]	4	02 December 2021
Participant information sheet (PIS) [Post Interview Information Sheet]	4	16 December 2021
Participant information sheet (PIS) [Participant information Sheet]	6	21 January 2022
Research protocol or project proposal [MRP Proposal V8 22.09.2021]	8	22 September 2021
Schedule of Events or SoECAT [Schedule of Events]	2	22 September 2021
Summary CV for Chief Investigator (CI) [Summary CV for Chief Investigator]	2	22 September 2021
Summary CV for student [Summary CV for Student]		27 October 2021
Summary CV for supervisor (student research) [Summary SV for Supervisor]	2	22 September 2021
Summary CV for supervisor (student research) [Summary CV for Supervisor]	2	22 September 2021

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.

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:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

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

IRAS project ID: 301163	**Please quote this number on all correspondence**

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

Yours sincerely

pp.

Professor Paula McGee
Chair

Email: southbirmingham.rec@hra.nhs.uk

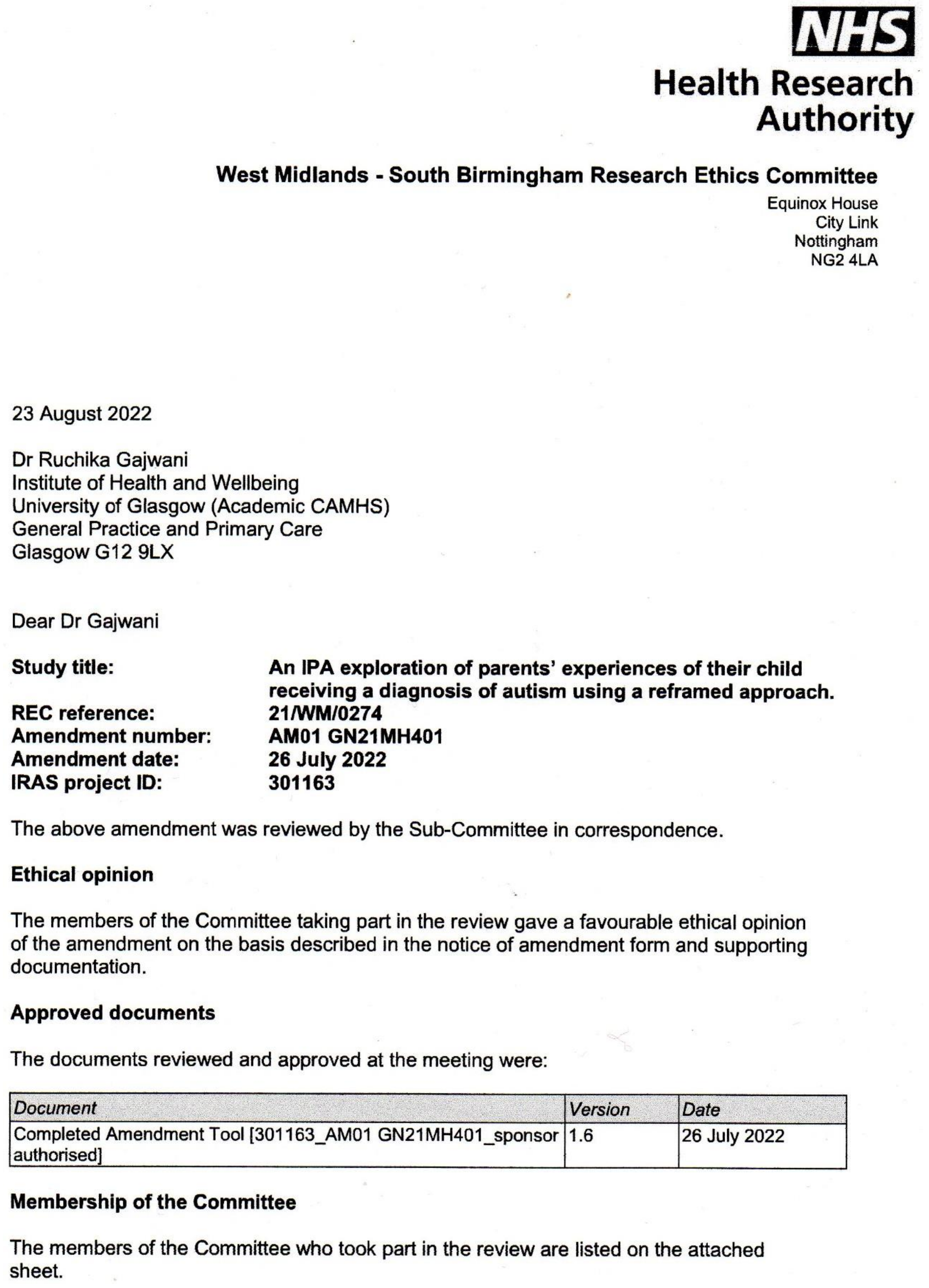
Enclosures: "After ethical review – guidance for researchers"

Non CTIMP Standard Conditions of Approval

Copy to: Ms. Emma-Jane Gault

Dr Ruchika Gajwani,

Appendix 2.5 Amendment Approval Letter



NHS
Health Research
Authority

West Midlands - South Birmingham Research Ethics Committee
Equinox House
City Link
Nottingham
NG2 4LA

23 August 2022

Dr Ruchika Gajwani
Institute of Health and Wellbeing
University of Glasgow (Academic CAMHS)
General Practice and Primary Care
Glasgow G12 9LX

Dear Dr Gajwani

Study title:	**An IPA exploration of parents' experiences of their child receiving a diagnosis of autism using a reframed approach.**
REC reference:	**21/WM/0274**
Amendment number:	**AM01 GN21MH401**
Amendment date:	**26 July 2022**
IRAS project ID:	**301163**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [301163_AM01 GN21MH401_sponsor authorised]	1.6	26 July 2022

Membership of the Committee

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

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

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.

HRA Learning

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

IRAS Project ID - 301163:	**Please quote this number on all correspondence**

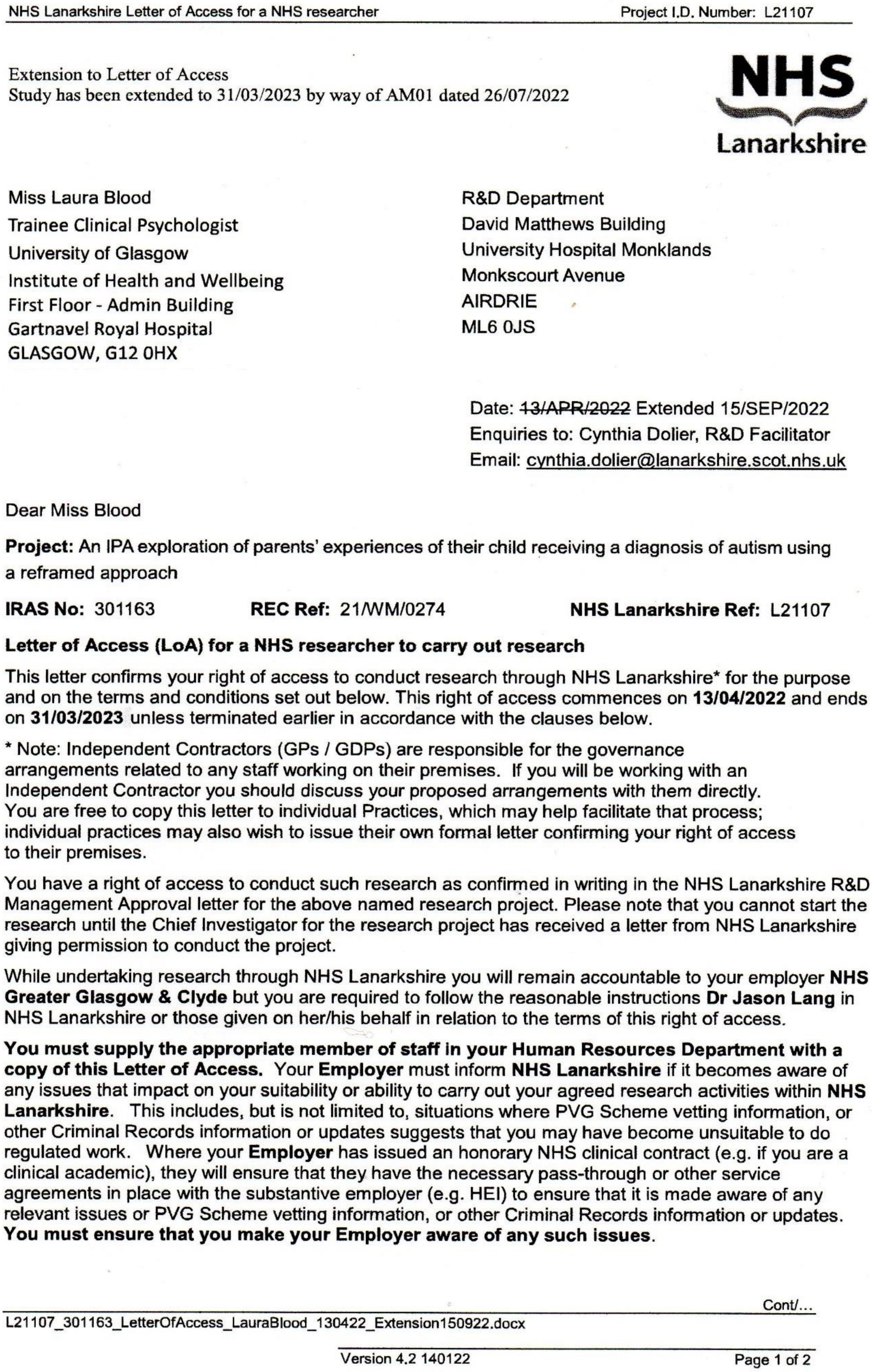
Yours sincerely

Dr Kathryn Kinmond
Vice Chair

E-mail: southbirmingham.rec@hra.nhs.uk

Enclosures:	*List of names and professions of members who took part in the review*
Copy to:	*Ms. Emma-Jane Gault*

Appendix 2.6 – R&I Approval: Letter of Access



NHS Lanarkshire Letter of Access for a NHS researcher Project I.D. Number: L21107

Extension to Letter of Access
Study has been extended to 31/03/2023 by way of AM01 dated 26/07/2022

NHS
Lanarkshire

Miss Laura Blood
Trainee Clinical Psychologist
University of Glasgow
Institute of Health and Wellbeing
First Floor - Admin Building
Gartnavel Royal Hospital
GLASGOW, G12 0HX

R&D Department
David Matthews Building
University Hospital Monklands
Monkscourt Avenue
AIRDRIE
ML6 0JS

Date: ~~13/APR/2022~~ Extended 15/SEP/2022
Enquiries to: Cynthia Dolier, R&D Facilitator
Email: cynthia.dolier@lanarkshire.scot.nhs.uk

Dear Miss Blood

Project: An IPA exploration of parents' experiences of their child receiving a diagnosis of autism using a reframed approach

IRAS No: 301163 **REC Ref:** 21/WM/0274 **NHS Lanarkshire Ref:** L21107

Letter of Access (LoA) for a NHS researcher to carry out research

This letter confirms your right of access to conduct research through NHS Lanarkshire* for the purpose and on the terms and conditions set out below. This right of access commences on **13/04/2022** and ends on **31/03/2023** unless terminated earlier in accordance with the clauses below.

* Note: Independent Contractors (GPs / GDPs) are responsible for the governance arrangements related to any staff working on their premises. If you will be working with an Independent Contractor you should discuss your proposed arrangements with them directly. You are free to copy this letter to individual Practices, which may help facilitate that process; individual practices may also wish to issue their own formal letter confirming your right of access to their premises.

You have a right of access to conduct such research as confirmed in writing in the NHS Lanarkshire R&D Management Approval letter for the above named research project. Please note that you cannot start the research until the Chief Investigator for the research project has received a letter from NHS Lanarkshire giving permission to conduct the project.

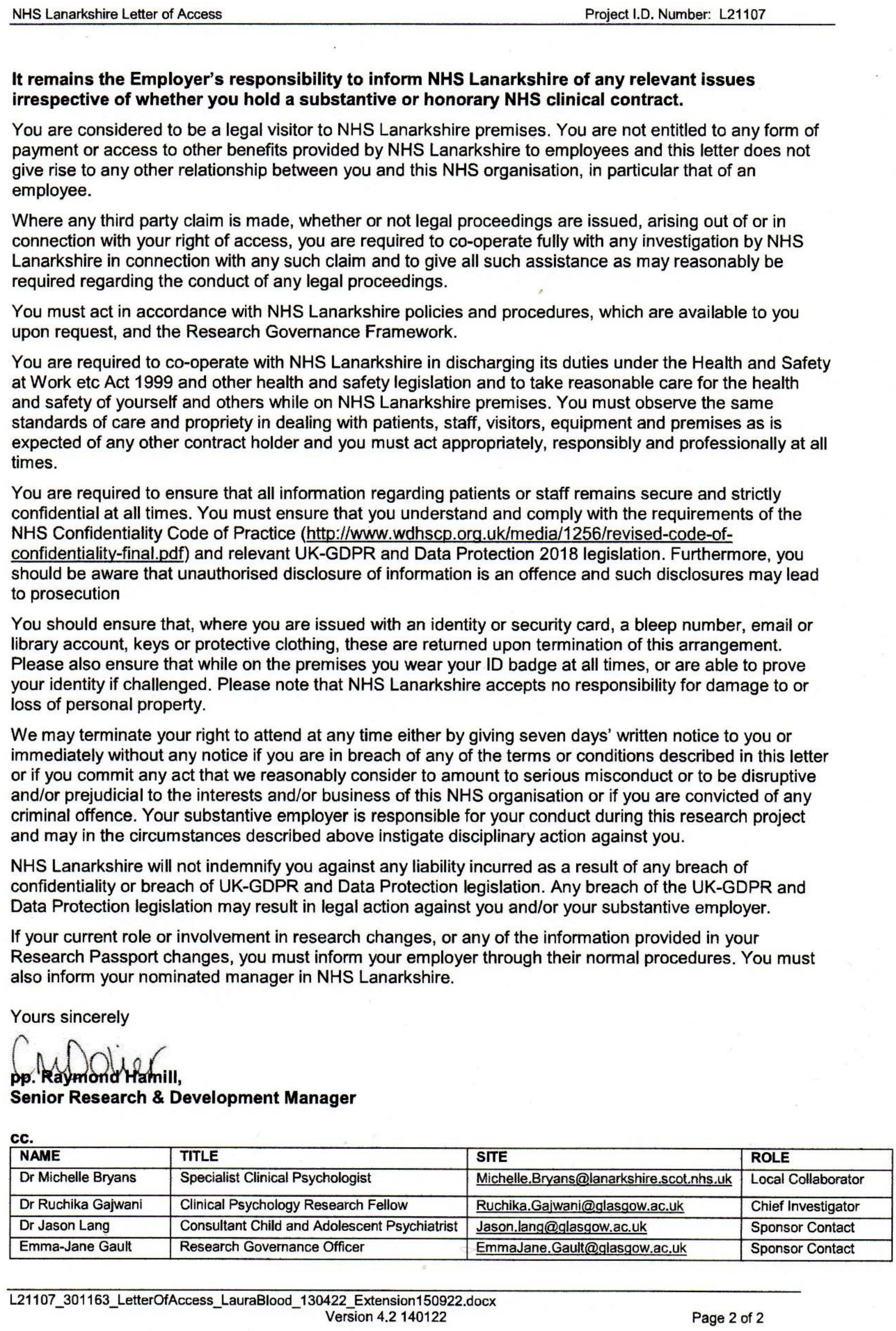
While undertaking research through NHS Lanarkshire you will remain accountable to your employer **NHS Greater Glasgow & Clyde** but you are required to follow the reasonable instructions **Dr Jason Lang** in NHS Lanarkshire or those given on her/his behalf in relation to the terms of this right of access.

You must supply the appropriate member of staff in your Human Resources Department with a copy of this Letter of Access. Your **Employer** must inform **NHS Lanarkshire** if it becomes aware of any issues that impact on your suitability or ability to carry out your agreed research activities within **NHS Lanarkshire**. This includes, but is not limited to, situations where PVG Scheme vetting information, or other Criminal Records information or updates suggests that you may have become unsuitable to do regulated work. Where your **Employer** has issued an honorary NHS clinical contract (e.g. if you are a clinical academic), they will ensure that they have the necessary pass-through or other service agreements in place with the substantive employer (e.g. HEI) to ensure that it is made aware of any relevant issues or PVG Scheme vetting information, or other Criminal Records information or updates. **You must ensure that you make your Employer aware of any such issues.**

Cont/...

L21107_301163_LetterOfAccess_LauraBlood_130422_Extension150922.docx

Version 4.2 140122 Page 1 of 2



It remains the Employer's responsibility to inform NHS Lanarkshire of any relevant issues irrespective of whether you hold a substantive or honorary NHS clinical contract.

You are considered to be a legal visitor to NHS Lanarkshire premises. You are not entitled to any form of payment or access to other benefits provided by NHS Lanarkshire to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by NHS Lanarkshire in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with NHS Lanarkshire policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with NHS Lanarkshire in discharging its duties under the Health and Safety at Work etc Act 1999 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on NHS Lanarkshire premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.wdhscp.org.uk/media/1256/revised-code-of-confidentiality-final.pdf) and relevant UK-GDPR and Data Protection 2018 legislation. Furthermore, you should be aware that unauthorised disclosure of information is an offence and such disclosures may lead to prosecution

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that NHS Lanarkshire accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

NHS Lanarkshire will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of UK-GDPR and Data Protection legislation. Any breach of the UK-GDPR and Data Protection legislation may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in NHS Lanarkshire.

Yours sincerely

pp. Raymond Hamill,
Senior Research & Development Manager

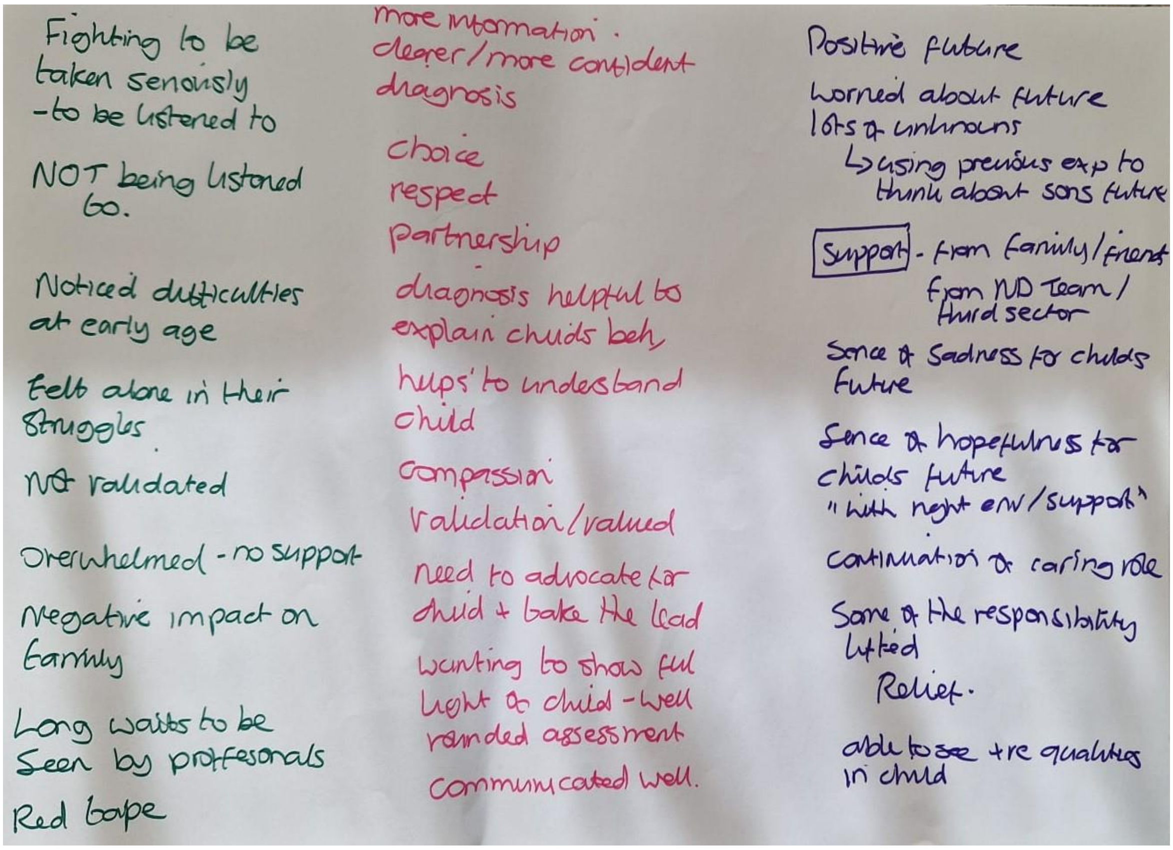
cc.

NAME	TITLE	SITE	ROLE
Dr Michelle Bryans	Specialist Clinical Psychologist	Michelle.Bryans@lanarkshire.scot.nhs.uk	Local Collaborator
Dr Ruchika Gajwani	Clinical Psychology Research Fellow	Ruchika.Gajwani@glasgow.ac.uk	Chief Investigator
Dr Jason Lang	Consultant Child and Adolescent Psychiatrist	Jason.lang@glasgow.ac.uk	Sponsor Contact
Emma-Jane Gault	Research Governance Officer	EmmaJane.Gault@glasgow.ac.uk	Sponsor Contact

Appendix 2.7 – Interview Analysis Table Sample

Experiential statements		Exploratory notes
“It’s not his fault” Not being heard	Speaker 1: erm, yeah, so, [00:04:10] Probably from a very young age you know my son [name] has shown signs of just being a bit different you know and erm perhaps needing more support [00:04:25] erm at home and at nursery as well. Erm so at nursery he used to have like a support worker working with him. Erm, we saw a paediatrician at the time. And we also had [00:04:40] to sleep Scotland involved. The paediatrician had, you know, looked at [child] during and the appointment had sort of make judgments based on how [child] was interacting with him. And he felt that [00:04:55] there was no sort of signs of anything there, that was sort of autistic if you like, or anything that needed further support so he just sort of signed [child] off. Meanwhile though we still continue [00:05:10] to experience erm some challenges and differences with [child] very emotional particularly when he started school. So we had sort out again speech and language [00:05:25] and...in sort of desperation to get further help before [child] starting school and erm... primary one, I would say that [child's] a very emotional side that was always present. And that started to turn violent [00:05:40] in primary one. And erm...I think that the school environment at that point was probably too much from [child]. Erm...The school were suspending him in primary one [00:05:55] because of violence. And we felt like there was a gap in who we could turn to because we were taking [child] to the GP. And the GP, again, like the paediatrician [00:06:10] was looking at [child] and seeing that [child] could concentrate on his game. And again, they would say that there was no signs of autistic behaviour, that he was able to focus on his game, he was able to make some eye contact [00:06:25] they, they weren't making any referrals. So again, we were having to fight and school were also fighting help us get referrals also eventually with the schools help at that point, because of [child] getting suspended and things, which was bazar, but it happened, we got CAMHS involved [00:06:40] Which was the first stage of erm, I don't think they were the neurodevelopment team, but we got told that [child] couldn't see an actual psychologist or a psychiatrist until he was at least eight. I don't know why that was but that's what we got told so we saw CAMHS and CAMHS, the clinician that we dealt with erm... [name] I think, it was [name] something. Erm... he again reiterated that because of [child's] age, that the doctors	Known for a long time that son was different. “You know” repeated – what she’s saying is obvious to her Turned away by professionals – brushed off. Challenges and differences – does not say difficulties Desperation – want to get child help before he goes to school “Very emotional” reluctant to say overly negative things about son “Turned violent in P1” - stated the school environment at the reason for this -externalising child’s difficulties Gap in who they could turn to who would help them. They spoke with GP so has someone but the GP was not hearing their concerns Use of “we” “us” – sign of togetherness with the family Fighting to get support for child – to get referrals to the right place CAMHS became involved “because of child getting suspended and things” – things had escalated enough for service involvement Uncertainly – repeated situation to relay the silliness of it

Appendix 2.8 – Group Experiential Themes Analysis Sample



Fighting to be taken seriously
-to be listened to

NOT being listened to.

Noticed difficulties at early age

Felt alone in their struggles.

Not validated

Overwhelmed - no support

Negative impact on family

Long waits to be seen by proffesonals

Red tape

more information.
clearer/more confident diagnosis

choice

respect

partnership

diagnosis helpful to explain childs beh

helps to understand child

compassion

validation/valued

need to advocate for child + take the lead

wanting to show ful light of child - well rounded assessment

communicated well.

Positive future

worried about future
lots of unknowns
↳ using previous exp to think about sons future

Support - from family/friends
from ND Team / third sector

Sence of sadness for childs future

Sence of hopefulness for childs future
"with right env/support"

continuation of caring role

Some of the responsibility lifted

Relief.

able to see +ve qualities in child

Appendix 2.9 – MRP Proposal

URL: https://osf.io/4cejb